Caregivers Wear Plaid

A GUIDE FOR CAREGIVERS FOR SOMEONE LIVING WITH AN AUTOIMMUNE DISEASE

BY

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Caregivers Wear Plaid

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Our Mission

Patty and I have a passion for this book and you. We do not want to see you end up like many guys do, their wives and family when confronted with a disabling systemic autoimmune disease. It is a difficult time for both of you, wishing to return to the norm you enjoyed and that you desire in the future. Unfortunately, whatever your circumstances are it is your new normal. We understand.

Patty and I decided to bring our years of experience as someone living with lupus for over 50 years, and I, her caregiver, what we have learned along the way in hopes that we make your journey a little bit easier. We have served as Board Chair for the Lupus Foundation of America's North Carolina Chapter; remain involved with the Lupus Support Group in our community. To write Caregivers Wear Plaid was simply an extension of our passion and involvement to help caregivers and their 'care' learn more about dealing with the circumstances.

As Patty says, "You need to learn how to manage the disease and not allow the disease to manage you!" That's true for both of you!

We hope that you will find our book and other information beneficial and that you will tell others about our book so they may benefit too.

Summary: Caregivers Wear Plaid helps caregivers deal with a family member living with a long-term autoimmune disease, such as lupus or another life-altering tragic event. Primarily written for men, Caregivers Wear Plaid imparts information on what it means to be a caregiver; what to expect from and how to deal with the medical community, insight into lupus, or any systemic autoimmune disease, a tragic event that incapacitates that requires the need of a life-long caregiver. Caregivers Wear Plaid also provides insight and tips on living a quality, purposeful life as a caregiver to a spouse or close family member. Understanding and being understood, caring about someone else, and having someone who cares about you is the foundation to being a good partner, a good family man, and a good caregiver.

Disclaimer

Before you read any further, I want to clarify that I am not a doctor. The opinions and ideas expressed in "Caregivers Wear Plaid" are from my own experiences in life, business, and being a caregiver to Patty, who has lupus and 42 other diagnosis's. I encourage you not to delay getting professional medical advice on the questions you may have or content in this book that you may dispute or do not clearly understand. What you do with this information: accept, reject, adopt, is your responsibility. The information shared within "Caregivers Wear Plaid" is to bring awareness into one's life as someone who lives with and cares for someone living with lupus, any other debilitating autoimmune disease, or tragic circumstances requiring the need of a caregiver. This book should not be viewed or accepted as a substitute for professional medical advice. I encourage you to seek a qualified medical provider for treatment or another medical diagnosis.

Colossians 3:12-14

"Therefore, as God's people, holy and dearly loved, clothe yourself with compassion, kindness, humility, gentleness, and patience. Bear with each other and forgive one another if any of you has a grievance against the other. Forgive as the Lord forgave you. And over all these virtues put on love, which binds you, your wife, family, and others together in perfect unity."

It is vital to know that love can conquer all when living within someone else's limitations!

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Author's Notes

Brain Fog

Often referenced as the "Clouding of the brain," with "Brain Fog," your wife will not understand everything nicely. She will have trouble putting clues together and will have difficulty thinking logically through a situation. Retention of information and logical thinking can also be problematic. The good thing about brain fog is that you know it will ultimately lift and that she will be able to compute like an average person. It can last one day, one week, or longer. "Brain Fog" is prevalent in many diseases and can be caused or exasperated by: fatigue, stress, lack of sleep, diet, dehydration, some medications . . . the action of or interaction with other medicines, and inflammation. Brain Fog and forgetting are synonymous with one another. Using Post It reminders or smartphone alarms, notes, etc., are an excellent way to combat this issue.

Creatinine

Your body produces creatine at a constant rate to support muscle contraction, which then, through your blood system, excretes it through your kidneys. The question is: how efficiently are your kidneys filtering creatinine from your blood? If creatine levels are high, as determined through a blood test, it can indicate that your kidneys are not filtering correctly or are damaged. Kidney damage can lead to dialysis and a transplant. The above is a simplistic explanation but proves it is important to keep doctor appointments. The kidneys are one essential area doctors will pay attention to regarding your wife's overall health. Keep in mind that many with lupus do not progress to the stages of organ involvement. According to Johns Hopkins Medicine, about 50% of people with lupus will have some kidney involvement at some point in their life.

Energy Moments

You will discover that when you and your wife go out to a movie, a party, a concert, or dinner, your wife will have what I call "Energy Moments." This extra gear of 'Energy' that women with lupus can invoke during these times masks what is happening inside. Thus, she appears not to look sick, but these are only moments in time that she can sustain appearances. Look for her "high sign," indicating that it's time to go home.

Energy Passes

I'll explain this further in the book, but your wife is given, by the powers above, only so many passes, enough Energy, to perform tasks during the day. She will never know how many she has. Some days are better than others, but the reality of fatigue she is feeling and her ability and or inability to trudge through is soon apparent. It can be a good day if she receives more than five Energy Passes on any given day. A good day, of course, depends on how advanced her lupus has become. Some days are better than others. There seems to be no consistency other than the Energy Passes given each day can be used up quickly even if not managed well.

Energy Savers

That's you, the caregiver. You can't imagine how many Energy Passes you can save your wife on any given day by doing simple things that will typically zap her strength and use up her Energy Passes. For example, making the bed in the morning or making her breakfast before you get out the door is enormous. The number one symptom associated with almost all chronic disorders is fatigue. Extreme fatigue is a constant for most living with lupus.

Energy Users

These are the day-to-day tasks that use up your wife's Energy Passes. i.e., getting dressed, taking a shower, making breakfast, eating breakfast, having a conversation, driving to work, working, making the bed, making dinner, cleaning the house, getting the kids dressed for school, making the children's lunches for school, doing the laundry, folding the clothes, grocery shopping, clothes shopping. The list goes on and on, the things your wife does typically, or hopefully with you. She will use up the limited daily Energy Passes she has.

Flare

A term used to describe when your wife's lupus becomes more active, i.e., rash, fatigue, joint pain, etc.

Light of Life

The more your wife stays inside, stays within herself, does not socialize with others, and gets out to enjoy a usual sense of life, the more she will withdraw and lose her identity. In other words, the more she can get out of the house and interact with others, the better her attitude toward life will be. It's moments in time, but moments she will cherish and enjoy.

Living within her limitations

This term or statement is the absolute reality that you, as a caregiver, need to accept, embrace, and establish new processes/habits to be effective in your desire to do everything you can for your loved one. So, if you haven't gathered by now, your wife will have limitations on what she can and cannot do due to the progression of her disease.

GLOSSARY OF TERMS

THE MASK

With lupus, 'The Mask' refers to a rash that will appear on your wife's face as if she is wearing a mask. The mask is an indication of Discoid Lupus versus Systemic Lupus. It also refers to how people with autoimmune diseases do not look sick, especially when they are in public. Of course, it is natural for one to put their best foot forward even when the symptoms of their medical issues are visually apparent.

SYSTEMIC DISEASE

Systemic diseases can affect one's entire body, but in terms of our discussion, the systemic disease can target one or more specific organs or tissues in the body. A systemic disorder can refer to, for example, an infection in the bloodstream. Chronic inflammatory system diseases (CIDs), Rheumatoid arthritis, lupus, multiple sclerosis, gout, and sarcoidosis are examples of CIDs. These diseases can last for a very long time and are not infectious. Other CIDs diseases are contagious and typically last a brief period. Examples are the flu, scarlet fever, the common cold, strep throat, and pneumonia.

The Caregiver's Burden

Reference Zarit, Reever & Bach-Peterson 1980, deals with the multidimensional stressors caregivers encounter physically, psychologically, emotionally, socially, and financially due to the burden placed upon them as the primary caregiver. And, Kasuya, Polgar-Bailey & Tekeuchi 2000, "The caregiver's perception of the burden, not those of other family members or healthcare providers, determine the overall impact on the caregiver's life." In "Caregiver's Wear Plaid," I hope to address the perception, the reality, the attitude, and the actions that make this reality of being a caregiver a more effortless adjustment.

The Cycle of Lupus

As a writer, you want to make ideas as simple as possible to understand. Thus I invented "The Cycle of Lupus Chart," hoping that I provide you with a simple explanation of what the journey looks like for your wife and you from symptoms to the rest of her life. Unfortunately, there is no finite; in other words, everyone with lupus reacts very differently and then very much the same. It is part of what the Lupus Foundation of America refers to as "The Cruel Mystery." Other autoimmune diseases are very similar in symptoms, and why lupus is so challenging to diagnose.

Patty reminds me that one of the most challenging things a husband, significant other, or parent initially has to deal with is understanding that their wife or child, even though they do not look sick on the outside, is very sick on the inside. Education and awareness are the best things to overcome any negative thoughts you may have other than "Why isn't there a cure for this damn disease yet?" An excellent question to which there are many major ongoing research initiatives. The hope is that the answer to one autoimmune disease leads to the answer for all of them.

The Privacy of Pain

The grief, anxiety, and depression living with an autoimmune disease have severe physical and emotional symptoms and can significantly affect one's life. These fears can morph into withdrawal from life. The Privacy of Pain is a downward spiral that friends and neighbors can further exasperate, and even relatives fade into the shadows to exclude what used to be regular social interaction. The result is the Privacy of Pain, where acceptance of reality has not been embarrassed, and coping skills have yet to be learned or put into practice. If this is scary to you, it should be! However, there are ways to reverse this effect.

Triggers

Lupus manifests itself in many different ways and is not always the same as others living with lupus. Some triggers can cause flares, such as sunlight, medicines, or allergies. Your wife will begin to learn what triggers a flare in her. There is no finite. Depending on the activity of her lupus and a compromised immune system, she should consider staying away from certain situations, such as a family member who has a cold or going to a large indoor event, which increases the exposure to contracting a virus or infection.

There is a good article in WebMD that can give you more insight into triggers:
https://www.webmd.com/lupus/understanding-lupus-prevention

Note: Immune suppressant medicines raise the risk of contracting viruses, such as COVID-19. If this virus or variant thereof comes around again, note that extra precautions should be considered especially if she has other morbidities. Often, individuals with lupus have more than one comorbidity.

Dedication

This book is dedicated to all the people providing care and being an advocate to another.

On November 18, 2016, a sweet soul and determined 35-year-old lady lost her battle with lupus. Her name was Shellee Reeves, and she cared for everybody and anybody who needed help. From children to adults to abandoned animals, Shellee cared. She wore her heart on her sleeve and volunteered for everything she could, whether she was sick or not. The last time Patty and I saw Shellee alive was in Raleigh, North Carolina, at the annual summit for those living with lupus. She rolled a pole with an infusion bag swaying to her every move and a smile, excited to see us. Less than three weeks later, she would be dead.

Patty Dunn Shellee Reeves. Sean Lowther

No one who knew Shellee was prepared for this, especially her fiancee, who was with her every step of the way. She always had a smile on her face, no matter her pain. She was determined to beat lupus. She was a fighter with a big heart that lupus tragically stopped, but not her spirit.

Patty and I went to the hospital the day before she died and spent time with Stephen, her fiancee. She had been in a coma. The doctors had taken her off life support the day before. The next morning Patty told me that Shellee had passed

away during the night. Heartfelt emotions welled within us as our day evolved. We had things to do, places to go, people to see and there was this sadness in the thought of each spirit for another.

The day after Shellee died, I told Patty I would take some time to reflect and continue writing this book. Suddenly, my iPhone flashed, and a candlelit up on the screen. That candle app had never been activated by itself before or since that incident. It's easy to think that it was Shellee and . . . I believe it was. She is now in a better place, knowing that she was loved by more people than anyone could imagine. She was a person who had less and gave back more than most: what a beautiful person, a beautiful example to others.

Since Shellee's passing, Patty and I realized that we each think of her almost every day. On March 17, 2018, I would be speaking at the Lupus Foundation of America's Annual Mardi Gras Gala. I had been rehearsing what I would say, and I would open my remarks with a dedication to Shellee. As I awoke that morning, I heard a beeping sound. Beep . . . beep . . . beep. At first, I thought the sound was coming from the TV in our bedroom. Patty likes to sleep with it on, and I have comfortably adapted over the years. I soon realized that the beeping sound was not coming from the TV, so I went into our family room to find our Bose radio alarm beeping. We have never set that alarm on the radio before, nor had it ever gone off by itself before. In fact, we never listen to it! I looked up and acknowledged that Shellee was in the room.

The presentation went well that night. Two hundred fifty people in black ties and gowns were listening to my story about Shellee and another young lady named Syra. We met Syra the evening before a Butterfly of Hope Breakfast 13 years earlier. While helping to set up the event, the conversation among volunteers inspired Patty to say that she was a 35-year survivor of lupus. Syra began to cry uncontrollably. Patty, recognizing that something was wrong, went up to Syra and put her arms around her to comfort her and said: "What is wrong? Why are you crying?" Syra looked up at her and said: "I didn't think I would live that long!" she exclaimed. I used this

story to segue my presentation to Patty who was now, at that time, a 48-year survivor.

Four weeks before the LFANC annual Mardi Gras Gala, I asked Patty what she would like to do for her birthday. After all, it would be her 75th, which is a significant milestone, especially for someone living with lupus. Patty wanted to stay home for her birthday and stay quiet. I accepted that because Patty traveling to the beach or on other occasions is very exhausting and demanding on her.

And then the phone call came from our LFANC Chapter's President & CEO asking if I would accept being honored as King at this year's Mardi Gras Gala, which was being held on St. Patty's due to location availability Day. How fitting was that for what I had in mind. Patty's birthday is on the 18th of March, the day after St. Patty's Day. Patty knew the call was coming, and her eyes lit up in hopes that I would say, "Yes!" How could I not? Before I knew it her gown was ordered, the seamstress came to the house, the tuxedo was ordered. I came up with the bright idea to invite Patty's son and wife from Mobile, Alabama, and my three daughters . . . a secret we were able to keep from Patty before the event.

Our son from Mobile surprised Patty on the evening before. To Patty's surprise, they stopped at an exclusive restaurant to pick up dinner and walked through our front door. "Happy Birthday Mom!" they exclaimed as we sat down to a wonderful dinner together.

The next evening, all dressed to the t's, we made our way to the Bank of America Corporate Center Founder's Hall in Charlotte, North Carolina, where the Gala was being held. One of our daughters, Kelly, was able to attend and surprised

Patty as she came to our table. As the evening progressed, I was finally crowned King and pretty much began to expressed what you have just read. I dedicated the evening to Shellee and talked about Syra, Patty and our relationship in 4th grade; high school and our getting back together 20 plus years ago.

Below - Yes, that is me with a frown on my face. I think I was upset, because the teacher would not let me sit next to Patty! She always had my back, and I her's! My God, I had hair and I was wearing a plaid shirt. Was I destined to do this?

And then, to Patty's surprise, I told the 250 plus people in attendance in their gowns and tuxedos to please stand and honor Patty not only for her service to the LFANC and that she was a 48 year survivor of lupus, but that it was her 75th birthday We all sang happy birthday to her and of course a cake was brought to our table for her to make a wish and blow the candles out. Paparazzi appeared, and a magical moment occurred.

It was quite a night as you could imagine and a birthday celebration that she, nor I, would ever forget. For the rest of the night Patty was surrounded by family, friends, and many new acquaintances. And just think, she did not want to do anything on her 75th birthday but stay home and be quiet!

I would have never been down this lupus road if it were not for Patty, and I am by far a much better person for having travelled this varied pathway with so many

others I have come to know and love along this journey. So I dedicate this book to my Patty too.

Patty and I also want to dedicate this book to you. There is no greater gift than the opportunity to care for and give to another living with a chronic disease, such as lupus, another autoimmune disease, or a tragic event that caused life-altering circumstances. We are all going down the same road, experiencing issues and challenges. We have a lot to give you to make this journey a little bit easier and then some. That is our mission.

Whether you are a short-term (broken arm, etc.,) mid-term (recovery from major surgery), or full-time caregiver (she needs your help more and more), you will learn a lot from our experience in the short run and the long run too.

Welcome

Caregivers Wear Plaid is written primarily for men who need help and guidance in dealing with a loved one who is challenged due to an autoimmune disease or other life altering event. A lot of what Patty and I talk about can apply to anyone dealing with these circumstances. Having said that, when I started writing Caregivers Wear Plaid, it was primarily intended for those whose wife, significant other, child, parent, friend, is living with lupus. What is relevant to one is relevant to many autoimmune diseases, especially those that are systemic and life-altering. However, most autoimmune diseases are chronic (persistent) versus fatal. I came to realize that my focus was narrow and that tragic circumstances above and beyond autoimmune diseases can come into a person's life requiring a husband or significant other, parent, to become part-time, or progress to full-time caregiver to their loved one. So our view of the world has been broadened through writing *Caregivers Wear Plaid* to share what works universally and too to improve caregivers and their "Cares" day-to-day quality of life. Having said that, the focus of our book is primarily for caregivers who are living with or a caregiver to someone with lupus.

If you learn one new thing in our book that will help you as a caregiver, then our mission has been accomplished. Of course, we hope that it is more. There is a lot in our book that can help any caregiver dealing with their unique circumstances. From the choices one needs to make, to the 'how to' deal with friends, neighbors, and relatives; the medical community; your pharmacist, sex, stress, and so on. It just seems to go on and on within the 32 chapters. After three years of researching, writing, talking to professionals, and so on, we realized that there is probably more that can and should be said. But at some point, a book must come to an end and find its way into the universe. However, this is not the

end, because on our website, www.caregivers-wear-plaid.org and our Youtube Channel, we will share additional information.

What qualifies us to write Caregivers Wear Plaid?

Patty and I became involved with the Lupus Foundation of America's North Carolina Chapter, countless years ago. Patty served as Board Chair, and several years later I found myself in that role too. In the ensuing years, I have produced what we believe is the largest video library in the world on lupus. What is scary is that what we produced thirteen plus years ago is just as relevant now as it was then. That is not good news as we are always hoping that a cure will be found for lupus and all other autoimmune diseases that are out there. But it does show what can be accomplished by getting involved, doing a little bit here and there, and over time it becomes a valuable body of work helping others. These videos are being remastered for *Caregivers Wear Plaid* with links available on our website to reach more people around America and yes, the world too through the internet. Patty and I trust you will find a way to get involved with the organization that provides services and guidance for the autoimmune disease you are living with as a caregiver. It's a wonderful way to learn, contribute and give back.

Because Caregivers Wear Plaid is for men living with someone who has lupus, there are, in fact, only a few chapters specifically written on the subject of lupus. If, after reading Caregivers-Wear-Plaid, you feel others you know may benefit, please let them know about our book. That means any man who has a loved one living with a disabling autoimmune disease or incapacitated, challenged, requiring her man for extra loving care due to circumstances that have become life-altering.

With that, may we give you a special blessing that whatever trials you are dealing with that you and your loved one(s) find the strength and purpose to become the best you can under the circumstance to which you are given. To seek the light within your comfort and for a cure that ills your wife.

The Caregivers Lament

Definition: A passionate expression of grief or sorrow

We talk about this in "Caregivers Wear Plaid," because becoming a caregiver for and to someone you love was not something you expected you would have to do, at least not this early or even later in your life. One would think that most caregivers are women and seem to be better suited for these responsibilities. It's one thing to nurse a child, help them with their homework, and raise them to your values. That is part of life. But, with lupus and many other autoimmune diseases, it seems that it affects women more. That is true with lupus where 90% of those who have lupus are women. So, here you are now with your wife, a child or significant other, whom we have elected to call your wife in this book, and she is dealing with a systemic autoimmune disease that will require varying degrees of help and support, or she has experienced a severe event in her life that has become disabling requiring your help. At first glance these new demands on your time are probably not to discerning, but in time will evolve to a level of care you are unaccustomed to.

Some guys will simply end the relationship, get a divorce, walk away. If that is the case, your wife is lucky. She might not see that at the moment. No one wants to be abandon under these circumstances, but let's face it, you weren't a good husband in the first place and she may have not been a good wife either. Whatever the case, I wrote *Caregivers Wear Plaid* to help you and your wife better understand what is going on in the hopes that you do stay together for the right reasons. If this is where your head is at the moment, give both of you a chance of understanding one another and what is taking place. You could very easily be the most important person in another persons life. Thus, I quote from *Colossians 3:12-14:*

'So, chosen by God for this new life of love, dress in the wardrobe God picked out for you: compassion, kindness, humility, quiet strength, discipline. Be even-tempered, content with second place, quick to forgive an offense. Forgive as quickly and completely as the Master forgave you. And regardless of what else you put on, wear love. It's your basic, all-purpose garment. Never be without it.'

Some husbands will fail to recognize that their wife is screaming on the inside wondering why she can not see or accept what she is experiencing.

Some will simply ignore their wives because they are so involved in themselves. They find it hard to accept or difficult to focus on what is going on with their wife which will lead to more emotional upheaval and stress in both lives.

Some husbands' will evolve into the role of caregiver and do the best they can knowing little about the disease.

Others will become *committed* to not only helping their wife but looking for ways to help others, by supporting their specific community (as defined by their wife's disease) by being there, by being supportive, by raising money for a cure. As Sandra Raymond, former Board Chair for the Lupus Foundation of America, once said, *"With no money, there is no mission!"* We embrace that sentiment and trust you will help out when and where you can.

But, for now, you need to think about where you fit into these scenarios. May I suggest that you celebrate the opportunity before you. You can learn a lot about yourself, become a better you, and more importantly a better person to others through circumstance to which you had no choice but to accept or reject.

We hope that your choice is to accept the role of caregiver enthusiastically and as passionately as you can and learn as much as you can about lupus or the systemic autoimmune disease you and your wife are dealing with. That is your choice. What I know to be true is that to grow is to progress and to progress is to change whether in your business life, personal life and as a caregiver to someone you love. To remain otherwise in a "comfort zone" is to not live within the reality of life and what faces you now. It all starts with the power of Choice.

CHAPTER 1

The Power of Choice

If I could walk a moment in your shoes, I would tell you to ensure that you maintain the best balance you can in your life. Living with someone with lupus or any systemic autoimmune disease is not a short-term proposition. Too often, we can get caught up in the moment, the emotions, and not see the forest through the trees. So I encourage you as a caregiver to look at your situation from the 50,000-foot level so that you can have a better perspective of what is going on and live the best life possible. You will come to learn or discover that change is a constant that you need to adapt to as your wife's disease progresses. i.e., the only thing consistent with lupus and most other systemic autoimmune diseases is inconsistency. It's your willingness and flexibility to take on more responsibilities in the relationship as needed because she does not have the Energy Passes to help out like she used to. Thus, you learn how to live within your wife's limitations.

Change is a good thing. For example, one definition of insanity is doing the same thing repeatedly and expecting a different result. Life can be very rudderless, and often we are forced to seek change due to circumstances beyond our control, i.e., being laid off from a job or being faced with a very sick wife. Conversely, as much as we want to change, we often lack the courage, awareness, and financial ability to step out of our norm and make a change. We find ourselves in a rut of life. Of course, the life you had with your wife before the onset and diagnosis of her disease is one you may not want to change or to make some minor adjustments. If lupus or any other chronic disorder does not adversely affect your life, I would be amazed. It doesn't have to, at least to the degree you might fear.It's a good chance that the symptoms your wife is experiencing have been sneaking up on your relationship for some time with her family and friends. The stress, anxiety, and fear of the future are natural, and to me, there is only one way to overcome

them. To have the courage to face your fears because what you fear has no foundation of truth. "What you fear will come upon you." (Job 3:25 NLT). The only advice I can share to overcome these fears, as mentioned, is to have the courage to face them; talk about your concern with your wife, family, and, yes, your friends too. If you don't, you will watch your life slowly close into the shadow that constantly surrounds your wife's disease. It is not necessary to accept that. Thus, the family is essential; friends are important, and most importantly, you are the one to ensure that both you and your wife live in the light of life as best you can.

Easier said and done, but as you evolve as a caregiver, you will see that your wife's lack of Energy Passes has only diminished by your inability or desire to provide Energy Savings and Energy Moments. That is interaction with those you and she loves as often as possible. I have watched Patty get energized when she is around others, especially those she cares about, our grandchildren, and people in a similar situation. These Energy Moments reinforce the fabric of her life and spirit to carry on. It's uncanny that she seems normal in everyday situations outside the house but exhausted once out of the element (coming home) because her Energy Passes are used up. It takes fortitude to wear this mask of lupus, but it is important to her overall psychological well-being and those with whom she is interacting. So, keep your wife in the light of life as often as possible.

No person changes their old ways to seek the new until they personally find a reason to do so. You have many good reasons to become that caregiver your wife needs as her disease progresses, begets another medical issue, or, may we be excited to say, goes into remission. Being a caregiver, for sure, is different. But I know, I hope, that you embrace the role because, whether you realize it or not, you are embracing a lot of your wife's circumstances. So, get yourself to 50,000 feet and understand the view you are looking at and dealing with. You'll be glad you d i d !

Systemic autoimmune diseases are different

Systemic autoimmune diseases are different from other disorders in that the immune system attacks body tissue. In essence, the immune system turns on the body, creating inflammation that breaks down tissue and thus potentially damages internal organs, such as the kidneys, lungs, heart, and even the brain. Each autoimmune disease has its own characteristics. In Caregivers Wear Plaid, we mainly concentrate on lupus because that is what we deal with daily. However, what one deals with having a partner with lupus is very similar to other systemic autoimmune diseases, even in other disabling life events.

Though lupus is a disease that can kill, it is more often than not a disease of disability. i.e., a physical and/or mental condition that prevents a person from living everyday life. With lupus that equates to fatigue and what is typically referred to as Brain Fog, being confused or forgetful, the degree to which varies significantly depending on how active the lupus is at any given time. That means that lupus can go into remission . . . so there is hope. These symptoms are seen in other autoimmune diseases, so take some time to research the symptoms of the autoimmune disease your wife has.

To the caregiver, lupus is different from a terminal disease, where for the grace of God and a cure, the individual being cared for has a near expected end of life. Therein the caregiver has a short-term requirement to help out. Most autoimmune diseases are not fatal, but their chronic symptoms can progress and make life more uncomfortable.

Patty has lived with lupus for over 50 years. It is important for those living with lupus or other autoimmune diseases to know this because many, when diagnosed with lupus, think they have been given a death sentence, and that is not the case. Whatever the degree to which your role as a caregiver evolves, it can become more

challenging as the years go by, depending on the level of disease activity your wife is experiencing. As a caregiver to your wife, you play a very important role in her mental and emotional health. That is not to say that everything she does, does not anger you . . . but you will come to learn that some things are better unsaid because you know it will cause an argument . . . which is stress . . . something she does not need. You probably don't either. However, there will be times your values and position are important to stand up for. Let that not concern you now. Over time, you will recognize what causes angst and what does not as your wife tries to adjust to her new and ever-evolving norm. Losing your temper can quickly happen. After all, you are human too, but apologize and communicate. Never walk or run away from your feelings or hers'. If you think it is difficult for you, imagine how difficult it is for your wife! Having said that, if your wife crosses the line, it is time to take a stand as your values, etc., should not be violated or challenged.

Compassion, understanding, and proactive actions, like emptying the dishwasher, making the bed, and yes, even doing the laundry, can go a long way to making your relationship closer and more meaningful. I know that doing these chores is not the norm for most guys. In reality, they do not take that long and mean a lot to your wife. I have had friends tell me that I was a saint and that they would never do it! I'm no saint but place the shoe on the other foot. We should be honored to help our loved ones, but for the grace of God, there go I. I questioned how good a friend some of my friends must be if that is their attitude toward their wives. God for be they are ever faced with these decisions. Hopefully, they will step up if the shoe is on the other foot. You never know the rhetoric.

The difference between a rut and a grave

If you don't change and keep on keeping on doing what you have always done, you will find yourself in a rut of life. Too many individuals quietly dig this hole, and it is needless to do so. The power of change and accepting new norms make a

difference. Why? Because it gives you more significant purpose in life, and with that comes even greater knowledge and ability to reach out and help others too. What is the difference between a rut and a grave? The depth of the hole.

"But I like the rut I am in!" you exclaim. I can understand that. Everyone wants to find a comfort zone they can stay in, but as life progresses, so does your comfort zone. It is better to adjust first than to be forced to adjust. Being an accepting caregiver who embraces the challenge and opportunity to help another will push you out of that rut and allow you to live a more meaningful life.

The Internet is not your friend

One of your choices is to go to the Internet to get your information. There is a lot of good information on the Internet, and there is also not. Knowing the difference is very difficult for someone newly diagnosed to discern. The best thing you can do is find out what resources are available to you, i.e., who are the best doctors in your area concerning your specific autoimmune disease treatment. Who are other patients using for their treatment, and what resources do they recommend?

Since the premise of this book is that your wife has been diagnosed with a systemic autoimmune disease, she is going to need a rheumatologist. Knowing others in a similar situation gives your wife good information about whose practice she wants to be a patient. The key is to do it as early as possible. More will be discussed later in another chapter, but know that rheumatologists are becoming fewer and harder to find. So make sure your wife's primary doctor recommends one as soon as possible. It could take up to a year to be accepted into their practice.

If you research "Caregiver" online, almost everything you will find deals with someone dying of a terminal disease. The difference between someone being a caregiver for someone dying versus someone who has a long-term illness is time.

As mentioned earlier, Patty has lived with lupus for over 50 years. So, there is longevity. With proper care, diet, and emotional support, those living with lupus, on average, are living a normal life span.

This chapter has been about choice. Think of all the things you have chosen in your life. The car you drive, and the way you dress, was your choice. Your friends are your choice. The career you have chosen were your choice. The wife you married, and the children you have, were your choice. To get drunk on Friday nights with your buddies was your choice. When you think about it, just about everything you do in your life is your choice, with few exceptions. Here is another option you need to consider:

Try to understand each other!

To your wife, love your husband as much as you can, but try to understand him a lot.

To you, love your wife a lot and don't try to understand her at all! The key is to listen to each other, respect one another, openly communicate with one another, and do the right thing for one another!

Awareness thru communications produces, hopefully, equal understanding. It comes through knowledge and applying what one learns from others and each other. When Patty and I are not communicating well to the point, it is an issue; it is more often than not a misunderstanding. However, it is important to be heard,

and thus we move to the bedroom, sit and talk things out. How we feel, the issue respecting where we are coming from. We did this often in the early days, but today this kind of scenario may happen once a year, if then. Try it. You may find it eases your life.

CHAPTER 2

Living Within Her Limitations

On more than one occasion, I will use the phrase "living within her limitations." I learned this perspective when I met a man, a caregiver I played golf with while on vacation, whose wife has serious medical issues that significantly limit her quality of life. I asked him, "what is the most difficult thing you find to deal with as a caregiver to your wife?" He said, "Living within her limitations." I had never heard it expressed that way before. I realized how prophetic his statement was. I mentioned it to Patty, and she said: "I have never heard it put that way before either, but he is right!" In reality, that is what you will learn how to do or adjust to as your life together goes forward. He also indicated that though their life has been a struggle, there were a lot of blessings too, and one of those was their deeper faith in their God, who gave them greater comfort. It is amazing what one can learn when we open up about our situation and communicate with others! Recognize that as a caregiver, you will be challenged to rise above your natural limitations. We trust you will do that through wisdom gained here and willingness to be that person who makes a significant difference in the life of the person you love.

In Chapter 3, "A Baker's Dozen," I list 13 key things a caregiver should be aware of. Number 13 deals with the importance of taking care of yourself, and that is a key concept that many caregivers forget. It does no good to have both of you sick. So here are some insights, not limited in number or scope, but you should think about them.

Insight One: Think first of her before you.

Insight Two: Compromise before the war. Living with someone with lupus requires one to make concessions. It's better to lose the battle versus always trying to win. At least in a relationship that holds a lot of truth. Always think win-win, and if you lose a few, what's the big whoop! A happy marriage needs compromise and balance to survive, especially when living with someone who has an autoimmune disease such as lupus.

Insight Three: Seek to understand what your wife is dealing with. Education and awareness are vital to finding civility and joy together. Learn everything you can about lupus or the autoimmune disease or circumstances you and your wife live and deal with ongoing.

Insight Four: Problems are not solved through guilt. Solutions are uncovered through interaction (communications), recognition, and awareness of the other. Talk your feelings out. You'll be surprised about the support you receive from your wife as long as you are supporting her needs.

Insight Five: Putting the puzzle back together. The "New" Normalcy. Life is all about change. Don't let lupus define you or your loved one. Understand there are limitations and accept them graciously. Cherish time together and make each moment count. The puzzle of togetherness first comes with love for one another. Let lupus rekindle that flame if that is needed and if not know that love can conquer all relationship issues.

Insight Six: Bring balance into your life. Lupus calls the shots if one allows it too. Lupus is not mind over matter. However, a positive attitude is very important. It determines how many Energy Passes your wife will get every day. Thus, plans

must be flexible on what to do at home, work, where you go, and what you can do. Your wife will learn to manage her lupus on her terms. You need to do the same thing and respect her terms because she has no choice, and you do!

Insight Seven: Manage what you can. You cannot be all things to your wife, and she cannot be all things to herself unless she recognizes her limitations and yours too.

Insight Eight: Patience is a Virtue - It's tough to maintain under adverse health conditions. It affects everyone. Talk about any frustrations gently. Ask for suggestions and ideas to limit your frustration and hers too.

Insight Nine: Do not ignore your symptoms: Anger, anxiety, frustration, confusion, guilt. Recognize your needs and do something about them! Living with someone who has lupus is stressful. To be a good caregiver, you MUST see to your own needs. Give yourself permission to "take a break." And, don't feel guilty about it! Find someone who will listen to you vent your feelings, and often that is someone else who is in your shoes. It is not healthy to keep things inside . . . it'll explode one day. Recognizing "loving with all your heart" means you have to be fit enough to do it! Being a good caregiver is not about you in her eyes. It's about her. She deals with the day-to-day effects of her disease and most often does not believe others, especially you, to understand. Be kind, caring, supportive, loving, and be yourself and take time for yourself. It's a good conversation to have with your wife if you have not already done so.

Insight Ten: There is a higher being - What is, is, and what will be, will be. Place your hands in those of your faith and know there is a universal power that guides all of us. Embrace it and find comfort within it. For example, if I leave home and forget my cell phone, I do not get upset with myself. I'm first glad that I remembered it, and two, I figure God just stopped me from being in an accident

down the road. So He delays me and saves me from a fate much worse than leaving my cell phone at home.

Insight Eleven: Communications, Communications, Communications - Check in on your wife periodically during the day. "Are you doing O.K? Is there anything I need to stop and get on the way home?" Your wife needs that emotional support, knowing that you are there and care. TouchPoints three times a day is not overdoing it, whether by the phone, email, messaging, etc. Your wife needs to know unequivocally that you are in her corner.

Insight Twelve: Always tell her you love her with all your heart. Women can not hear these magic words enough, especially when dealing with lupus or any other autoimmune disease. It is natural for them to begin to feel insecure with their partner. "Do they still want to be with me? Do they still love me? Will they always be there for me?" Insecurity can lead to the untrusting of others, especially you. Insecurity leads to stress, and that is one thing you as a caregiver do not want to add to. Know the person on the inside, not what you are seeing on the outside. It's keeping her confidence in herself, which is the opposite of insecurity, that is so important. So though you may not like what you are seeing happen to your wife, know there is an exceptional person inside who needs your help, understanding, and a trusting love to sustain her during the more difficult times and enjoy those better moments.

Insight Thirteen: Allow daily life to be as normal as possible. As a caregiver, you want to do all that you can for your loved one, but it is also important to allow her to do what she can do for herself. The simple task of getting up from her chair to walk into the kitchen to fill her glass with water is an exercise that helps build or maintain muscle. It's doing something for herself that gives her a level of independence. An independence that is slowly being taken away from her. It reinforces her identity that at least things at home are somewhat normal, comfortable, and secure.

CHAPTER 3

A Bakers Dozen

Before you start reading this book in-depth, I wanted to give you the top 13 things you need to know about lupus and any other autoimmune diseases. I entitled it a "Bakers Dozen" and realized that you might come up with some too as you go down this pathway of being a caregiver to your loved one.

The first thing you need to know is that autoimmune diseases are not contagious. Yes, it can be handed down from one generation to another. Still, there is no evidence indicating that contact with someone living with an autoimmune disease is contagious.

The second thing you need to know is that there is no known cure for autoimmune diseases at this writing. However, drugs are available to manage specific autoimmune diseases. Later in the book, I will talk about some of them.

The third thing you need to know is that your wife, child, girlfriend, significant other, etc., needs to learn how to manage her disease and recognize that if she doesn't, it will control her and you too! For example, if your wife forgets to take her medicine(s), you may not have sympathy for her. It may be that she does not want to take her medication (s), and that is an issue. On the other hand, she could easily forget to take her medicine(s) due to "brain fog." That's what you think it is and is very prevalent in those living with lupus and some other autoimmune diseases. An excellent caregiver will be more sympathetic to her issues and remind her to take her medicine(s). An excellent way to check whether your wife is taking her medicine(s) is for her to use the seven-day plastic pill organizers for her daytime medicine(s) and one for her nighttime medications. This is not for you to

look over her shoulder or be perceived as doing so. If you see that today's pill organizer compartment has not been opened, a friendly reminder is always appreciated.

Additionally, it takes anyone living with a debilitating disease, such as lupus, to come to grips with their medical circumstances. This is not easy stuff; very emotional on many different levels and difficult to accept. That is the journey both of you are on because, in reality, it is difficult for you to understand and accept too. This causes nothing but heartaches unless you are aware and wise enough not to be part of the stress. Not always easy to do. So learn as much as you can about lupus or the autoimmune disease or medical circumstances your wife is living with.

The fourth thing you need to know is not to worry. No matter who you talk to in the medical community, probably the worst enemy you and she have is stress. Oddly enough, it is something that both of you can control or significantly minimize if you have a desire to.

The fifth thing you need to know is that depression is a byproduct of stress. We all have stress in our lives to varying degrees, and having a chronic disease, like lupus, not only causes stress but can lead to depression too. Some days are better than others, and then there is a crisis. Imagine a 16-year-old young lady who is rushed to the hospital on her sweet 16th birthday and is going into kidney failure and finds out that the cause is lupus. Or, you are a young 22-year-old young woman who is diagnosed with lupus and her father does not believe that she is sick; your friends wonder why you are always tired and can't participate in fun nights out, or her lupus has flared up and she does not want others to see her in this condition. These are true stories, and reactions to lupus and can cause a lot of stress, especially in those who are younger, which can lead to sadness and depression. This is known as reactive depression to the disease and common in all chronic illnesses. "Why me!"There is also clinical depression, which is a chemical imbalance in the brain that can lead to depression too. As a caregiver, if you are

seeing signs of depression, you should encourage your wife to talk with her doctor. There are treatments, such as antidepressants and other therapies for treating depression. As a caregiver, this is where your awareness of the disease is important as well as your emotional support and love. You will know what depression looks like just by the way your wife is reacting, such as losing interest in things or showing the feeling of helplessness, and so on. Whether you are a parent or a lover, caring, understanding, and supporting are important components to your child or wife's quality of life.

The sixth thing you need to know is that nine out of ten people living with lupus do not look sick. This is not a Jekyll & Hyde. Unless your wife has a visual rash, you will not see much difference between her and someone normal looking. Know that what is going on the inside is not necessarily what is being shown on the outside . . . especially in public. Michael J. Fox, the actor who has Parkinson's, said you have "two things to reckon with. You deal with the condition, and you deal with people's perception of the condition." This is so true with those living with lupus as well, but also for caregivers as you will need to deal with the ups and downs lupus brings your way. This includes your potential depression living with and caring for a loved one who has a debilitating autoimmune disease.

The seventh thing you need to know is that your wife is given only so many daily Energy Passes each day. Energy Passes do not come from a store, and they are not dispensed uniformly. Some days your wife will have ten Energy Passes, and other days only 1 or 2. Having none is an exception but not out of the realm of possibility. It just depends on how active her lupus is on any particular day. What is an Energy Pass, you may ask? Individuals living with lupus and most autoimmune diseases live with constant fatigue. It's not the same as being tired. It is fatigue that manifests itself in the inability to have enough energy to do anything, such as getting out of bed, shower, having a meal, etc. The quality of her life will vary greatly depending upon your wife's disease activity. Fatigue is not

alleviated no matter how many hours of sleep she gets. It is probably what drove your wife to the doctor at the beginning of this journey: "Why am I so fatigued!" And it is probably the last thing for you, as a caregiver, or family members, to accept and understand because outwardly, she does not look sick.

The eighth thing you need to know is that lupus can go into remission. Yeah!!!!!!!! A lot of that depends on, well, we just don't know, but if it happens you'll need to be thankful. However, this is not a time to rejoice to the extent of not being careful to sun exposure, and other potential stressors or activators. If your wife is put on a new medicine, there is always the potential risk of a flare. And then there are always those thoughtless incursions into one's life. Maybe staying out to late, having to much to drink. The body human will react in its mysterious ways when living with an autoimmune disease. In other words, your wife goes into a flare for no apparent reason. It is just what it is!

The ninth thing you need to know is that lupus and other systemic autoimmune diseases can kill. We have lost too many friends, neighbors, and acquaintances to lupus. It hits home real quick when that occurs and age does not discriminate. Because these diseases are inflammatory, they can cause multi-tissue damage to internal organs such as the kidneys, lungs, and heart. Thus, your wife should follow the doctor's orders and keeps her appointments. This is not a disease to fool with or be fooled by and needs to be managed by a primary doctor who is well educated about systemic autoimmune diseases and a rheumatologist. Though the life span for someone living with lupus 50 years ago was not good, today with proper treatment and care, your wife can live a normal life span.

The tenth thing you need to know is that 1 out of every 123 to 150 women have lupus. No one knows for sure the actual count. It's the best guess that the number of individuals living with lupus falls into that range. Lupus is an equal opportunity disease in that children as young as infancy are diagnosed with lupus. For more information on children, go to Chapter 19. It's a little scary, isn't it? When I ask people if they know anyone who has lupus, generally one out of three

does. Lupus is far more prevalent than most realize. So, you are not alone. Approximately 50 million people in America suffer from one of the more than 100 known autoimmune diseases according to the American Autoimmune Related Diseases Association (AARDA). And 75% of those affected are women. That means 20% of the population in America is suffering from an autoimmune disease if the statistics are correct. Regardless, autoimmune diseases and how they affect women's health issues are rarely discussed and should be. Also, the average annual health care costs for someone living with lupus can become very expensive if one does not have good insurance. See Chapter 26.

The eleventh thing you need to know, as just mentioned, is that men can have lupus too. Men represent approximately 10% of those living with lupus. We do know of one couple who both have lupus, genetically unrelated as husband and wife. It raises the question: "Who takes care of the caregiver?" when both husband and wife are sick. They do it together and if need be with the help of friends, clergy and other professionals. He lived to the ripe old age of 92 and she is still plodding along, so there is longevity.

The twelfth thing you need to know is that being a caregiver is not easy. It takes a lot of adjustments, willingness, kindness, compassion, and love to be there for the one you are committed too. You need to know that your wife does not want a caregiver. She may become indignant, downright ornery, because she wants to do things for herself, which is a good thing, but not always common sense. Thus there is a fine line between being helpful, respectful or being a thorn in her side. God-for- be if I step on that preverbal mistake of action or speech and she erupts. That causes additional stress in her life and yours too. But, for her, it can lead to a flare and more serious medical issues. It is what it is and you will learn over time what trips the trigger . . . and then there are just those times. Take it with a grain of salt, because one illness can beget another through interaction that becomes stressful. It's not about you! Having said that, if you get pissed off, you have emotions and needs too. Just don't let it get out of hand if at all possible.

The thirteenth thing you need to know is to take care of yourself; time away doing the things you enjoy without guilt of doing so. The worst thing that can happen is that you get sick and cannot care for your wife, children, and household needs. Realize that your wife will feel guilty that she cannot do certain things anymore, such as doing the wash, emptying the dishwasher, or cooking meals. So, communicate with one another to work these feelings out. Feeling guilty for both of you is a normal emotional response, but not if you communicate with one another and express your true feeling.

I'm sure as you travel down this road you will come up with other more important things to add to your own Bakers Dozen. At least this is a start for you. I'll talk about these thirteen and other subjects in greater detail throughout the book.

Well, that's my Bakers Dozen. You may not know the origin of the phrase. It goes back to the 16 century in England where the price of bread was monitored by government regulators for the price of wheat used to make each loaf. The penalty for a baker to short change, cheat a customer, was rather stiff and often resulted in a beating. So bakers figured out that if they put an extra loaf of bread in a dozen, thus 13 or even 14 to make sure, the chances of them falling a foul of the regulators and irate customers would be minimized at best. As a caregiver, doing that little extra thing can help you from falling a foul of your wife and her temper. Big things are important, but it is the little things that really make the difference.

CHAPTER 4

The Privacy of Pain

I initially gave my book a subtitle, "The Privacy of Pain." My editors did not understand it, so I decided to make it a chapter instead. Understanding your wife's mental, physical, and emotional pain is essential.

The privacy of pain happens to people when your loved one becomes sick and withdraws from the life they once knew. It's the period one goes through coping with and accepting the new reality of their life. Autoimmune diseases, such as lupus are not easy to deal with. But like anything else, through knowledge and understanding, one learns how to deal with their disease and its potential outcome. So too, as a caregiver, you will learn over time that your life will be enriched for being allowed to serve another in ways you may have never considered in the past. In essence, you become a better person. More sensitive to the needs of others because of the shoes you and they are walking in.

The privacy of pain is a cycle of emotions. Like your wife, you will probably go through the same stages of grief that I call "Acceptance ." Those stages are: 1) Denial, 2) Anger, 3) Depression, 4) Bargaining, and 5) Acceptance. These are classic signs that most people go through when confronted with a disease diagnosis and, oddly enough, for the caregiver. With lupus, and I assume with other debilitating autoimmune diseases, one can ultimately get to acceptance, and then something happens that can drop your wife right back into depression, anger, and even denial again. For example, Patty was put on statins by her primary doctor and almost immediately she started feeling joint pain. Of course, she waited to see

if it would go away, but she asked her primary doctor to take her off them when it didn't. Two years later, seeing neurologists who could not figure out what was going on, we were referred to Duke University, where Patty was diagnosed with Statin Induced Acquired Myotonia. Ever heard of it? Her neurologists didn't either until we got to Duke. Within four hours, they had her diagnosed. Two months later, it was confirmed. Unfortunately, the pain associated with Myotonia is high, and all treatments did not correct the situation. As mentioned before, one disease can beget another. Today, Patty is one of three patients at Duke who are dealing with these circumstances. Statin Induced Acquired Myotonia is not as rare as one might think. Most diagnosed by their local doctors' experience zero effects after being off statins for nine months. When I was prescribed statins, I lost my immediate memory. That is not as rare as one might think.

The privacy of pain is also a cycle of adjustments to what your wife can and cannot do and the extra responsibility those changes bear upon you as a caregiver. It is learning to live within her limitations.

The privacy of pain is also keeping a disease inside versus sharing it outside. One of the best things one can do is search out others with lupus through support groups. It is very therapeutic to recognize that they are not alone, willingly sharing with others. It's not a pity party, but instead building friendships and knowing that she, your wife, is helping others or being helped by others in her shoes. The saying, "I begrudged that I had no shoes until I met someone who had no feet!" Every person living with lupus is at a different level of pain and circumstances, whether medically, emotionally, or financially. In our experience, those who become part of a support group feel better about who they are and their lives.

Recognizing that there may not be formal support groups where you live, you can check with The Lupus Foundation of America, LupusOne, or other organizations that support such efforts. If that does not work, enough people

are living with lupus in the shadows and when approached will want to talk, get together, start a group. You can learn more about support groups in Chapter 22, *The Power of Support groups.*

A difficult question

The privacy of pain for a caregiver raises a very direct life question too. A question to which the answer lays in one's values. Do you, as the husband, significant other, with children or not, stay or do you go? Chapter 5 - *The Elephant in the Room* explores that question.

CHAPTER 5

The Elephant in the Room

"A life is not important except in the impact it has on other lives!" Jackie Robinson, first black man to play in the modern day major league baseball.

I remind you that I am not a lawyer and am not providing legal advice here, nor am I a psychologist or other professional trained to help individuals work through life's trials. I am simply expressing what I have observed over the years as a caregiver and husband, and I am passing these learnings along to get you to think before you take any action that you may regret. I decided that this topic should be addressed upfront so that we can get it out of the way and concentrate on more important topics . . . not that considering divorce is not important. It is expensive, divisive, and never as easy as one might think. Even though that may be your wish, there is no such thing as a mutual agreement. I sincerely hope that divorce is not in your mind. Again, if divorce is in your mind, I encourage you to take time to think it through before taking any actions.

We periodically hear that "my wife had a screaming fit last night and wanted to know why I was staying with her because of her disease!" This is a reaching out for confirmation that you still love her, care for her, want to be with her regardless of her health issues.

This is an emotional time. A time that has led up to a point where your wife needs all the support and understanding she can get from you and other family members. She has finally been diagnosed, and now you know that she was not

been faking symptoms; that she has a disease that can have serious health issues, even be life-threatening.

There are many reasons why people get divorced, but I can tell you the number one reason is a lack of communication and failure to listen to one another. As noted by Lisa L. Payne, Kim Oliver & Deborah Roth's article: The 10 Most Common Reasons People Get Divorced 09/16/2015 - The Huffington Post. The authors' site "becoming lost in the roles," which occurs over time transitioning from being single, married, having kids, getting wrapped up in individual roles, to the point that couples forget they are a couple and before long discover they don't have anything in common anymore.

According to the American Psychological Association, about 50% of marriages end up in divorce. Throw a systemic autoimmune disease into the scenario, such as lupus, diabetes, heart disease, arthritis are and the divorce rate becomes much higher. It's not the diseases, but rather the issues in the relationship before the symptoms and diagnosis that adds more fuel to the thought process. More fuel to the fire. I know, it is painful and certainly does not fulfill anyone's initial expectations. But, this is life.

I think there is another reason that comes before the stresses of life outside the marriage and that is the language of touch. The lack therein is the first indication that not all is well in the relationship. The pain, the fatigue associated with autoimmune diseases can evolve into less loving, less kissing, less hugging, less holding hands, less touching and then the separation begins to occur unless you understand what is going on.

I go back to communications, which often is not a two-way conversation unless you are willing to *listen* and understand your partner, her issues, her needs, her desires, and yes, she understanding yours too. That leads to the most important

language: listening. We guys are not always good at that, and I have often failed in this regard throughout my life. Let your wife talk and express what is going on in her, her fears, concerns, wants, and needs from you. She needs to be comfortable and confident enough in the relationship to express her true feelings and her true fears. Don't think this is a one-way conversation because though she is the one who is sick does not mean she should not respect your feelings, fears, and concerns too. This is the language of emotions. Holding them in or expelling the anger; the joy, the laughter. The emotions of our life and how we handle them play such an important role. Remember the language of:

- Touch
- Communications
- Listen
- Emotions

I can't understate how important these languages are to the success of your relationship. Remember, above all else, love conquers all.

Today is a great opportunity for you and your wife to regain what you once had. There is nothing greater than one individual's love and compassion for another. If the shoe was on the other foot, what would you expect from your spouse and family? A lot of understanding and doing the right thing!

If you are considering a divorce, Patty and I encourage you to seek guidance from a professional psychologist or marriage counselor, especially if you have children. It is all about communication and truly listening to one another. So have the courage to sit down with your wife and share your thoughts and concerns as you enter into this new and ever-evolving role of caregiver. Share your fears and concerns and how to move forward together as a team. You will be surprised at how close you will become to a greater purpose.

Again, Patty and I encourage you to seek guidance from a professional psychologist, marriage counselor, or minister if you are considering divorce, especially if you have children. It is all about communication and truly listening to one another. So have the courage to sit down with your wife and share your thoughts and concerns as you enter into this new role of caregiver. Share your fears and concerns and how to move forward together as a team. You will be surprised at how close you will become with a greater purpose in mind. And wow, over time, you just might, you and your wife, find yourself helping others through a similar situation. It will take some teamwork and adjustments between the two of you to create a new normal, but you can make this work. It will also take faith in your God and self that you are capable of taking this responsibility on in your life. Think in terms of being positive, caring, and compassionate.

Remember the languages of touch, communication, listening, and emotions. Your wife needs all the reinforcement and trust she can get from you.

Enough said. In the next chapter, I will talk about the Evolution of a Caregiver. It's basic stuff, but it is nice to know where you are in the scheme of things.

CHAPTER 6

What is a Caregiver

Everyone is a caregiver! Let me explain. You take care of yourself through good hygiene, ensuring that you have a roof over your head, food to eat, clothes to wear, a car to drive, and a job to earn money. You have learned to take care of yourself. As stated, "who you are speaks so loudly I can hardly hear a word you are saying." Now you are part of a team that works together to support your relationship, your family, your friends, and so on. Now you find yourself presented with a different challenge, which I prefer to see as an opportunity. Don't get me wrong. I wish deeply that your wife was not living with her disease intruding on her normal life and you. But, this is the reality. Your wife is not in the game like she used to be. To use a baseball analogy, she no longer has the stamina to play the game; take that swing at life as she used to. Her ability to play the field is filled with errors, or she is too slow to make the play. What has happened to your team member is confusing at best and heartbreaking at worst. Your wife no longer can come off the bench and play the game she once played; hit the home run in the bottom of the ninth to win the game like she used to. But, she can certainly cheer you on and do the best that she can for the team, knowing that she is living within a secure, nurturing, loving environment.

Being a caregiver, be it to a parent, spouse, child, another family member, or friend, is a commitment to another individual to provide what they cannot do for themselves. That care will come in many different forms, but most often in a helping hand with understanding and compassion. Caregivers most often provide non-medical tasks such as personal care, household tasks, companionship, and "Yes," being Uber Boy. Caregivers also serve as their loved one's advocate. Your wife, living with lupus or another disabling autoimmune disease, will, in most cases, be able to take care of her daily needs, but not all that she wishes to do with

her limitations. Again, you will find yourself living within those limitations, being that extra hand, anticipating her needs, and being there for her. If her autoimmune disease progresses to where her needs are greater, know that this is what love is all about. Helping her dress, shower, use the bathroom, and so on.

Caregivers are probably the most forgotten people in caring for a loved one. Unless you have had the opportunity to walk in someone else's shoes, there is no way you can understand or appreciate a good caregiver's commitment and compassion. But, now that you are one, I assume you probably have many concerns. I hope our book addresses them or, at minimum, reduces your fears.

You're not alone

Realize first that you are not alone. Probably 60% of caregivers worldwide are unpaid family members, most notably husbands, when it comes to lupus because, as noted before, 90% of those living with the disease are women. In my case, I am a lover, clothes washer, dinner maker, advocate, Uber boy, listener, and hopefully comfort to my wife. Oh, I iron too. I don't pretend to be good at any of those mentioned above, but it is difficult to mess up laundry, getting Patty from one place to another when she cannot do so herself. So that the house does not become a total mess, we have a cleaning lady come twice a month. While she is here, it gives me a chance to run errands.

Often when our lives change because someone becomes sick in the family, we tend to believe that we are alone. Your wife's doctor was not thrilled to tell her that she has lupus. Of course, that is kind of good news/bad news in that she and you finally know what she has . . . why she is tired all the time, joints aches, etc. However, rarely does a doctor recommend seeking out emotional support for your wife or yourself, and that is probably one of the most important things needed; the understanding and compassion from family, friends, neighbors, co-workers and

yes, you! Unfortunately, that does not always happen. As mentioned before, most individuals living with lupus do not always look sick. They are not wearing a cast or walking around with crutches for everyone to see and sign. It's not apparent on the outside what is going on the inside, and this is probably one of the most challenging things for you to understand, let alone others.

What does an excellent caregiver look like?

1) Compassionate:

Being an excellent caregiver, in my opinion, is someone who understands the autoimmune disease their wife has. Excellent caregivers are compassionate about what their wife, child, or family member needs to live the best possible life under the circumstances. If you do not have the compassion to look beyond yourself and become the helping hand, you are in for a long hard road through your ignorance and/or lack of appropriate values. That's a pretty hard statement, but lupus and other potentially disabling autoimmune diseases are not to be fooled with. It can be heartbreaking, definitely life-altering, and as noted in our dedication . . . deadly!

Dr. Kelly McDougal, a health psychologist at Stanford University, suggests that those who show compassion to others are generally happier and healthier when they focus on the other persons suffering and not their own. In other words, don't be compassionate to others expecting something back in return. You do it because you care about the person and know that you can and are welcome to help.

2) *A Servants Heart:*

It's more than doing the wash, cooking meals, being Uber boy if needed. It's an attitude that one is not born with. It is learned, just like a great salesperson. I have never seen a newborn considered a great salesperson. It is learned over time in our formative years. Having A Servant's Heart can be learned and practiced in our adult years. We are all serving someone. Who else better than the heart of your life. Your attitude towards life will be life's attitude towards you. You are not in a fun situation, but trust me, your attitude toward being an excellent caregiver will make an exceptional difference in your loved one's life and your's too.

3) Being an Advocate:

Being an advocate for your wife is extremely important from the standpoint of being supportive of her and her needs and building an honest and trusted relationship with her and her doctors as her medical team grows. Most doctors see an advocate (caregiver) as a patient, too, because they are willing to walk through the door with their loved one, be supportive and interested and fill in the gaps of understanding. One of your wife's greatest fears is that you will not be supportive, be the advocate she needs, and build that trusting relationship with her and her doctors. Know that you are part of her medical team too.

Initially, Patty was scared that I would tell the truth about what was going on with her. In our medical journey, we discovered, purely by accident, that Patty had a B12 Deficiency. Remember, one medical issue can beget another. Vitamin B12 supports cognitive function and can relieve mood swings, anxiety, depression, etc. B12 provides a boost in energy too. 5-Hour Energy Drink, which is the most popular on the market, provides 500 mcg or 8333 % of the average daily requirement of B12. It is an amazing nutrient that doctors often overlook.

It's not a bad idea to ensure your wife's B12 is checked when she has a blood test.

Pernicious Anemia

Not everyone has an issue with their B12 because they get enough daily through their normal diet. But some, like Patty, have Pernicious Anemia, where B12 is not processed by food into the body system to produce fuel (energy), thus causing tiredness, confusion, issues with reflexes, etc. Pernicious means harmful, damaging, and can lead to death if not treated. Thus, B12 shots are the order of the day. Most often, one shot a month, but it could be three times a week in more severe issues. The good news is that the body takes what it needs and flushes the rest out. The better news is that B12 is inexpensive.

Once I shared Patty's symptoms, the doctor reached the obvious conclusion. Though Patty was upset with me initially, the responding results made her feel like a new person.

4) An Excellent Caregiver is flexible and resilient:

In every adversity lays the seeds for success. You may not see that now, but mentally, you will when things are not going your way. Doctors are late; your wife goes into a flare, you call a friend late to let them know that you guys can not make their dinner party or go to the movies with them tonight due to your wife's lupus flare, or give away those great tickets you had for a concert. Every adversity lays the seeds for success and understanding, which means opportunity. One lesson from that is that you learn to be unselfish by putting your wife first. You will also learn patience, a virtue you will need to exercise. Part of that is to understand what you are dealing with. Not everything will go as planned, so go with the flow,

pace yourself, and things will be easier to deal with. If the above bothers you, imagine how your wife feels.

One New Year's Eve, we had reservations for dinner at a wonderful restaurant and tickets after that, front row seats, to a Gaither Vocal Band New Year's Eve Concert. If you have never attended one, it's a real treat. Patty's appetite was near zero at dinner, and she was not feeling well. As much as she wanted to go to the concert, she simply did not have the energy to do so. She asked to go home, and that is what we did. Imagine if we were going out with another couple and we had to call off the evening in the middle of dinner. This is real life, and she is far more important than any concert. Of course, we were not happy to miss the show, but there will be other events and other nights out. You see, it is not about me. It's about her, and it's about me being a supportive partner/caregiver as you should be too. No angst. It is what it is!

Not everyone will sign-up for this. But with greater awareness and understanding of lupus, etc., we hope that you are or become that partner, caregiver extraordinaire that understands, is supportive, and one with her to enjoy life as well as you can with as little stress and fear as possible. For most, lupus and other disabling autoimmune diseases are not going to go away, and like Shellee, to whom we dedicated this book, there are no guarantees other than to live each day to the fullest.

5) An Excellent Caregiver strives to improve

Writing this book has been a learning process above and beyond all our years together living with lupus. I pretty much have my emotions and responsibilities in place, but I am always learning by reading, getting involved, and listening to others in a similar situation. I attend almost all events for the Lupus Foundation of America in the State of North Carolina, as well as our support group. I listen, ask

questions and learn a lot from other caregivers and those living with lupus. Do not allow your wife's Privacy of Pain or your emotional concerns withdraw you both from the world of family, friends, neighbors, co-workers, or the lupus community. Yes, like other autoimmune disease there are support groups where those ideas and what works are shared, and good friendships are made. Often these support groups are mostly comprised of women for obvious reasons, but you would be surprised how welcoming they are to us men. One of the biggest issues women with lupus have with their men is: "They don't understand what I am living with!" Learn everything you can about lupus, research, programs, and services available to help your wife, and you can live a quality and full life together.

6) An Excellent Caregiver always has a good attitude:

What? Of course, you will get upset from time to time, but I am talking more about being optimistic. No one wants to hear a complainer, a woe-is-mer. If you remain positive and optimistic, this will make your wife feel much better about her situation (be it lupus, another autoimmune disease, or a tragic event and your relationship. Needles to say, this reduces stress, which potentially reduces flares, and your wife's family will think a lot better about you; that you are compassionate and willing to take on more responsibilities (do what needs to be done) in the relationship. If you dread coming home, you will not be an excellent caregiver. How can I say that? Your actions will speak so loudly that your wife will hardly hear a word you are saying! If an "Attitude check" is in order, park it at the door.

Don't get me wrong here. Just about everyone in my neighborhood has something to complain about, and I can pipe in from time to time. But when it comes to your wife, be careful what you say. The emotions and realities she is dealing with are different from yours. One simple thought expressed incorrectly or in a frank manner can lead to an argument. Stress will affect your wife a lot more than it will you. So, think of her first. A lot easier said than done.

An example: Patty has difficulty walking and uses a walker to get around the house. She wanted me to play golf with friends. Something I have not been able to do for a long time. After the first nine holes, I called home, and there was no answer. I called three more times before we got to the tenth hole. I told my friends that I needed to go because, in my mind, Patty was on the floor and not able to communicate with me. When I got home, she was fine. She had been on the phone with our son and did not know how to answer my call and keep our son on the line. It would be easy to get upset, but I was relieved that she had not fallen and hurt herself. I suggested that she could always call back when she saw the call coming in from me, which was something that had not occurred to her at the time. I will have plenty of other golf outings in my life, as you will have your moments. Do not let the emotions of the moment create greater stress and strife. It is not worth it!

7) An Excellent Caregiver maintains a happy home

Humor is a lot better than being pissed off all the time. Reducing stress within the home is very important. The way you do that is in the above keys and your willingness to minimize or eliminate negativity in the home. I'm not suggesting that everything is always good, but it is better to be positive during negative circumstances than to create an uproar. If Mom and Dad are always yelling at each other, that does not make for a happy home. So here is some simple advice that I saw on the wall in a restaurant:

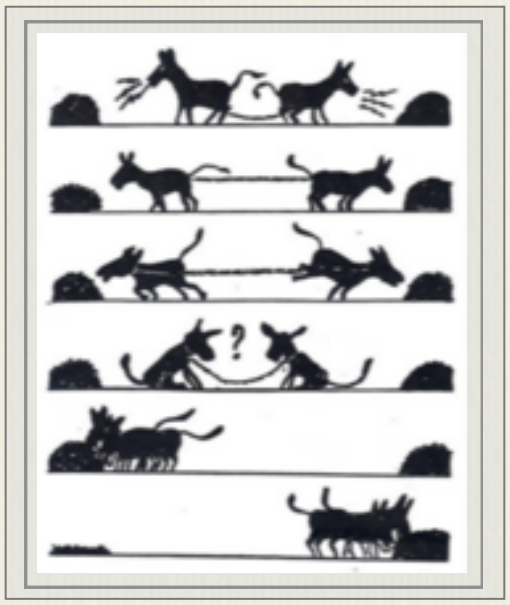
First, engage your BRAIN before putting MOUTH in GEAR. And when you do open your mouth, be sure that what you say is NECESSARY, that what you say is done so in a KIND way, and that what you are saying to your wife is TRUE. Again, there are often words exchanged between husbands and wives that both wish they could withdraw. So I ask you one simple question, to which I do not need to know the answer, but both

of you need to think about it. Is what you are saying to one another true, necessary, and most importantly, is it kind? Is your tone of voice and body language saying something different than what you intended, or is it that who you are speaks so loudly that your wife can hardly hear a word you are saying because the words said do not match the tone of your voice and body mannerisms?

If you deal with your spouse's needs with a positive ATTITUDE; replace feelings of inadequacy and guilt with a DESIRE to learn all you can about her disease; COMMUNICATE AND ESTABLISH SHARED GOALS; create a PLAN OF ACTION to take over responsibilities that she can no longer do on a regular basis and then simply WORK at it. You will discover over time that you will ADJUST and ADAPT to a new norm. It's not easy, but it's worth it!

8) An Excellent Caregiver does not feel guilty . . . unless they are

I know it is easy to feel guilty. I used to feel that way when I went off to play golf with my VFW buddies. So, I brought the subject up to Patty, and she was very supportive of me getting out. If we have any problems with each other, we talk to one another about it and get it out of our system. I don't need to apologize as much as I used to. Because we communicate our concerns and feelings, we do not seem to have too many contentious moments in our life. We are a team doing all we can to help Patty's situation and work with others in a similar situation. Patty notes that her time alone is essential for her to relax and not have to deal with me. She uses the word "Jubilant," which tells me that she is O.K. by herself. As time has gone by, her health issues have progressed. I find her need for my time to be with her more important to her. A good portion of this book was written while Patty was watching TV and me at the kitchen table. It allows us to have a conversation and talk about the book's content. She is always adding something, which makes this book even more valuable because it is not just my perspective and experience, but hers too as someone living with lupus.



When I commuted to work, I would send Patty an email when I got to my office and would send her an email when I left work so that she knew I was on my way home. I also communicated with her during the day to make sure she was doing O.K. Did she need me to stop on the way home for anything. We always would end with "I love you." Today, I am fortunate enough to be able to work from home. Patty's health has worsened, and to have this opportunity to be at the house and still get my work done brings a sense of relief and safety that if she needs me, I am right here to help.

9) An Excellent Caregiver is an excellent teammate

I'll talk a lot about this in the book. Talking out loud to each other about your fears and her fears is important. Talking about fears seems to make them easier for both of you to deal with them. Also, know that what you "worry" about will come upon you. Not overnight, and maybe never. But, it adds undue stress to your life. So don't overthink it. stress.

I love the graphic on this page, and I have no idea who created it, but I have had it for countless years. Do not take any personal reference that your inability to live together within her limitations makes an "ass out of you and her!" There will come a time when you will have learned that the ropes that bind you are a lot stronger than the circumstances that separate you. In other words, working together, in concert with one another, and your ability to anticipate your wife's needs will make a life for both of you more enjoyable, purposeful, respectful, and thereby easier. The graphic certainly portrays the importance of working together

as you build your team of doctors, communicate with friends, neighbors, and relatives, and understand your role as a caregiver.

It isn't easy to know what is going on with your loved one on the inside. This is not a bandaid over a cut or a foot in a cast. It can be challenging, especially if you are working and unable to communicate or check in regularly because of your job. My duties in the home have certainly changed as Patty's lupus and other medical issues have advanced. When she has Energy Passes, she does what she can, and I let her do that because I know it is good for her physically and psychologically. And yes, it takes a lot of my time and energy to juggle housekeeping, preparing meals, taking care of the outside of the house while juggling my work, writing this book, and so on. Oddly enough, I do not feel stressed by this, though I know there is a certain level. Over time and given time, we adjust to our circumstances. It becomes a routine where I use my time more efficiently, and we spend more time together than ever before.

The Life of Patty

Your family could be very much like ours, where our children are not exposed daily to the life of Patty. Like most people, they are involved with their lives, their children, work, school events, and so on. We do not have any other relatives in the area that we can rely on, so we are pretty much dependent on ourselves. It is why a support team outside of your family is essential. One of our friends, who has lupus, loves to cook and apparently for an army, even though it is just the two of them. Her husband is over at our house on occasion with sumptuous soups and other delights. Since writing this paragraph, his wife's lupus has advanced to the point where cooking has become a physical challenge.

I may not be the greatest cook in the world, but I have become more comfortable deciding what we will have for dinner, preparing meals, and speedy cleanup in the kitchen. Of course, if you can afford take-out every night, that is one thing. My friend is desperately trying to learn how to cook, and according to him, he is getting a lot better.

He and I also travel to various lupus events, allowing us to vent and reduce stress. The easiest way to do that is to speak with others in a similar situation and ask: "What do you do?" You not only learn but help others think about their situation and how they can make things easier. So I encourage you to reach out to others. It's an excellent way to share feelings and gain support.

InDirect Caregiving

You might not be the direct caregiver. It might be your child who has lupus, and your wife is the primary caregiver. I talked about this during the "Bakers Dozen, but repetition is the aide to memory, and frankly, this is a big problem . . . acceptance. Know that your attitude toward your daughter's lupus, what she is dealing with medically, physically, and emotionally, is real and complicated. Imagine a teenager, vibrant and energized in her youth and all of a sudden being diagnosed with lupus. It is frightening to a parent, but imagine what it is to your daughter. Simply accepting, supporting, and being positive around your daughter can make a big difference for her, especially in the stress associated with lupus. She needs to know that you love her and understand, as do others in the family . . . be supportive and help out where and when you can, which may not be a lot. It's the attitude that counts! "Dad gets it!" This is also true for your wife because though she is older and wiser than your daughter, lupus is a very emotional disease to live and cope with.

Final thoughts on this chapter

Patty and I have been closer than we could have ever imagined due to her lupus. I would do anything for a cure, wouldn't you! More research is going on today than ever before to find a cure for lupus.

Who you are speaks so loudly that I can hardly hear a word you are saying! This is paraphrased from Ralph Waldo Emerson's famous quote, which means actions speak louder than words. Actions, not intentions, are what morally counts! To your wife, words are very important, and good intentions have a limited life span, but your actions will determine how good of a caregiver you become.

In the first edition of Caregivers Wear Plaid, I had a chapter on the evolution of a caregiver. I removed it from the 2nd edition as it would probably scare most people that it takes so long to come from a novice to an expert. I'm not sure there is anything known as an expert caregiver. It's doing the best you can in a loving and caring way. Like other disabling autoimmune diseases or other life-altering events, Lupus is more often than not a progressive disease, progressive circumstances. As I quoted Jackie Robinson earlier in Caregivers Wear Plaid, "A life is not important except in the impact it has on other lives!" The process evolves and improves by utilizing the tools and awareness from our experience, as expressed and shown in Caregivers Wear Plaid.

CHAPTER 7

What About You?

You and or your wife may not want to accept the diagnosis, and that causes potential problems within itself. It would help if you recognized that lupus is real, debilitating, and life-threatening and that your wife is not faking. You will learn to survive through this process as your wife is trying to thrive. You can adapt to your situation. It's a choice. It is also a choice for your wife, but not when the effects of lupus are in prominence; it is what it is! In chapter 13, I will talk about the Cycle of Lupus, which will give you a better understanding of the disease. But let's talk about you for a moment and what you can do to live within your wife's limitations and still have a quality of life.

First, you will probably take on more responsibilities inside the house, such as cooking, cleaning, changing the linens, vacuuming, dusting, washing clothes, and doing the dishes. On the outside, it could be doing the shopping, though today, you can order groceries online and have them delivered to the house. You'll be the Uber boy when it becomes difficult for your wife to drive and the advocate as you join her at every doctor visit that you can. It all starts small, but as and if the disease progresses, you will find you have more responsibilities. The idea is to adapt to those responsibilities before they become a discussion.

"Honey, can I help with . . . ?"

Adjustments require time, and how you manage them is the key. If you want to eat, someone has to cook or make dinner. Patty has gone from making meals; she loved to cook, to having difficulty, to physically unable to cook. I now do all

cooking. I've learned a lot, and to her amazement, I'm doing a pretty good job with her guidance. Sometimes I surprise her with my concoction for dinner, and I will pick dinner up for us at least once a week. For Patty to go out to dinner or lunch has become a major use of her *Energy Passes*, so we infrequently do so. We find it convenient if Patty feels O.K. to stop at a restaurant for lunch when coming back from a doctor's appointment. Today we try to schedule two doctor visits on the same day so that we can have lunch between appointments if possible.

Every Sunday, I take the sheets off the bed and throw them into the washing machine. As that is going on, I will make breakfast for us. She loves blueberry pancakes. Thus, more than one thing is going on at a time. Once the wash is finished, I iron. "Oh no!" you exclaim. I never asked Patty to iron our sheets over the years, but now that I have control of the wash, I frankly like ironed sheets, and Patty does too. She didn't like ironing. It doesn't take long. After breakfast and before the sheets are finished washing, I will make the bed.

Here's the deal. You have to be willing to change. The things I do around the house are not burdensome, simply because I have accepted the routine. We do have a lady come in every two weeks to give the house a good cleaning, and she does. She always complains that she is not finding any dust. It's kind of funny because she holds up the duster and exclaims, "This is all the dust I found this visit!" In essence, she is wondering why she comes to clean the house, but that is something that Patty wants to be done. So, you pick your battles, and some of them are not worth fighting. If you have children living at home who can jump in and help with the chores, what a great lesson for them to know how important it is to help out and discover that doing these chores is not all that difficult. There will come a day that Patty is no longer with us, and I pray that happens before I go. My point is that I will not only know but have learned how to self-sustain with what in the past has been considered a wife's role in household chores. Of course, once I am old and feeble, that is different. I think we all want to remain as independent as we can for as long as possible. The idea is to go with the flow as

your wife's disease progresses or regresses. That's the way it is with lupus and many other autoimmune diseases.

Use moments in time

When it comes to cleaning inside the house, using 'moments in time,' or as some may refer to as swift cleaning, makes the chores easier. For example, cleaning the bathroom can be a chore, but it only takes a few minutes to clean the toilet; it only takes a few minutes to spray the shower with disinfectant and wipe the shower head down. If you see it as things that should be done versus an attitude of "why me," then it becomes routine to take a "moment in time" here and there and keep up with what otherwise could become a medical risk to your wife. You can also use the "see ums theory." If you see something that needs to be done, do it . . . right then . . . such as a toilet that needs cleaning. We all have good intentions, but good intentions do not always get done, do they? A lot can be accomplished using 'moments in time,' and your wife will appreciate it.

If your circumstances are not as neatly packaged as ours, you may need some additional help. This is when you can invoke help from family members. If your wife's Mom lives nearby, it is a motherly instinct to help out. Don't look at her as intruding. She can be very helpful and more than likely wants to be . . . especially if your wife is still working and her Mom is not. She can come over once a week and clean the house during the day.

It's interesting that when someone gets sick with a short-term issue, such as a broken arm, neighbors will rise to the occasion and bring dinner over. Of course, that does not last long as a rule, but you might have that neighbor willing to help out inside the house as a friend or for a small fee. There are options.

Most importantly, between work and home, there are those things that you want to do. Hesitate not to go and do them, but communicate first. You need that time with buddies and special projects, but as a caregiver, your number one responsibility is your wife and children if you have. So don't wander away too often or hide in your Man Cave. You are that loving partner who provides emotional support and just being there to fight off loneliness . . . depression.

Take Care of Yourself

None of us know what the good Lord has in store for us regarding our time here on earth. Indeed taking care of your health can extend it. The physical and mental sides of our life are important to take care of. Your weight, eating properly, and maintaining a positive attitude will better help you manage your life well through the changes you are being confronted with as a caregiver. In essence, you do not have time to get sick because she needs you to be there for her. I came to realize that if both of us were sick, she would not be in a position to take care of me, and then things could get really difficult and more expensive. Patty and I both came down with COVID in 2022. We had all our booster shots, and the home testing kit said: "You both have the latest variant." Our annual physical was set up with our Primary Care Physician for the following week. I called his office to cancel and also sent a note through the doctor's online portal. A call came through from his office that he wanted to talk to us both that night. When was the last time your Primary Care Physician called you at night to help? My symptoms were minor compared to Patty's. But, he wanted to put us both on an anti-viral medicine to get us through the process and to make sure that I, as Patty's caregiver, did not get any sicker than I already was.

If you are younger, not close to those retirement years, realize that you are not infallible. The years will go by faster than you can imagine, and the "I Wish I Had" question will become a reality. There is never a better time than now when you are a caregiver with a lifelong partner to stay healthy and mentally focused.

In 2017 the average life expectancy for a male in North America was 79. It is interesting to note that in 1797 the Encyclopedia Britannica stated the probability of life was a mean thirty-two years and two months. In 1900 that number increased to 47 years. By 1966 the 70-year mark was reached, and now it is even higher, as stated above. Why are we living longer? Well, a lot has changed throughout the years. Science, technology, personal and public hygiene, better living and working conditions, and diet. The chance of living longer is greater than ever before, but if you do not have your health, it can be a living hell. Unfortunately, we do not always have control over our fate, but that should not limit your thinking about taking better care of yourself, especially during this time of being a caregiver. Your wife needs you! In reality, your wife's life is a living hell that she will learn to adjust to and ultimately accept. What is not needed is both of you are in a similar situation.

Smoker?

You can always point out those individuals who have been lifelong smokers. Their skin is wrinkled, and they usually look a lot older than their actual age. It's one of the first things a doctor, or their nurse, will ask of you when you first visit them. Smoking has many health ramifications, none less than limiting blood circulation and worsening stress levels (yes, you think it is the opposite, that it is a way of coping with stress), which all add up to a degenerative effect on one's health. Smoking is more often associated with heart and lung disease. So if you are a smoker, I highly suggest that you stop. There are many effective ways to stop smoking today, and your doctor can certainly help you with it. However, I recognize that no person changes their old ways to seek the new until they personally find a reason to do so. Your wife's lupus is a good reason to take action. If your wife smokes, the negative effects of living with an autoimmune disease are even more critical for her to stop. With significant ad campaigns, smoking in young children has decreased significantly over the last twenty years. Vaping has taken its place, and the increase in usage is on the rise without any understanding

of the dangers to one's health. Scientists suspect there is a lot. Today vaping has come under attack as the ingredients are being laced with other chemicals that are resulting in death. Your wife can not escape the reality of her disease unless she takes better care of herself. There is no panacea, and illness is illness, but under the circumstances, you need to be taking the best care of yourselves as you can.

If dealing with your wife's illness is getting to you, seek out professional help. A welcomed ear willing to listen to your angst is often found in someone else who is dealing with the same situation. Patty and I may not have all the answers, but we have walked in your shoes for many years.

Finally

It is paramount that you take time for yourself. I have talked about feeling guilty, but there is no sense in you both being limited. Enjoy your hobby and friends when you can. Get to know your neighbors for the socialization it will bring you, and you never know . . . you might need their help doing something like picking up the mail when you and your wife are out of town on a trip.

If you can still travel, know that your wife may have limitations, such as her ability to walk any distance. I think of those cruises on the Rhine River or to Paris. For us, 80% of our time would probably be spent in the stateroom and not taking the day tours up the hill to see a castle, and experience the shopping. The lack of Energy Passes can make any trip difficult but remember: It's better to have Moments in Time than no moments at all. So whatever escapes we have, we are very thankful. It's the small things that count, and if all we do in a day is have dinner in a quaint Parisian restaurant, it's a memory worth having.

Recently we had the opportunity to see Andrea Bocelli in concert. It was an expensive bucket list but worth every moment. Patty now needs a wheelchair to get around when away from the house and oxygen. So the logistics were new to us. We were able to get valet parking right next to the event and disabled seating, which was terrific. Everyone was helpful, even when we needed to find a private bathroom.

Patty and Sean at an evening with Andre Boccilli 2022

Some Sage Advice

In the late 60s, I had the fortune to read a book entitled: The Golden Age. It was written by John Paul Getty, the richest man in America at the time. His book, among other things, dealt with retirement and how to prepare for it. This is what he said:

First, take care of your health. If you do not have your health, retiring can become a living hell. I can tell you that as positive as Patty remains, depression is a constant companion and why I spend a lot of my time with her.

Secondly, develop a hobby or something you are interested in that you can do once you retire. There is no question that boredom kills. A fireman recently told me that many of those retiring from his fire department, after thirty years of service, are retiring to an armchair, not staying in shape, and dying within a couple of years of their retirement. Men who used to be physically fit, as their job

demands, pass away early due to boredom and not staying fit. I'm sure you know of someone who fits this description.

And third, make sure you have put enough money away for retirement. There is a good chance you will live into your 90s. None of us want to become dependent on our children as we want to maintain as much freedom of movement as possible.

CHAPTER 8

What About Your Wife?

Now that you have a better understanding of what a caregiver is, let's look at what a 'care-receiver' is. That person you are taking care of. Your wife, who is a patient. I hate to use the word patient. The words "Thriver, Survivor, Warrior," are words often used to describe people living with lupus, but those words do not depict what is going on and frankly represents a negative connotation. So, I have changed the word 'patient' to the word 'lover,' because that is what she wants to be. She wants to love life, love her husband or significant other, her children, parents, doctors, friends, and what has been taken away from her so she can 'love' the way she used too. That, of course, is a lot easier said than done, but it is not impossible.

But, before I get to that, in Chapter 14, The Cycle of Lupus, I outline all the steps any normal person is going to experience as their disease awareness evolves. It can take years to get through the 'cycles' and why I know it is so important to move through them as fast a possible not as a victim, but rather as an opportunist. Again, I know. It isn't easy, but I know too many individuals who have found a better meaning, a better purpose in their life. "Yes," they wish this was not the case, but it is and unless a cure is discovered it will remain the case accept for one simple ingredient. And that is your wife's attitude and your attitude toward being the best caregiver you are capable of becoming. And trust me, you are a lot better at this than you can imagine.

There are countless examples of people living with lupus or another autoimmune disease who have taken their circumstances to new fulfillment that would have never expected such an opportunity to come there way. Not everyone can write a book nor serve on a non-profit board, but everyone can dream. And, from that dream, such as this book, evolves into something that can touch others. But just as important, dreams evolve and can fulfill a passion with a purpose that transcends themselves. You as the caregiver can be that encouragement when the time is right. That means that you can't force a square peg into a round hole unless the hole is wider than the circumference of the peg. In this case, it takes time before a snug fit can be achieved, unless your wife is one of those extraordinary people who see what is going on and the positives that can come with it.

A case in point: Sara Gorman, after being forced from a career due to her disease found new hope in writing a book, "Despite Lupus" sharing her experience on how to live well with a chronic illness. In the write up on Sara's book, she shares what it "has taken to regain the health and wellness she lost due to years of struggling to overcome lupus. Through personal anecdotes and practical exercises, Sara describes the proven, workable steps it takes to live well with a chronic illness." Sara is a sought out speaker and has a line of pill bags available on her website: https://www.pillfold.com/collections/book

Christine Misrandino, www.butyoudontlooksick.com, wrote "The Spoon Theory." A way to explain to others what lupus is like. Christine uses spoons as an analogy to what I call Energy Passes. Christine has had many challenges in her life due to her lupus. But as she says, today she is back on her horse, has a 501(c)(3) foundation and is a sought out speaker and contributor.

There are thousands of volunteers who every year raise funds, inspire others, participate as moderators, support group leaders, volunteer at events. They are our unsung heroes who bring the personal touch, the reality of their disease to

what we call 'The Boots on the Ground.' It is one thing to raise money for a cure and participate in a walk, bike ride or other fundraising events, but what programs are in place to provide help and guidance to those suffering from their disease in their communities . . . 'The Boots on the Ground.' Very few do. This is an area that both you and your wife can research and search out others to come together and support one another in the journey you are on. Of course, Patty and I hope that you visit our website for updates and our forum to participate too.

Sara and Christine are just a few of those making a difference every day in the life of others, They have one thing in common. The desire to be more today than they were yesterday and the encouragement and support to others to reach their dreams. So too, when your wife is ready, the opportunity to share her unique talent, ideas, services, are there to help others and thereby themselves with greater purpose.

It the dream to be free to dream and experience life at all levels within a body that is susceptible to short-circuited expectations through limited physical, mental and emotional truths. I want your wife and you to feel free to dream and know that there is nothing impossible for each of you to achieve individually and together. Patty and I both served, at different times, as board chair for the Lupus Foundation of America North Carolina Chapter (LFANC). Over a period of 15 years, I produced the largest video library on Lupus by videotaping workshops, our annual summit speakers, and so on. It is amazing how 'moments-in-time' can evolve into a body of work to help others. Patty did not sit around, nor should you or your wife. Patty is often sought out for comfort and understanding to those who remain on the "Angry Trail." Their search for understanding and awareness on how to cope and live with lupus is an important therapy for your wife and you. Though Patty's health is failing, she always has time for those in need and support group meetings provide significant help too.

My predecessor at the LFANC became involved because his wife had been diagnosed with lupus. He had called the office looking for information and asked how he could get involved. Bill worked for a major company in town and through that relationship he was able to bring additional resources in the way of equipment and sponsorship to the organization.

But Let's be realistic for a moment

It's a long journey from point A to point B. Today, your wife is a patient. So let's get off of the 'love' thing for a moment, because your wife is not 'loving' what's going on inside her body. She is probably not 'loving' too much about what is going on around her. And that probably means you too! She is more than likely filled with angst, hate, fear, desperation on what the future holds for her and her family. For the newly diagnosed "patient," this is a scary time and so too for any family as her disease progresses.

You need to know that your wife is going to need a lot of medical attention if or as her disease progresses. And as with many autoimmune diseases, one begets another, which will more than likely require other specialists joining her team of doctors.

To be sure, those living with lupus or any other autoimmune disease are 'lovers' in need of medical help and guidance as they live with a very mysterious autoimmune disease. Her life has been upended and yours too. To be a patient is to love what one had with greater enthusiasm for what one will have and can be. "Why would your wife not want to go back to who she was?" you ask. Of course, she would, but in almost all cases that is unrealistic. A prayer, a hope, but unrealistic. For most their wife's disease will progress, but there are those moments of improvement that are so well appreciated. The release of some stress, pain that can bring a little normalcy back into her life. A life that was forced down a

different road to a new purpose in life if one wishes to discover it and travel down the path. It's like Google maps. Put in the destination and each turn and time to destination will be given. That hopefully will come in time. The realization that she is no longer a victim, but rather someone who can make a difference in the lives of others and thereby her own. It is becoming and doing the best that she is capable of doing.

It is why a supportive attitude from you and your family is so important. It will allow your wife or child to outshine others simply because they can see the opportunity in front of them that other's don't due to their circumstances. But, this is not an easy road to travel. It is filled with doubt, stress, anxiety, depression, fear and a lot of fights to get better. To that end, I hope you know that your lover is really sick physically. It's what is going on the inside and not the outside. As expressed, there is the mental and emotional roller coaster that comes along with that. Going beyond one's daily allotment of *Energy Passes* can result in mental fatigue that manifests itself in the inability to focus on what she is doing, such as reading or working on a project. This level of frustration can move to emotional stress and depression and evolve into an inflammatory response that results in more fatigue. Constant fatigue, stress, and inflammation can take a toll on anyone. Because there is no way for you to walk in her shoes, there is no possible way you can understand what your wife is truly going through. In a way, I don't think those living with lupus and other systemic autoimmune diseases understand totally what they are going through either. What your wife wishes to be reality is not and that is hard to understand and accept. And frankly, accepting one's lot in life is not something that I prescribe too. It takes courage to live with lupus as too many other debilitating diseases. And, it takes courage to overcome the fears associated with lupus that allow one to live the best quality of life possible under the circumstances. We see examples of this in Shellee, whom we dedicated this book too, coming to a lupus summit with an IV rolling behind her. We see this courage and desire to live in military personnel who come back from war missing a limb or worse. We see this in the Sara's and Christine's, and the countless stories of the human spirit rising above the circumstances they have been given. Your wife, at

some point, will come to this realization, but for sure it is an angry trail to go down. This journey and what it looks like in greater detail is shared in Chapter 12, "The Cycle of Lupus."

I heard one individual living with lupus say that it took her years to finally accept the status quo of her medical uncertainties. Her hope to go into total remission was not something that she could expect anymore. Getting to a place of acceptance is not a recognition of defeat. It is the beginning of recovery by shedding the stress, anxieties and fears that she won't get well enough to live her life in a more meaningful way. i.e., by focusing on her life's desires and dreams versus the disease of lupus. I hope that makes some kind of sense.

Having said that, knowing what your wife wants to do and what she can do are two different things. She wants to go to the beach and layout it the sun, but that is not a good idea. She wants to keep on working, but her fatigue, brain fog, and other complications are making it difficult for her and her employer. We will talk about workplace accommodations in chapter 23, "What If Your Wife Can No Longer Work?" Your wife wants to do this and do that, but she soon comes to realize that there is a price to pay at the level of her fatigue. In conversations with others living with lupus we constantly hear, "I went and did this knowing full well I would pay the price for it tomorrow!" Thus, along this angry trail, your wife comes to realize that she needs to make choices that she did not have to make in the past. For example, when Patty and I go visit our grandchildren three hours away, the trip in itself from point A to point B uses up a lot of Patty's energy. I know I don't always get it either, but it is true. The interaction with our grandchildren, which is holding, talking, doing, will wipe Patty out within a couple of hours. But, they do not see that because the fatigue is experienced on the inside and not shown on the outside. But, when it is time to go, we have a way of signaling each other to wrap the visit up. And then, we are back in the car where Patty will sleep a good portion of the ride home. This is normal. So living with lupus at this degree is something Patty is willing to do because it is life and she

wants to participate. She may not like it, but she has accepted her norm and learned how to live within it.

At one of our Annual Lupus Walks, Mary would always lead everyone in warm-up exercises before the walk started. Mary was in the hospital for six days before a Walk For Lupus Now event. She told the doctors that Saturday she would be leading the exercises at the Walk, and she did. "I knew I was going to pay a price for it the next day, but I was determined to lead everyone and show that you really can make difference!" she said.

Carol, who is a pharmacist advanced to where her lupus made it impossible for her to work anymore. She would come to Lupus workshops and speak about her journey. Though exhausting, helping others with lupus became her mission. After years of not being able to work, she is now back in her career. It was her positive attitude as she traveled down this angry trail of lupus that she found purpose. A purpose, that helped her along the way. It mattered not that the drive was exhausting, that speaking and interacting with others was exhausting. Her purpose was greater than herself and she was willing to help others in a similar situation. She also knew that by sharing with others she was helping herself too and helped her come out from behind the shadows of lupus.

From anger to acceptance is a long trail to travel down, and that is the same journey you are on whether you realize it or not. The only difference is that you are not living with all the physical and mental symptoms of the disease. Certainly, you can fall prey to the emotional effects an individual can experience when living under stressful circumstances.

Can I Help You?

The following are probably the four most important words you can use with your wife. "Can I Help You?" Caregivers are there to help and by asking you to open the door to her needs. Surely, she does not want your help, because she wishes she could do things herself. It makes her angry and frustrated that she can no longer do what she needs help with now. But that is not always the case. Our cardiologist remembered back to when he was in the 6th grade the important lessons he learned at dance school.

1) When at a dance, never not ask someone to dance. I would suggest this is true at any event where you could engage in conversation. Aways be willing to engage in a conversation with someone else to whom no one else is talking to.

2) Always offer a woman your hand when she is getting out of the car.

3) Always offer woman assistance.

Somewhere along the way in our society, these common courtesies have been lost by many. I hope you are not one of them. "Can I help you?" whether a person needs assistance or not is a great way to embrace an attitude of the servant and that of a servant's heart. Actions do speak louder than words too.

You will find many clues within this book that will help you achieve your dreams while both of you are living with her lupus or another autoimmune disease. Whether you realize it or not, you have become a patient too that requires at least emotional help to better understand and accept through change how great this life together can truly be. So buckle up for this angry journey together and turn it into something positive for others and thereby yourselves too. Become pro-active versus reactive and engage in the process of getting better. One key component of this experience is building your medical team, and what we have to

say about this may contradict your previous experience working with the medical community, which we respect greatly. See Chapter 17, "Dealing with the Medical Community."

Don't think that you are alone. The above picture was taken at a "Walk for Lupus Now" event in Charlotte, North Carolina. Over 4000 walkers attended, each with their own stories, but most importantly showing their support for a loved one with lupus too.

CHAPTER 9

You're a Patient Too!

To overlook this simple point can be very detrimental. Most doctors realize that when a caregiver comes to an appointment with their wife, they recognize that there are two patients in the room. Your wife and you. The Lupus Foundation of America, in conjunction with Eli Lilly and Company, conducted a survey in 2016 on the effects of being a caregiver. The study was entitled: "UNVEIL." Here are a few of the key findings:

1. 74% of caregivers surveyed indicated that their productivity at work is affected.

2. Approximately 50% of caregivers indicated that their social life with friends had been impacted.

3. 94% surveyed expressed concerns about anxiety, stress, and the long-term health of their loved one. Research by Francis Lewis, a scientist, indicates that depression and anxiety affect 25 to 35% of spousal caretakers.

4. 75% of respondents said they helped out with the cooking, grocery, and other shopping needs and did the house cleaning.

What this all mean is that your normal world has been disrupted to the degree that your wife needs your help. So, you have a choice to listen to her and be that spousal support that she needs. Or not listen to her and give her the spousal support you think she needs. Of course, there is a third option, and that is to not support her at all, which I talked about in Chapter 5 - The Elephant in the Room. However you want to look at it, your relationship with your wife has changed and this will obviously create stress, which can affect your over all health and attitude over time.

Who takes care of a caregiver?

Themselves! The average guy will more than likely go into denial, be angry, confused, and have their life's normal process altered beyond their belief. The average guy will more than likely stay within themselves when they need to reach out to others for help or commiserate. But don't let this allow you to wallow in your own sorrow. You have a lot to step up to, to which you are more than capable.

These are valid concerns, emotions, and added responsibilities for any caregiver living with their wife who has a disabling autoimmune disease or other long-term medical circumstances. Unfortunately, resources for you to get help in understanding what it means and takes to be a caregiver are challenging to find, certainly at the doctors' office, unless you raise your hand for help. Even then, you might not get much. Asking for help is often hard for guys to do. Life as a caregiver is called: Rise Above It! So first recognize that you need help too, and other than going to a shrink, I suggest you "first seek to understand," as expressed in Stephen Covey's 7 Habits of Highly Effective People. Stick with me here, for what I am sharing will help you as a caregiver and your professional life.

Stephen Covey's 7 Habits of Highly Effective People

Habit 1: Be proactive

Habit 2: Begin with the end in mind

Habit 3: Put first things first

Habit 4: Think win-win

Habit 5: Seek first to understand, then to be understood

Habit 6: Synergize

Habit 7: Sharpen the Saw

I had the fortune to spend a whole day with Mr. Covey (now deceased), and I hope he doesn't mind me using his seven habits to share keys to being a good caregiver. His habits work just as well for being a caregiver as it does for becoming successful in business. I may use them out of order, but I know you will find them insightful and helpful.

There is an 8th Habit: "Effectiveness to Greatness," which is to "find daily fulfillment and excitement" in both your lives. I hope following these simple Covey habits will bring you both to that point of daily fulfillment and excitement.

https://www.stephencovey.com/7habits/7habits-habit7.php

When I was first introduced to Covey's teachings, a coworker, who's wife had Cancer showed up to work bald. His wife was going through Chemo Therapy and this was his way of telling her that he was with her all the way and that they would both be bald together. He was being proactive and providing positing re-enforcement to his wife. The funny thing is that was over 30 years ago and he decided he liked the look so much that he remains bald to this day. He was ahead of his time.

1. *Be Proactive*

Patty and I both believe that as you go through this journey as a caregiver it is important to be proactive versus reactive to the circumstances thrown at you. For example, Patty was diagnosed with potential kidney failure due to her lupus. It happens to be the organ of choice for lupus to attack. When she asked her doctor what the next steps were, she heard: "Go home, look for a match. You'll go on dialysis and then a transplant. That is the best you can hope for!" she exclaimed. That would be the normal reaction of most. Go home, find a kidney donor and hope for the best? But, we decided to be proactive and searched out one of the top

research doctors in the country on kidney disease. What surprised us was that he was not only willing to see Patty, but he could do so almost immediately.

After tests, the doctor sat down with Patty three days later to share that she had been misdiagnosed. Yes, she had kidney involvement with her lupus but not to the extent that her other doctor had diagnosed. That was over 19 years ago, and Patty's kidneys are holding their own. The diagnosis could have been the same, but we decided to be proactive versus reactive, and it paid off. Can you imagine Patty's emotional stress and concern and mine if we had not been proactive?

In another experience, Patty spent over two years with two neurologists who could not figure out why her arms were so sore and tightening up. When the second doctor said, "I do not know what to do other than recommend pain medicine!" We decided to be proactive and asked to be referred to Duke University's Medical Neurology Department in Durham, North Carolina. Maybe they, as a research practice, would have an idea of what was going on. We were somewhat surprised that the neurologist would not initially refer us. "I cannot identify your medical issue!" she exclaimed. "What makes you think they can at Duke?" That did not last long as we insisted on being referred. The neurologist, realizing how proactive we were, consented to our request. We had three neurologists working with us on our first visit to Duke. Patty was diagnosed within four hours. Patty was the second person diagnosed at Duke with Statin Induced Acquired Myotonia. At least we knew what we were dealing with. Unfortunately, Patty falls into a small group that does not react positively to treatment. We were proactive in Patty's medical journey versus being reactive to a doctor's inability to diagnose. Most wouldn't accept the initial lack of diagnosis. i.e., Ignorant patients get ignorant results! Nor should you as your journey of discovery continues. Patty's Myotonia continues to be a medical issue for her. Patty's primary doctor had put her on statins because of high cholesterol. We do not blame him because no one, even our doctor, could have suspected that it would cause Myotonia. Today, Patty's Myotonia is gone, but the muscle damage it caused remains. At least we know.

Thus, be proactive and not passive as a victim would react. We are not willing to accept "No" for an answer, nor should you. Take "No" out of your vocabulary

Thus, be proactive and not passive as a victim would react. We are not willing to accept “No” for an answer, nor should you. Take “No” out of your vocabulary and look for the positive. Investigate all possibilities. You may not get an answer, but at least you have gone the extra mile.

2. Begin with the End in Mind

Stephen Covey’s second habit is to “Begin with the End in Mind.” I know that this is difficult to do when you just think about what it is that you want to accomplish in your life. Keeping the End in Mind for a caregiver means providing the best quality of life for your wife, family, and friends. If you have a problem with that, fast forward to Covey’s 6th habit: Synergize. Then you can come back here, so note the page.

What is Keeping the End in Mind? Let’s hope it is a cure! The End in Mind can be death, and in years past, early death, generally due to kidney failure, was typical. Dr. Olivia Ghaw, an Assistant Professor of Medicine, Division of Rheumatology at the Icahn School of Medicine at Mount Sinai, suggests that “80 to 90% of people living with lupus can expect to live a normal lifespan.” There is also the indication that lupus is far more active during the years before diagnosis up to the age of 40. That is comforting when Keeping the End in Mind.

Keeping the End in Mind is to be your wife’s advocate in that she follows her doctor’s directions, takes her medicines accordingly, and keeps her doctor appointments. The key is to minimize or eliminate flares. Flares are what

potentially cause damage, scarring of the kidneys, and reduced function that can become life-critical. The kidney condition is called lupus nephritis, and without proper care can lead to dialysis and then a kidney transplant. That's what Patty and I were facing many years ago that did not evolve. Depending on the severity of your wife's disease, spending the day at the beach with her is catamount to causing a severe flare. Stress can cause a flare. An infection can cause a flare. Keep in mind that lupus is a disease wherein your wife's immune system is her enemy and that the drugs she is taking are designed to suppress the immune system and thereby the negative symptoms of the disease. Your wife's immune system is not her friend or protectorate to the degree that you or I would have to fight infections. One of the simplest things you can do to help is washing your hands as often as need be: when you come home from work, before you put the groceries away, get ice out of the freezer for her water, and so on. Wash your hands! With soap! A tip when washing your hands is to sing happy birthday to yourself. The entire song as you wash your hands. That will help to make sure that any germs present are pretty much washed away.

Keeping the End in Mind, pericarditis or fluid around the heart, or myocarditis or endocarditis, the inflammation of the heart are other potential damage points targeted by lupus. If your wife has water retention issues, this can lead to heart issues and the use of diuretics, which in turn can lead to kidney issues. It can become a balancing act between staying hydrated and over hydrated. One protocol affects the other. For example, your wife is showing signs of water retention as presented in her swollen ankles. Her doctor puts her on a diuretic to get rid of the water. Your wife's kidney is like a sponge, and alleviating the water can have a negative effect on her kidneys. i.e., a dried-out kidney is like a dried-out sponge. The balancing act comes when her kidneys, like a sponge, are having all the water squeezed out, thus resulting in her creatinine level going up. This insult to her kidneys can have possible short-term and long-term damage. Your wife may never experience these issues with her lupus, but know that things can get pretty complicated medically if the disease process progresses. If this is a concern with

your wife's autoimmune disease, take note and be proactive by getting her to her primary doctor.

Keeping the End in Mind, if you want to have children, make sure that you engage your wife's primary doctor and gynecologist in the discussion before becoming pregnant. We know many wonderful stories and beautiful children brought into this world through loving parents with lupus. However, there can be tragic consequences, too; miscarriage or other pregnancy issues, such as negative medicine interaction with the unborn child.

Keeping the End in Mind that one disease often begets another. Sometimes that is just in the cards, and sometimes it is caused unintentionally by medicines that introduce other adverse conditions, such as Patty's Statin Induced Acquired Myotonia resulting from a common prescription by a doctor with uncommon results as shared earlier. You cannot fault the doctor. Medicine is not a perfect science. The doctor and the medicine do the best they can do.

Keeping the End in Mind is that if your wife takes care of herself and you take care of her, follow the doctor's orders. The chances of her living everyday life with some adjustments and acceptance of "that's the way it is" can result in a long and happy relationship in all that is meaningful. Today, Patty's medical issues have progressed to include her heart. Each doctor we see says, "Man, you have a lot going on!" But, Patty keeps a positive attitude. Too often, patients go into an appointment looking for the magic bullet. For us, we have discovered over the years that one does not exist. There ain't no magic bullet! However, until one is developed, remaining as positive as possible can help a lot.

3. Put first things first

Wherein Patty needs to manage her Energy Passes every day, she also benefits from Energy Savers, and that is me. Over time, you will become comfortable in doing the big things as well as the little things. It's the little things that mean more, such as cleaning the stove, putting pens away, and keeping the side table next to your comfortable chair clean. The process of her simply getting up out of bed or her chair can be using one Energy Pass. Filling her glass with water and ice is an *Energy Saver* if you do it for her. It's one simple action that can save her an Energy Pass depending on the severity of her disease for that day and provide you with more quality time together.

When your wife says, "When you get a chance, could you do . . ." That is her polite way of saying, "Do it now!" This makes sense because if you do not 'Do it now," you will more than likely forget, which then results in her reminding you that you failed to remember . . . and that angers her and frustrates you, because after all . . . you're a busy guy too! The answer is: When your wife says when you have time . . . get up out of your chair and "do it now." It makes life so much easier for everyone. The other answer is to keep a 'To Do List' and look at it at least daily so that you, in fact, do get done what is on the list. Well, reminded.

Newton's Third Law: "For every action, there is an equal or opposite reaction."

It has probably crossed your mind that if I am always getting Patty her water, she is not getting up out of her chair and getting a little benefit from walking and using her muscles. Patty does not have a daily exercise regimen, and though it would be beneficial for her to get up, it is not always in the cards. With lupus it is always a trade-off. Having said that, exercise, like in all medical things, is one of

the best things your wife can do. Patty's rehab visits every week have been the best medicine for her.

I make breakfast every morning for Patty to help her save energy, but imagine if she had to get the kids up, dressed, fed, lunch box filled, and take them to school before going off to work. Yes, this is a shared responsibility in many families, but by the time your wife gets to work, a good portion of her Energy Passes are used up for the day. By the time she gets home from picking the kids up after school, she is past exhaustion, and you wonder, "how her day was?"

Other *Energy Savers* are for her to be more organized with her time. For example, if she has the energy to go food shopping, what other stops can she make along the way, such as dropping off cleaning, getting her nails done, and so on. Maximizing time, being better organized can save energy. That suggestion applies to you too.

4. *Think Win-Win*

Patty and I are always aware that win-win opportunities will come our way, not only in our own lives, but that of others too. We recognize that we are both looked upon as mentors to the lupus community and therein rests a great responsibility. It's an opportunity to receive energy from those we interact with. You see, we get as much from them as they do from us. We have the ability, knowledge, and experience to help and the reward of helping others become more aware today than they were yesterday on how to manage their disease. These opportunities come at support group meetings, lupus walks, other outings, symposiums, and random out of the blue phone calls. It's a community and we are not the only ones. Through others, we all become stronger in dealing with and living with lupus as a patient and as a caregiver. It's not easy stuff by any means, but what

other option do your wife and you have? She will have her autoimmune disease for the rest of her life.

Thus, we realize that every interaction we have with someone is a win-win, because we know we receive positive reinforcement to our mission in return. For you, look to win-win opportunities with your wife. A drive into the countryside, doing things you enjoy together, spending more quality time together. Conclusion: there are many win-win opportunities where she and you will feel better about your circumstances. Just being with Patty sitting together brings her comfort and conversation, and interaction. So as much as you might want to be running around and doing your thing, it can have consequences. I have given up doing things knowing that Patty needs me to be with her, if just for comfort. Enjoy the small things and if big ones come along, enjoy them too.

What bugs her about you?

These are opportunities for win-win by being more proactive in how you react appropriately to her needs versus holding on to old reactions that do not work with new conditions. No person changes their old ways to seek the new until they find a reason to do so! At some point, you will realize the condition/response you make is what upsets the apple cart and thus generates stress in both of you. Unfortunately, that additional stress is another potential nail in the coffin. That's what win-win is all about! Reducing nails!!!!!

What bugs Patty more than anything at the house is that my office is usually a mess, which I call organized chaos. For the rest of the house, you can eat off the floor or any piece of furniture you desire without fear of catching anything. If company or family comes over, I try to straighten my office, but more often than not, it ends up with the door being closed. The other area is the garage. It's neatly packed as can be without going bankrupt with built-ins. We probably need a little

more space to store things, but at least we can get two cars into the garage with ease. I guess that we are doing better than most. Patty may not like these two areas of her concern, but she has come to understand that I need my private space where I can do my creative work, store business supplies, etc., and thereby this major fault in me is at least understood whether accepted or not. Ah, the differences between us!

P.S. As mentioned earlier, we have a maid who comes every other week, and "Yes," I have gotten better at keeping an organized and less cluttered office.

Incidentally, if and when you retire, if the only thing you have to do is clean out the garage and reorganize it, you will have a very short retirement. I'm getting better at throwing things out that I do not need anymore, but I still have trouble parting with some things. I also have a lot I would like to accomplish in my life before it is over. This book is an example of that. It keeps most of us alive and vibrant with interests that keep our minds working and sharp. Thus, if you are at retirement age, make sure you become engaged in something worthwhile that keeps your mind active and alert. That whole discussion is for another book. Being active in your local lupus chapter, if you have one, can certainly keep you busy. Go to: https://www.lupus.org/chapters and enter your state for a support group in your area if one exists. And, if you do not have one, search out others to at least think about starting a support group. I will talk more about that later in the book: Chapter 21, "The Power of Support Group."

5. First, Seek to Understand and then Understood

Education is your savior. If you cannot understand lupus or the autoimmune disease you are dealing with, it is very difficult to understand what it means to be a caregiver. If you cannot understand the challenges your wife is facing, you can not understand the fears she is living with. It's the "not knowing" concerning you, your children if you have, her job, if she works outside of the house, and so on. You can

help with many insecurities if you understand what the "cruel mystery" of her disease brings. If you put that effort forward to understand this disease and get involved with your wife's life at a different level than you could have ever imagined, your needs will be better understood by you and her and better met!

In 2019, tests showed that Kim Kardashian had the antibodies for lupus. "I feel like I literally am falling apart" she stated on Keeping Up With the Kardashians. "I have to go to the doctor and see what's going on because I can't live like this," Kim said. She went on to say, "I have a baby on the way, I have law school. It just can really scare you when you start thinking about how much this is going to change my life." Now you might say this is Kim Kardashian, but you have to give her credit for coming forward because autoimmune diseases do not discriminate even with the rich and famous. She is also bringing attention to the disease and the importance of being diagnosed as early as possible. Greater focus brings greater understanding and that is your challenge as a caregiver because your life is or has changed also.

"You don't understand!" she exclaims, as her frustration with lupus comes pouring out, because of something you said, did or did not do. When was the last time you came home and all hell broke out? You may not be able to defuse the outburst, but it is in her best interest and yours that you do not add to it. Having said that, abuse on her part or your part is not acceptable behavior and needs to be discussed whether she wants to or not. The question is when that should occur and only you understand that. There is no good time and avoidance is not an answer. This is the importance of communications between the two of you. Patty and I have had those discussion. In reality, if you do not address it you can become a slave to it and that is simply not healthy in a relationship. What I am saying here, is do not add to her stress, if at all possible, and do not allow your stress to add to her stress.

Your actions may very well "suck all the air out of the room." This can become very frustrating when you know that you are doing everything you can, and then some to help. For example, though your opinions may count, they may not be accepted well and thus cause undue stress. Often this will come from her own frustration. I wouldn't want to be in my wife's shoes for all the tea in China, but if I can help serve the tea and make life a little more tolerable . . . My efforts are greatly appreciated, but I am not in her shoes. In some cases it's better to lose the battle than to win the war. Or, it's better to lose the battle and end up with a negotiated peace.

When your loved one starts exhibiting the symptoms of lupus, by the time she is diagnosed you have probably become frustrated with your new norm. Living with someone who has lupus first starts with understanding the disease and the limitations it places on her and you too. It's not fun, but through understanding, compassion, and caregiving action, you will learn to adapt and thrive in your new norm. Life is a process of adjustments most often brought upon us by an outside force versus our own volition: The loss of a job, the birth of a child, the diagnosis of a disease, an operation or procedure that has gone awry, and so on. Some changes are positive while others are not. But, to grow is to progress, and to progress is to change, and that will happen if you accept your new reality with your wife and become supportive, an advocate, and an active partner/caregiver.

For most women with lupus, their symptoms were recognized by her years before diagnosis. Symptoms progress over time, doctor appointments, tests, etc. Ultimately, she is diagnosed with lupus. A word, lupus, that neither of you has probably ever heard of before then. The good news is that after years of concern and frustration, you both have a name for what is going on. Though it is not good news, it defines and lifts the mystery of what is going on and thereby a pathway to learning, understanding, managing, and the ability to openly explain her disease to others. So in that sense, it is a relief. When you are sick, you want to get well. When you do not know why you are sick, you want to know why and to get well.

It's this process of unknowing that becomes very frustrating and scary to her. It is life-altering.

If she has Mylar or discoid lupus, a rash, and/or SLE, Systemic Lupus Erythematosus, you know that she doesn't look sick when she is outside the comfort of her home. She appears as if nothing is wrong with how she carries herself, interacts with others, and performs her job if she is working. Her outside persona becomes the exact opposite when at home or outside a social or work environment - fatigued, in pain, little energy to perform some of the smallest tasks. It's not that she has been faking, but rather her desire to maintain her image, her identity and suppress the outward vision of her that others see. It takes energy and fortitude on her part to keep up appearances. But once she is out of that

If she has Mylar or discoid lupus, a rash, and/or SLE, Systemic Lupus Erythematosus, you know that when she is outside the comfort of her home, she doesn't look sick. She appears as if nothing is wrong with how she carries herself, interacts with others, and performs her job if she is working. Her outside persona becomes the exact opposite when at home or outside a social or work environment—fatigued, in pain, and has little energy to perform some of the smallest tasks. It's not that she has been faking, but rather her desire to maintain her image, and her identity and suppress the outward vision of her that others see. It takes energy and fortitude on her part to keep up appearances. But once she is out of that environment, the veil is quickly removed in response to the ieffort she has to put forth to disguise this disease. What Energy Passes she had are exhausted for the day. Lupus symptoms range from acceptable to intolerable and are never the same in everyone but are very much connected to the disease. It is why the Lupus Foundation of America has coined lupus as "The Cruel Mystery," that here-to-fore has escaped giving up the clues to a cure.

There is a lot you will discover about your wife and yourself as each of you progress together with lupus. The impact on your life will be very much the same

as hers. Denial, anger, depression, stress, anxiety, fear, guilt . . . you are not immune from these emotions.

6. **Synergize**

Covey says, " If you plant two plants close together, the roots commingle and improve the quality of the soil so that both plants will grow better than if they were separated." It is the process of working together so that you and your wife become more effective in dealing with her disease. It takes time, observations, awareness, knowledge, and willingness to grow into the role of caregiver.

When you and your wife got married, you agreed to become a team. Often, those expectations are not fulfilled. According to the American Psychological Association in America, the US divorce rate in 2017 was 40% to 50%. A study conducted by the University of Michigan showed that 75 percent of marriages where the wife has a chronic disease end up in divorce. We know that women are better nurturers than most men and better mentally prepared to care for an ailing husband.

Conversely, most men need to learn how to nurture, and oddly enough, that is the major reason the wife wants a divorce because they think their family and friends can take better care of them, or at least that is what the study implies. I'm afraid I have to disagree with that part of the study. More men want out because they do not want to deal with their wife's illness. According to our primary doctor, many guys walk away, and it's not the right thing to do. So I encourage you to think twice if divorce is in your thought process and think about doing the right thing and being there for your wife, children (if you have), and family. Your burden on others could be far more tragic than one could imagine, all due to your selfishness. I know that is hard to hear, but that's the way I see it. Look at all the positives and push the negatives to the side.

If the marriage was in trouble before the lead-up to and diagnosis of lupus, you have a lot to work on as a couple. Remember, "In sickness and health" is just not words. It is a bond that again . . . hate to be repetitive . . . comes through a lack of communication and the inability first to understand to be understood. Now that your wife is dealing with a life-threatening disease is not the time to cut and run. I know, here I am writing a book about being a caregiver, to cherish and love your wife, being there for her every need, and it sounds like I am telling you to run out the door as fast as you can. In some cases, that may be the right thing for both of you. In other cases, it can be a moral failure in one's values, which is O.K. Doesn't make you a bad person, but it doesn't make you a good person either. It is what it is. The key point here is there are professionals that can. Of course, we want you and your wife to stick together, no matter how tough it gets, because, through that process, you will synergize more so together than you can ever imagine and come to realize how important your relationship and life are not only to you but your children and family too.

In some situations leaving is a positive outcome, but I contend that for most, it is our inability to communicate with one another that comes to that end. It's about building the strength in your relationship, identity, and working on your weaknesses. We are not all good at this, but like anything else, repetition is the aid to memory, and through better understanding, you will be better understood in regards to your fears and concerns as well as hers. The roots begin to intertwine. Not everyone goes through this stage. Many have a servant's heart, are in love with one another, and many have children they want to bring up in a good family environment regardless of how sick Mom is. If needed, we highly recommend you talk to your primary doctor together to seek guidance and other professionals. It is worth the effort. If not, then at least you know you put the effort forward, and there is a lot to be said for that. Needless to say, it is not easy.

7. Sharpen the Saw

Sharpening the Saw in Covey's terms is to live a balanced life "for self-renewal in the four areas of your life: Physical, social/emotional, mental and spiritual." These are all good points. Frankly, I am not sure what balance looks like because so few, if any, have been able to achieve it. So, I suggest to you that having balance in your life (job) is a fallacy based on the wishful thinking of corporate America. But you can Sharpen the Saw as a caregiver in how attentive, aware, and supportive you are of your wife's medical circumstances and needs. This is not something to shy away from, but rather embrace, be proactive and continually improve upon. It's good that Patty can do things for herself. As they say, "Exercise is the key to good health," but so too are good uses of Energy Passes. There are many places where you can help out (See first things first). It is not cumbersome when you come to realize how easy it is to do small things that add up to big results. Also, know that your wife likes her private and quiet time. Again, 'first, understand to be understood.' There are so many ways you can improve your life personally and your wife's. This book hopefully helps you as a caregiver. I recommend three books that have helped me through life for your personal development. I am sure you also have those that have helped you too.

- ✔ Covey's 7 Habits of successful people by Stephen Covey.
- ✔ Think and Grow Rich by Napoleon Hill - This is the bible as far as I and many others to personal development. The book has nothing to do with money.
- ✔ The Golden Age by John Paul Getty - his writings had a profound effect on me in 1969 and they hold true today in my life.

All three authors' lived long and prosperous lives. Their wisdom carries forward and is just as true and viable today as it was when they first wrote their books. Boy, did they have it right!

CHAPTER 10

How to Explain Lupus to Others

It is very difficult to explain to other people what lupus is. Yes, it is an autoimmune disease, but not everyone recognizes what that means. Because your wife does not look sick, it becomes even more difficult for friends and family to understand what is going on, especially pre-diagnosis. Yes, I said, "family!" If not all your family or part of your family has removed themselves from the conversation, it is simply because they do not understand lupus. So, communicate, communicate, communicate. Otherwise, you may see them distancing themselves from you and your wife. I know that sounds crazy, but we see it all the time. We see the opposite, too, as a family becomes closer and more supportive when and where they can.

Here is how we explain lupus to others

Lupus is an autoimmune disease wherein the body's immune system turns against itself and sees healthy cells as foreign invaders and thus attacks them. Crazy, isn't it! The immune system that is designed to protect one becomes the enemy. This effect on the immune system can result in organ damage, such as kidneys, heart, and even brain. Fatigue is probably the most common symptom among all systemic autoimmune diseases, and that is very true with lupus. People living with lupus do so in a cloud of fatigue, not tired, but rather that feeling of no energy. Individuals experience living with this disease during periods when they have Energy but can use it up quickly. These periods of Energy are the Energy

Passes referred to earlier. For some reason, there are only so many granted daily. That varies based on the severity of the disease but is very prevalent. There is no finite understanding of how these Energy Passes come and go. Thus, those living with lupus learn how to maximize the Energy Passes they are given and not waste t h e m !

Energy Passes

Though we have referenced Energy Passes many times in this book, it is probably one of the most important understanding one can have when dealing with lupus or most other systemic autoimmune diseases. Fatigue is very much different than being tired all the time. Eight hours of sleep living with lupus does not generally reinvigorate one's Energy. Think of it in terms that individuals living with lupus are given only so many Energy Passes a day. Some days they are only given one Energy Pass. It can be used up simply by taking a shower or getting dressed. Even brushing one's teeth or having a conversation with someone can eat up an Energy Pass. Daily Energy Passes for most individuals living with lupus are limited unless they are in remission. There is no correlation between sleep, and the number of Energy Passes one has. A good night's sleep can result in no Energy Passes or many. Crazy, but that is simply what an individual living with lupus wakes up to each morning. Those living with lupus learn to manage their Energy Passes well or pay the consequences if they do not. It is all about one's quality of life and managing their energy levels as best as possible each day. Of course, some drugs can artificially create renewed Energy. It's called Prednisone, a steroid, which comes with consequences such as being hyper, weight gain, etc. It's known as the Devil's Cookie because once on it, for an extended period, it becomes difficult to get off. And it is not a cold turkey get off of the drug. We'll talk more about Prednisone in chapter 25. If your wife is on Prednisone and decides to stop, it is a weening process that guidance should be provided by your Primary Care Doctor or Rheumatologist. Follow their directions.

We Have Things to Do and Places to Go

An Energy Pass may not always be available when she and you decide to shop, go to the movies, a party, spend time with grandchildren, etc. When we travel to visit our grandchildren, our visit usually lasts about three hours, and we are out of there. It's not them. We love them dearly, but the price Patty will pay (exhaustion) if we stay longer is difficult for her. She knows her limits. Of course, this is difficult for our children to understand because when we are with them, Patty appears not to look sick.

You don't look sick!

The saying, "You don't look sick," is often heard when those living with lupus are out and about because the disease is on the inside and not visible unless she has discoid lupus. There will be more discussion about this in the book, but for now, you will become amazed that when your wife is out in public, she does not look like she is sick, especially if it is at a social event. If she was the life of the party before lupus, expect her to be the same with a little less vigor because she is trying to use the Energy she has in her best interest. She wants to feel and look normal, and there is nothing wrong with that. She can be great at masking how she feels, but as Energy Passes become used up, so does she. It's that Energy she must use to enjoy herself and others that can be overbearing. "You don't look sick" can also create a mischaracterization in the minds of others. If you do not look sick, thereby you are not. That's a nice perception to put forward but is difficult to cover up over time.

Friends

Those living with lupus quickly learn who their friends are. It's this desire to be a part of and interact with friends, and the fact that she does not look sick creates confusion with friends and family. As your wife withdraws from her social world, those who do not understand will slip away, stop inviting her and you to parties, and so on. They do not understand or know that your wife has this disease we call "Lupus." And if they do, they do not understand how lupus can intrude on the things that used to be so normal. This is not fun for your wife or you. Sit down with your friends and explain what is going on and that when she is feeling better you want to maintain their friendship. It's nothing personal. Do not be surprised that the night you are invited to a dinner party, your wife does not have the energy to attend. A call goes out to the host, which can upset their plans. If this occurs over time with one or more friends, before you know it, you are no longer being invited because your friends probably think that you really do not want to come, be friends, versus the effect of your wife's disease. So communicate with your friends.

One person thought that maybe the invitation for dinner was not being given early enough, thereby the reason for the cancellation. So they started asking for dinner dates three months in advance. This is a friend who clearly does not understand what is going on with your wife. If it is that much of an inconvenience or insult to this particular friend, it is what it is. Your wife can only do so much.

If your wife feels good enough to entertain and host an evening with friends, invite them over. I know this can often be a last-minute invite, and because of that, those you are inviting may not be able to attend. But many will come. If your friends understand what you are dealing with, they will not think that you are a last minute planner. Your wife is just trying to manage the social side of her disease. And hopefully, friends will better understand why she cancels their

invitations at the last moment. It's all about communication, and if this is not good enough for your friends, they are not worth having.

If we are at a party, we usually are among the first to arrive and the first to leave. It allows us to spend quality time with the host before everyone else shows up. Two hours of socializing are lovely for us, but Patty will let me know it is time to go with a nod. It's all about managing her health and not taking advantage of her Energy Moment. You will come to learn, if not already, that there is often a price to pay with exhaustion, and if not, that's all the better.

I usually stay out of Patty's way at parties. She enjoys socializing with her girlfriends, and I do not stand over her shoulder. I find myself in conversation with others and enjoy the evening and interaction.

Prioritizing

Because there is no guarantee on how many Energy Passes your wife will have on any given day, she will learn how to manage and prioritize quickly. Some days it is absolutely nothing. Other days, it might be just one, two, or even eight Energy Passes. Energy Passes vary from one person to another depending on how active their lupus is and to what degree. If your wife has the Energy to go to the grocery store, she may want to consider what other stops she can make along the way. By the time she gets home, she can find herself exhausted or have another energy pass. Energy Passes can pop up in the middle of the day too, and just like that . . . a wave of fatigue can overcome them. There is no rhyme or reason to this. It just is and can be very frustrating to a loved one, friends, co-workers, etc., because, again, for the most part, your wife does not look sick to them.

Maximize the time

When we visit our grandchildren, Patty will sleep most of the way more often than not. Some of our family lives nearby, and others are three to ten hours away. Even though she has slept most of the trip has no bearing on the amount of energy she has to enjoy family. It normally becomes an Energy Moment and then a price she knows she will pay on the other side. i.e., extra recovery time from the activities of the day before. Our children understand that our coming and leaving within several hours is not about them but how much Patty can physically handle. The young grandkids have no idea how sick their grandmother is, and Patty does everything possible to look like she is not sick in her dress, demeanor, and attitude when she is with them. But when it is time to go, it is time to go!

Family

You would think that family would be the easiest to understand, but it's just as hard for the family to realize what is going on. Before diagnosis, it is often felt by those closest that your wife is faking. No one can be this fatigued. You don't look sick, but boy, you sleep a lot! Somewhere along the line, a diagnosis is made, and education begins. These are very troubling times during the pre-diagnosis of lupus because your wife has no idea what is going on or why she is feeling the way she is. It is a terrible position to be placed in, but that is just how it is.

Fathers can become indignant. "No way my son or daughter has a disease like this. It did not come from me!" he exclaims. But unfortunately, somewhere back in their genealogical history, the disease evolved and appeared in his child. There is no rationale for who, what, when, and where. It just is, which makes it very frustrating and can cause a sense of guilt. Of course, this pathway to disease can easily come from your wife's DNA. There is no definitive answer to this question. What is known is that specific genes can contribute to the disease. It's like a

computer chip that has been improperly programmed or had a Trojan Horse Virus installed. It is possible to reprogram genes to run correctly, as the software on a computer chip, but it must be identified first. In a nutshell, that is the mystery awaiting to be discovered.

Co-workers

If your wife works, there is a lot more than just lupus going on. There is her stress on whether she will be able to continue to work. She stresses how her co-workers will work with her if they know that she has lupus. She stresses telling her boss what is going on and that she needs accommodations, such as flex time and naps during the day at the office. A lot is going on here that could ultimately leave her job and go on disability. The impact on yourself, her family, and her career can be significant depending on your financial situation. See Chapter 22, "What If Your Wife Can No Longer Work?"

These are just a few things you should be aware of as your world begins to turn, unwind, and look at how better to adjust to your new norm. It does not mean your life is over and you will not be out having fun with the boys and doing the things you like to do. But, it does say that you will be required to be a little more attentive, sensitive, and caring to the one you love by picking up where she had to leave off, understanding and communicating more. Just don't overdo it. Loneliness is a stressor.

It's not as bad as you might think

Taking on new responsibilities around the house is not as bad as you might think. When I was in my teens, I was fortunate enough to go away to a private school. As a newbie, I had an upperclassman assigned to me as my mentor. Each

newbie was assigned a job. My first was to clean a bathroom in the dormitory. It was filthy, but I had it cleaned and sparkling within a couple of days. I learned that it did not take much to maintain it either. The reward for doing so was to be able to have dessert after dinner. It was the only good part of the meal.

Several weeks later, I was taken off latrine duty, to my chagrin, and reassigned to clean a classroom. I was initially upset because I had gotten down the routine of latrine duty, and I had become very proficient at it. Like anything else, you will adjust to the new demands and time restraints.

Fast forward to basic training at Lakeland Air Force Base in San Antonio, Texas, and the Technical Instructor asked our group, "Who wants to volunteer for latrine duty?" Of course, we were all schooled to never volunteer for anything. I raised my hand to the snickers and disbelief of my new comrades. It was the easiest job I had ever had in the military. The reason being is that I had experienced things I thought I would not want to do and found out they were not all that bad to do.

Fast forward to our home today, where I do the things Patty normally did. The vacuuming, cleaning the bathrooms, doing the wash (and yes, I iron too), and even cooking the meals, but I have all that now down into a system, and it is no big deal. We now have a cleaning lady come in every other week, ensuring Patty that the house is cleaned. It makes her feel good, and it gives me a chance to run some errands while she is here. I often wonder if our cleaning lady wonders why we hired her as the house is kept pretty clean all the time. My point here is that experience brings understanding, and the better you understand, the easier it is to cope, doing the things around the house and other chores that help your wife's quality of life. Trust me, she feels guilty about all this, as you might too. It's a team effort, and I encourage you to keep it that way.

I know this is not something every man wants to do, but this is not about you but taking care of the person you love. Of course, there are those men who enjoy cooking and keeping a clean house and see running to the grocery store to pick up a few things as no big deal. When you realize that the washing machine does most of the work, the few moments it takes to fold and hang up clean clothes are not that big. If you see something that needs to be done, do it then, and it does not become a chore. So, if anything, you will learn to become proactive versus reactive, which is not a bad thing.

I will talk about the Five Stages of Acceptance in the next chapter. This will give you more clarity about your emotions, especially what your wife or loved one is experiencing and why.

CHAPTER 11

The Five Stages of Acceptance

You have probably heard of the "Five Steps to Grief," but on the off chance that you have not, a quick review will help you understand what your wife is going through. Too often, these steps apply to the loss of a loved one. In this case, the five steps are applied to someone who has just been given the diagnosis of lupus or another autoimmune disease. Immediately your wife will go into denial, whether you or she realizes it. That is probably the typical response to the diagnosis of lupus. The second response is likely, "I've never heard of lupus. What is it?" Regardless of the initial reaction, the reality of your wife's symptoms and diagnosis come home to roost in the emotion and reality of what is going on inside of her.

It is not to say that all individuals go through the "Five Stages of Acceptance," nor is there a designated time one stays in a particular stage. Thoughts can fluctuate from one emotion to another, i.e., denial, anger, bargaining, and so on. A review of these stages will help you understand your wife's behavior and, just as importantly, help you recognize the same stages, possibly in yourself. I prefer to call the "Five Steps of Grief" the "Five Steps of Acceptance," because that is when life really begins again . . . when the disease is accepted

In essence, your wife's self-identity is challenged. Her life has been turned upside down. What she easily enjoyed in the past, was able to do, is now more difficult. It is natural for her to withdraw from her past to a very uncertain future.

Psychiatrists tell us we will fall into five stages that evolve to acceptance. As a caregiver, you must be aware that her emotions are normal as she comes to grips with her medical circumstances and the adverse effects on her life. It is essential to be sensitive to her needs as she navigates through the new limitations challenging her life. Remember, your wife has probably been dealing with her lupus for several years. And thus, she has perhaps been in stages one and two, denial and anger, since her symptoms became apparent. The diagnosis brings clarity to her medical situation but certainly does not resolve anything. You now know your wife is sick and not faking her symptoms. And for her, it is a relief because at least what she has been experiencing now has a name. It clarifies all the emotions that you and she have been experiencing since your wife's symptoms first began to appear and affect both of your lives. Here are the stages of acceptance:

Denial: This is not a river in Egypt, but it may as well be if one sticks their head in the surrounding desert's sand and ignores the reality of their diagnosis. Again, the good news here is a diagnosis that explains why she has been feeling so tired and any of the other symptoms that have gone undiagnosed for so long. I have seen individuals with lupus who have refused to accept their diagnosis, the reality of what is going on medically. They want to live life as they had been and go down a pathway that is not in their best interest rather than doing the right thing—for example, staying out late partying, eating the wrong foods, not getting enough sleep, and so on. At some point, anger begins to seep into the equation. Your wife wants to remain normal, and who can blame her. This is not fun stuff!

Anger: Once there is a diagnosis, it is not uncommon for your wife to get angry. "Why me?" is the normal emotion. "I don't have time for this in my life? My God, how will my husband react to me; what about my children. I can't care for them as well as I used to. What do I tell my friends and family? Does our insurance cover this? What kind of financial burden is this going to place on our family if I can no longer work?" The questions go on and on, and the anger, the emotions, the stress are very real! If you are not experiencing the same feelings,

recognize that she is to the point this can be a very pivotal time in your relationship, i.e., her anger can be directed toward you, which always seems to be a natural target. Don't take it personally. She is releasing a lot of feelings, which is a good thing.

Bargaining: "If I had only done this or done that!" There is no one for your wife to bargain with other than her thoughts. You ask, "How did she bring this lupus upon herself?" There is no "if only I had's." There are no "what if statements." Your wife wants her health restored, and that possibly can happen if her disease goes into remission. Thus, bargaining has no benefit other than reinforcing one's "why me?" but a natural reaction. The reality is that she did not bring lupus or another autoimmune disease upon herself. Autoimmune diseases are not infectious! They are genetic.

Depression: Yes, it is real and a very natural stage in getting to acceptance. There are positive things one can do when one finds themselves depressed. For example, asking oneself, "What am I depressed about?" and "what can I do about it?" versus withdrawing from life, feeling lost, sad, wondering what tomorrow will bring, worrying about the past, present or future. Chemical imbalances can also cause depression in the brain. If depression is not addressed through one's thoughts, your wife's doctor can prescribe medicine to help her better cope with her feelings and thoughts. Support groups, whether at church or through the Lupus Foundation of America, are a great way to identify with others in a similar situation and begin to realize that one is not alone, you're not the first, and learn what others do to cope with their depression.

A young lady in her early twenties, I will call Mary, has lupus. She attends a monthly lupus support group. She calls Patty grandma and often calls for guidance. She now helps Patty get back and forth from the support group meetings as Patty's ability to drive is limited to short distances. Mary's involvement with the Lupus Support Group has made a significant difference in her life and her family's understanding of what their daughter is going through. When your

wife or child's illness has a name, it can open up doors to clear misunderstandings and family misdirected emotions to support.

Acceptance: This is the stage that is probably the most difficult because of all that has progressed beforehand. It's the final realization of what has happened and the determination to get on with life. She leaves the stress behind, manages the disease versus allowing the disease to manage her, and does her best without self-recrimination. It's frustrating when one cannot do the things they used to be able to do. Those roles can always be filled by the caregiver, other family members, or a friend. Acceptance is the process of learning to adjust to the circumstances, getting back into the game as best as possible, making new friends who have gone through or are in a similar situation, and most importantly, becoming more compassionate about life because of what life has dealt them. It's easy to walk in another's shoes when you have worn the same style.

Acceptance is not that everything is OK, but rather that it is OK and that you will deal with life from a more positive perspective. This thought, reinforced over time, significantly reduces stress, anxiety, worry . . . that whatever comes up will be dealt with in a positive way versus victim. The five stages are not finite. Though they may appear to be in chronological order, they are very interchangeable, meaning one stage can slip back to another even after acceptance has been attained. Each of us deals with these realities differently. I only suggest that a positive attitude in addressing reality is a lot better than a negative, defeatist reaction.

Again, you may have discovered that you have many of the same feelings as your wife. Of course her situation, medically, is very real. The reality is that your emotions and how you are handling these new responsibilities are real too. The good news is that time will bring you both to 'acceptance' and doing the best you can together to live and enjoy life. It is more than possible. Knowing that you are going through these stages, getting well educated on lupus or the disease you are

dealing with. We also suggest that you become aware of the resources available to help you and reach out. There is no reason to be embarrassed, especially with others in a similar situation who need help or want to help too.

"Today is only one day in all the days that will ever be. But what will happen in all the other days that ever come can depend on what you do today."

Ernest Hemingway

Your wife will depend on you today and, from now on, to be the caregiver/advocate she needs. What you depend on today was nurtured yesterday in the trust and acceptance of your wife that you are a caregiver/advocate she can rely on.

Colossians 3:12-14

"Therefore, as God's chosen people, holy and dearly loved, clothe yourselves with compassion, kindness, humility, gentleness, and patience. Bear with each other and forgive one another if any of you has a grievance against someone. Forgive as the Lord forgave you. And over all these virtues put on love, which binds them all together in perfect unity."

SECTION 2

The Autoimmune Conundrum

Conundrum: A question or problem having only a conjectural answer.

Repetition is the aide to memory. In this section, I know that I repeat information that some would say, "Why cover it again? You have already covered it once!" I'm sure your memory is a lot better than mine and often I am reminded about things I had learned before. However, these topics are important and a little repetition reinforces that.

CHAPTER 12

The Autoimmune Conundrum

As noted before, autoimmune diseases affect approximately 1 in 13 people in America. A genetic predisposition carries the risk of autoimmune disease in one's body. The predisposition you are born with, if triggered, results in one of 80 plus autoimmune diseases. Someone somewhere in the family tree had a predisposition to diabetes, celiac disease, asthma, arthritis, MS, etc. I have Gout, which is a form of arthritis. My doctor explained that the Gout in my system, when triggered, is like throwing a light switch, and the bulb turns on. Something triggered the disease to become active. Like other autoimmune diseases, there are medicines I take to eliminate the symptoms, but I continue to have flares from time to time. The secret here is to reduce inflammation before it evolves into something even greater and more damaging. Since writing this, I found myself in the hospital with a bleeding stomach ulcer from my gout medicine. My Rheumatologist suggested I take Febuxostat, a relatively new drug but very expensive. A 40 mg thirty-day supply is $249.00 for 30 tablets. However, thru GoodRX, you can get it for as low as $92.00 per month. It takes several months for your body to take total effect. Fortunately, my flares are now almost inexistent. Wouldn't that be wonderful for lupus or other autoimmune diseases that such medicine is invented to minimize the effects of the disease?

Your wife has had a predisposition to the disease she now has, and something triggered it. It is known that childbirth, exposure to the sun, and medicine, can trigger lupus. Many believe that environmental conditions can contribute too.

Many autoimmune diseases can be treated successfully, and others not so well. But, as we have mentioned more than once, there is no cure. This chapter will talk primarily about lupus, but a lot that is true with lupus is also true in many other autoimmune diseases. That's one reason why lupus is so hard to diagnose.

The Early History of Lupus

Lupus has been around for centuries, but it wasn't until the 13th century that a physician named Rogerius, a surgeon, gave lupus its name. It appeared to him that the lupus lesions, which we know as the mylar rash, looked very similar to the teeth bites of a wolf. Lupus means "wolf" in Latin. It wasn't until the 1870s, or thereabout that a young Hungarian dermatologist named Moritz Kaposi claimed that there were two forms of the disease . . . discoid (Cutaneous) lupus and what he called systemic lupus erythematosus. "Systemic (SLE)," in medical terms, means the entire body, and "erythematosus" means the abnormal redness of the skin or mucous membrane due to inflammation. However, today, four forms of lupus are identified: systemic lupus erythematosus (SLE), discoid lupus, drug-induced lupus, and neonatal lupus.

What is Lupus?

Today we have a better understanding of what lupus is. Though a lot is known about the disease, what is not is a cure. Not to be repetitive, but what lupus does to the body is confuse the immune system to identify healthy tissue (cells) as foreign. The immune system thus attacks healthy (cells) body tissue, no longer the defender against foreign invaders looking to attack one's health, i.e., germs, bacteria, and viruses, but instead joins the incoming raiders. Lupus can also lead to severe complications, such as lung disease, kidney, heart failure, etc. Inflammatory medicines and immunosuppressants suppress the immune system to minimize damage. It's crazy when you think about it. Your wife's immune system is

supposed to be there to protect her against germs and infections, and yet with lupus, her immune system joins forces with those invaders to work against her health. The Lupus Foundation of America coined the phrase "The Cruel Mystery," to describe lupus, and that it is!

Is there a cure for Lupus?

As mentioned before, there is no cure for any of the 80 plus known autoimmune diseases. There is more research going on today than ever before. Funding by the National Institute of Health (NIH), the Department of Defense, and other financial resources has prompted a flood of research for a cure. Unlike other autoimmune diseases, it is our thought that if the key is discovered to unlock the mystery of one autoimmune disease, many if not all other autoimmune disorders are a thing of the past. How great would that be!

Does Lupus affect everyone the same?

Unfortunately not, and that is part of the "Cruel Mystery" too, as symptoms do vary. As mentioned on the previous page, there are four forms of Lupus: Systemic, discoid, neonatal, and drug-induced.

Systemic Lupus Erythematosis (SLE) encompasses all systems in the body and is more associated with joint pain, fatigue, brain fog, and the potential for organ failure, such as kidney, heart, brain, lungs, eyes, other body systems such as nervous, hematologic and musculoskeletal systems.

Discoid Lupus is the inflammation of the skin that most often results in a rash that looks like a butterfly. These rashes often appear on the face, chest, and back and can appear on the arms and legs.

Neonatal Lupus is as it implies. It occurs only in newborns, and fortunately, there is a treatment for it - methotrexate.

Drug-Induced Lupus mimics Systemic Lupus. Drug-Induced Lupus will gradually disappear once off the medicine, but it does take some time to arrest significant symptoms.

Of the four forms of Lupus, "systemic" (SLE) and "discoid" are the most prevalent.

As a caregiver, it is hard to fathom exactly how much pain and uncomfortable your wife is and how it impacts your life living within her limitations.

Other Systemic Autoimmune Diseases that affect body systems

It is tempting to research other Systemic Autoimmune Diseases that can affect body organs and systems. Patty and I are not doctors or researchers and know that once your wife is diagnosed with an autoimmune disease, other than Lupus, there is a lot of information on the Internet. Don't always trust what you read. Your wife knows her own body better than anyone else. What medicines she reacts to in a positive way and those medicines that she does not. However, she and you can learn a lot from your Primary Care Doctor and other specialists. Most autoimmune diseases are not life-threatening or disabling, thus not requiring the progressive level of care that your wife may or does need with her Lupus.

No. Lupus is a complex disease of inherited proteins and genes that, when triggered, will be active and/or then go into remission, reappear, and possibly progress to a more serious life-altering condition.

I remember a husband telling me the story that he and his wife were on vacation at the beach and that she got severe sunburn. The next thing they knew, she was always tired, and a rash appeared, and she was not feeling well. He shared with me his frustration and anger that she had done this to herself. "If she had not gotten that severe sunburn, she would not have caught this disease!" he exclaimed. This was a marriage that was well on the way to breaking up. They had a two-year-old son at the time, and he was a handful that the husband had to take care of when he came home from work. His wife was too exhausted and headed for her bed when he walked through the door.

I explained to him that his wife had not caught Lupus. She had triggered what was already in her. Whether it was sunburn, childbirth, stress, or even medications, the disease had been in her genetic makeup before becoming active. Something was going to throw the switch, turn on the light bulb, and the disease would become active.

Today they have another child and are as happy as they can be, I surmise, because he began to understand the importance of his role in being a caregiver, a husband, a father, and an advocate. What helped him turn around was his exposure to the lupus community. His wife encouraged him to come to workshops and other events to listen, interact and become more familiar with and supportive of her circumstances. Finally, the light bulb went on in his head!

What triggers Lupus?

We have talked about triggers, but everything you can read about what triggers Lupus is prefaced with "Doctors don't exactly know what causes lupus." What we do know, as mentioned before, is that it is not communicable. What is known is that there is a genetic component to Lupus. Still, if you present the same triggers in two genetically prone people with active Lupus, there is no consistency in diagnosis. Photosensitivity to sunlight can trigger the disease. Ultraviolet light can trigger flares. It is known that Cytomegalovirus, Epstein-Bar virus, and Herpes zoster virus (shingles) can trigger Lupus. Researcher do not know why certain drugs, such as hydralazine (Apresoline), which is used to treat high blood pressure, has been a suspected cause. Other drugs, such as isoniazid, minocycline, procainamide, and quinidine, have also been suspected. According to Johns Hopkins Hospital, certain foods, such as Alfalfa and Garlic, "can send your immune system into overdrive and flare up your lupus symptoms."

Suppose an individual is predisposed to having active Lupus. In that case, there is a lot to be said about stress, especially dramatic events, i.e., a divorce, a severe injury or surgery, or the death of a friend or family member. Everyday day-to-day stress and ultra-violet light are more associated with flare-ups, but inconsistency is the only consistency in these reactions.

What is the most common symptom of Lupus?

Though many with Lupus will show signs of discoid Lupus, a rash on their face or back that appears to look like a butterfly or the masked face of a wolf, the most prominent symptom of Lupus is fatigue. Fatigue is internal. For someone who is overly tired, getting a good night's sleep will rejuvenate the body and the energy. Not so with autoimmune diseases depending on the severity. Getting a good night's sleep will not always rejuvenate your wife's energy. That your wife does not

look sick often causes misunderstandings and consternation among couples. "He doesn't believe me, my family doesn't believe me," is a constant source of stress for your wife. It is not uncommon for people with Lupus to also have fibromyalgia. I can remember when fibromyalgia first appeared. A co-worker had severe muscle pain in her back and fatigue. Her doctors could not figure out what was going on, and her husband thought she was faking. Sound familiar? Don't confuse fatigue with exhaustion, at least when it comes to someone living with Lupus or other autoimmune diseases. Exhaustion comes from just overdoing. A full day at work and then some; doing the wash, getting the kids out the door in the morning, or dropping them off at daycare. This can all add up to where the body is exhausted both mentally and physically. A vacation or being able to sleep in over the weekend can revitalize one's energy. Still, when it comes to Lupus, fatigue is waking up after a night's sleep and just feeling weak, tired, with little or no energy, and will vary in degree from mild to severe every day.

Can Lupus be inherited?

Yes. If one parent has Lupus, there is a higher chance their offspring will have Lupus. Relatives have a 5 - 13 percent chance of Lupus being present.

Can Lupus go away?

Lupus is a chronic disease, which means symptoms will come and go but will never totally disappear. The hope is remission and/or newly discovered treatments such as Benlysta (2011) and Saphnelo (anifrolumab-fnia) in 2021 and Lupkynis (voclosporin) in 2021. Benlysta was the first drug approved by the FDA in fifty years. As you can see, there has been an increase in research resulting in these new drugs coming on the market. There are ongoing studies and the promise of stem cell therapy. As always, these prescription medicines can only be approved under a doctor's care and guidance. There are also significant side effects and other

medicine interaction warnings. None of these medicines are a cure and can be used to treat active lupus nephritis (LN) with other drugs. Know that there are significant potential side effects.

What is the life span for someone living with Lupus?

Patty has been living with Lupus for over 50 years since her diagnosis, so there is longevity. The average person can expect to live a normal life span, but that depends on many variables and how well she/he takes care of themself over the years. The problem with Lupus is that one disease begets another disease. Thus a shortened life span could be the result of another disease or a complication with Lupus, such as sepsis (severe inflammation), blood clots, if she is on dialysis, and so on. Kidney disease appears to be the more prominent adverse effect of Lupus, and why it is essential, your wife must find a nephrologist for the first signs of kidney issues. Her primary doctor will be able to diagnose the potential of kidney disease by monitoring her creatine levels (determined through a blood test). i.e., when her doctor runs a normal blood test, he/she will test for creatine too.

Can my wife continue to work living with Lupus?

Yes, unless her Lupus becomes severe. More often than not, it is her level of fatigue and her inability to concentrate (brain fog) that will determine whether she can continue to work. There are accommodations, if her employer is agreeable, such as flex time (working from home), approved rest time at the office, and so on. More on this in Chapter 22, "What If My Wife Can No Longer Work." Your wife's inability to earn a living can bring significant financial strain upon the family and your relationship. Fortunately, since COVID-19, it is more acceptable to company's for their employees to work from home on a regular or flex-basis.

Can Lupus be defined as a disability for benefits?

The answer is "Yes." Your wife's loss of income can be buffered with disability benefits up to and including social security disability insurance (SSDI). As a chronic disease, your wife's health can deteriorate over time to the extent that she qualifies for disability benefits. The process of qualifying and receiving benefits is a lot longer than anyone expects. I have devoted a whole chapter to this topic. For more information on disability benefits and social security, go to chapter 22. On a side note, according to the Center for Disease Control and Prevention (CDC), only 46% of people with Lupus are employed.

Can Lupus affect your wife's eyes?

Yes. The following conditions are most often associated with autoimmune diseases, such as Lupus. Your wife should see her eye doctor at least once a year, especially if she has any of these symptoms.

- Dry eye syndrome,
- Dry eyelids due to discoid (rash) lupus,
- Retinal disease: This is where the blood supply to the retina is limited, which can result in a decrease or loss of vision.
- Scleral disease: the whites of the eye becoming inflamed and painful.
- Optic nerve disease: inflammation of the optic nerve.

Your wife should ask for an annual Field of Vision test (FoV) to make sure that her peripheral vision has not been affected by a drug. Dangerous effects from Plaquenil are not frequent, but it is still in your wife's best interest to have an annual eye examination or, as her primary doctor may advise.

A Lupus Conundrum

One of the go-to medicines for Lupus is Prednisone, the first drug used in lupus patients to manage and mask lupus symptoms. The byproduct of Prednisone is renewed energy and reduced inflammation. Extended time on Prednisone will ultimately result in weight gain and can promote bone loss. That is just about what every woman wants in their life . . . weight gain! Right? Prednisone reduces inflammation, which will reduce swelling and pain. Thus, there is a love-hate relationship with this drug. It is not uncommon to hear those living with Lupus wanting to get off all the medicines. There is always the risk of your wife being over-medicated. It has happened to Patty with the resulting action of adjusting her medicines and eliminating some too. There is no finite because everyone is a little different in how their body reacts to medicines. More on this topic in Chapter 25 - Medicines.

What is a lupus flare?

The Lupus Foundation of America sponsored a study to establish a unified definition of a flare that doctors internationally could accept and look to for guidance. It reads, "A measurable increase in disease activity in one or more organ systems involving new or worse clinical signs and symptoms and/or lab measurements. The increase must be considered clinically significant by the assessor (physician or clinical researcher), and in most cases should prompt the consideration of a change or an increase in treatment." For you and your wife, a measurable increase in disease activity is probably all you need to know. Over time you will come to learn what triggers (See Chapter 13 - Autoimmune Triggers) your wife's flares and/or noticeable progression of the disease. The severity of the flare will be known or not normal. When not normal, she should see her doctor as soon as possible, and if the severity of a known reaction to a flare concerns her, she should see her doctor as soon as possible.

One person developed a severe rash on her face that she felt was burning her face off. She tried all sorts of potions and oils. Her rheumatologist searched for the cause, but the issue continued. That is when we suggested she get a referral from her doctor to go to Duke University. On her initial visit, the doctor was so concerned that she excused herself and went immediately into consultation with higher-ups. They had never seen a case this bad. Fortunately, through the use of specific skin treatments, her issue was brought under control over time. What caused it is still unknown, which is very true with Lupus and other autoimmune diseases. It remains a mystery.

When symptoms of Lupus appear, such as mouth soars, fever, a rash, joint or muscle pain, enhanced or extreme fatigue, all these are indicators that the disease is becoming more active. This process of symptoms appearing is known as a "flare." I have talked about triggers that can cause flares.

Anything that can cause stress can cause a flare. Again, there is no finite, but it allows you to look ahead to know that a flare is possibly coming if your wife finds herself in a stressful situation, such as an argument with you, job stress, financial stress, and so on. Helping to reduce your wife's stress, if possible, is a major plus. There is no easy balance between being an upset husband (stress) and being a caring caregiver. I do not always meet those expectations, but I certainly start out trying to be a saint. After all these years, I still have a lot to learn in that category, and I would suspect you do too.

How long can a lupus flare last?

According to a poll by www.lupuscorner.com on March 2017, lupus flares last about one week for 63% of respondents. 25% report their flares lasted up to two weeks. It depends on how severe your wife's Lupus is at the time of a flare. Though fatigue can be considered a flare, do not discount the discussion we had

on Energy Passes. It seems that fatigue is a constant companion depending on the drugs your wife is on and how effective they are for her.

Does Lupus affect different ethnic groups?

Yes. 90% of those living with Lupus are women, and 3 out of 4 are of colored skin. It is different with young children as will be noted in Chapter 23: Your Child Has Lupus. Why 90% of women have Lupus, no one seems to know. It is more prevalent in African-American, Asian and Hispanic cultures. It affects all ages but normally becomes active between the ages of 15 and 40. What is known is that if one is born with a certain gene or protein, they are susceptible to active Lupus and that gene, variant therein, is far more prevalent in women than men. According to the Lupus Foundation of America, researchers have identified at least 100 genes that can contribute to Lupus. What causes Lupus to become active is varied. A baby can be born with active Lupus, though that is rare. Someone in their seventies or above can be diagnosed too, but that is also rare. As mentioned earlier, it can be triggered by a sunburn, having a child, or medicine. Some believe that the environment can trigger Lupus, but that has not been proven.

It's one thing to be diagnosed young and another to realize and accept the reality of the disease at such as young age. I'm not suggesting that adults are better equipped to deal with an autoimmune disease, but imagine being 15 years old and all of a sudden you become very tired, exhausted, fatigued. No matter how much sleep she gets, she is always tired. Brushing her teeth in the morning wipes her out for the day. This is not a fabrication but a true story of a very bright young lady who was excited about life, school, and friends, and all of a sudden, she would miss days at school, cancel weekend dates with friends, and so on.

Some days she could not even raise her arms above her head, and brushing her hair was a major ordeal that immediately took her energy. Fortunately, after weeks

of these symptoms, her mother took her to the emergency room. Just after she was admitted, she immediately went into septic shock.

Septic Shock

Septic Shock, inflammation, is when an organ is injured/damaged due to an infection. It can lead to low blood pressure, cell damage, organ failure and death. Imagine doctors in the emergency room trying to figure out why a patient is going into septic shock and specialists trying to get a fix on what is causing it. Fortunately, this young lady was in the right place at the right time. The doctors put her in an induced coma, and she was in the hospital for weeks recovering. Upon release from the hospital, it took only one month for her to be diagnosed with Lupus. Today she is a vibrant young lady, enjoying her life with only one major wish, and that is to get off her medications.

In essence, sepsis and what she went through was her savior, along with her mother, friends, and teachers, because the sepsis brought her Lupus to a head. Today she understands her limitations, and is the designated driver for her friends when they go out and party. She is a magnificent young lady. Is her case normal? Not really, but it shows you the magnitude and unpredictability of this disease in all its forms and circumstances.

Have I sufficiently scared you? I hope not overly so. Those who are diagnosed early often do better because the effects of the disease have had less time to do damage. Treated properly, adopting a healthy lifestyle often results in fewer medical issues. What others may not call normal becomes the new norm, and yours, too, as a caregiver, as you learn to live within your wife's limitations. This topic is so important that I have dedicated an entire chapter to Septic Shock - Chapter 23 - "The Sepsis Concern."

Potential organ involvement

Lupus can affect many organs, such as the kidneys, heart (myocarditis), and the brain, as mentioned previously. It can also affect the muscles (myositis) and the lungs (pneumonitis). When organ involvement is indicated, it is important to treat it as soon as possible. Otherwise, permanent damage or organ failure can occur. So your wife should make sure she is complying with her doctor's guidance in regards to medicines taken and keeping her appointments. Lupus is not a disease that allows one to stop seeing their doctors regularly because they are feeling better. Blood tests can tell a lot, as well as symptoms, and remember . . . one disease can beget another.

Can Lupus go into remission?

The answer is "Yes!" It is a mystery why, but it can. A more than normal active life is possible when one's energy is back, and all the other complications become an afterthought. Of course, those living with Lupus will always have issues with being in the sun and other triggers, as discussed. Just because she is in remission does not mean these other factors are no longer an issue. It does not mean she can go sunbathing again or put herself in stressful situations. There is no sense in testing the beast to only find it comes back worse than before. Those who go into remission still have a level of fatigue and do not feel as badly, and it does not mean she does not still have the disease.

Will my wife always have Lupus?

As just expressed, the answer is "Yes," but as said, it may not always be active. As mentioned before, there are new trials with stem cell therapy that are showing

some promise. As positive as some of the results have been, these are only trials, and long-term results are not known yet.

Diagnosis

The problem with diagnosis is that no one wants to think they are sick, and thereby they do not search out help from their Primary Care Doctor (PCP). The first issue is that the individual feeling sick does not have a PCP. Secondly is having insurance to cover a visit. Often, one hopes that whatever is going on will go away. Unfortunately, with Lupus and other autoimmune diseases, rainy days will persist until it is obvious that they need to see a doctor. Without a PCP, your wife will end up in an emergency room, which isn't a bad thing. She is in desperate need of medical care, and this could be the start of that part of her journey. All of this takes time with a level of denial. Because Lupus mimics so many other diseases, diagnosis can take months, even years, depending on how proactive the patient is and how good the PCP is.

In Chapter 14, "The Cycle of Lupus" I will go into greater depth on how Lupus is diagnosed and what the journey looks like. But the next chapter deals with triggers.

Patty and I encourage you to search for as much information on your wife's disease through the appropriate national organization, such as the Lupus Foundation of America, www.lupus.org.

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so important that I have dedicated an entire chapter to Septic Shock - Chapter 24 - "The Sepsis Concern."

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Lupus can affect many different organs, such as the kidneys, heart (myocarditis) and the brain. It can also affect the muscles (myositis), the lungs (pneumonitis). When organ involvement is indicated, it is important to treat it as soon as possible. Otherwise permanent damage or organ failure can occur. So your wife should make sure she is complying with her doctor's guidance in regards to medicines taken and keeping her appointments. Lupus is not a disease that allows one to stop seeing their doctors regularly because they are feeling better. Blood tests can tell a lot, as well as symptoms, and remember . . . one disease can beget another.

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In Chapter 15, "The Cycle of Lupus" we will go into greater depth on how lupus is diagnosed and what the journey looks like. But the next chapter deals with triggers.

Patty and I encourage you to search out for as much information on the disease your wife has through the appropriate national organization, such as the Lupus Foundation of America, www.lupus.org.

CHAPTER 13

Autoimmune Triggers

What triggers an autoimmune disease? First, there are 80 plus autoimmune diseases. Some are more common than others. No one knows how many people in the United States have an autoimmune disease. The National Institute of Health guesstimates 23 million, while the American Autoimmune Related Disease Association (AARDA) guesstimates over 50 million. However you look at it, it is a lot of people dealing with all sorts of autoimmune diseases. The Autoimmune Registry sites the top 10 autoimmune diseases as:

You can learn more at: http://www.autoimmuneregistry.org/the-list-1

1. Rheumatoid arthritis
2. Hashimoto's
3. Celiac
4. Grave's
5. Diabetes Type 1
6. Vitiligo
7. Rheumatic fever
8. Pernicious anemia
9. Alopecia
10. Immune Thrombocytopenia

There are no consistent triggers for all autoimmune diseases. Here are the common triggers:

1) Viruses

2) Bacteria imbalance in the digestive system. This is better known as Leaky Gut Syndrome and is a known trigger for many autoimmune diseases. https://www.naturalgrocers.com/article/autoimmune-diseases-inflammation-and-leaky-gut-connection

3) Sunshine

4) Gluten

5) Stress

6) Sugar

7) Dairy

8) Environmental Toxins

9) Certain Drugs

10) Nightshades (certain vegetables)

11) Chocolate

12) Grains

13) Genetics

For more information go to:
https://facty.com/ailments/body/13-triggers-of-autoimmune-disease/4/.

Lupus manifests itself in many different ways and is not always the same as others living with lupus. Some consistent triggers can cause flares, such as sunlight, medicines, or allergies. Your wife will begin to learn what triggers a flare in her. Again, there is no finite, but depending on the activity of her lupus, staying away from places where the level of risk is higher: A family member who has a cold, or going to events where there are a lot of people just increases the exposure of contracting a virus or infection. Some medicines and treatments can reduce symptoms. What triggers one autoimmune disease can be similar or completely different for each individual. However, there are some known triggers for lupus and known triggers that will result in a flare in other autoimmune diseases. Your wife will quickly learn what to avoid to reduce the risk of a flare.

The most common trigger is exposure to the Sun. Sunbathing between the hours of 10 am and 4 pm is not advised or ever because that is when the ultraviolet rays are at their highest. When outside, it is advised to wear sun-protective clothing: (www.Coolabar.com). The use of sunscreen as a constant

companion is too. Use at least 50 SPS. And, don't get confused that on a cloudy day that no UV rays are getting through to the ground. On the contrary, they still do. Not as strong. However, on partly cloudy days, there is what is known as the "broken-Cloud-Effect," wherein UV-B rays, the ones that cause sunburn, will increase anywhere between 25% and 40%, according to studies. So cover-up! It is better to be safe than sorry.

Associated with the Sun is heat. In June 19, 2006, New York Times article entitled: "A Sunny Day Can Mean All Sorts of Distress," it is noted that: "Summertime is not so easy for people living with certain autoimmune diseases. The Sun, heat, and even air-conditioning can intensify symptoms and cause problems that linger for months, if not years." The journalist notes that lupus, scleroderma, and Raynaud's phenomenon are of the greatest concern. The article also quotes Dr. M. Kari Connolly, a professor of dermatology and medicine at the University of California, San Francisco. He says: "a little bit of overexposure to the sun can present a whole lot of problems, and if we can get patients to be compliant with sun avoidance and protection, we can minimize the chances of their getting additional complications disease." In other words, an ounce of prevention is worth a pound of cure.

So, when we say, "stay out of the sun," there is a lot of history behind the caution. Because your wife is not outdoors that often in the Sun, her vitamin D, normally absorbed through sun exposure, should be checked, as should yours too.

Fluorescent light bulbs can cause a flare too? We will talk more about that in Chapter 22. What also can make your wife more sensitive to the Sun is sulfa drugs, such as diuretics. Other triggers for flare-ups include a cold or viral illness. Again, it is why every time I get home from shopping, I wash my hands. Remember to sing Happy Birthday to yourself. If the store provides a cart, such as food stores, I always use the wipes provided to sanitize the handle of the cart too. It's easy to get into the habit, but the last thing you want to do is be the cause of

infection to your wife. You have no idea where you can pick up a germ, bacteria, or virus that your wife's immune system cannot handle. Get in the habit of washing your hands!

This is the second edition of Caregivers Wear Plaid. My additional research has shown that Lupus is in the top ten of the most common autoimmune diseases, as is Sjögren's syndrome, scleroderma, and pernicious anemia. In most research, you will find different opinions or studies that vary in their results.

On a personal note

Pernicious anemia can cause severe vitamin B12 deficiency. It makes more sense to me as Patty has a severe vitamin B12 deficiency. In fact, it was the worst case her neurologist had ever seen. Fortunately, B12 is inexpensive and can be easily administered through a 1/2-inch syringe. Patty finds it painless to administer and takes a B12 shot as often as she feels it is needed. For more information:

https://www.healthline.com/nutrition/vitamin-b12-deficiency-symptoms#2.-Pale-or-yellow-skin

CHAPTER 14

The Cycle of Lupus

Most debilitating autoimmune diseases fall into this or a similar cycle. These cycles, regardless of the autoimmune disease have distinct stages that will affect your wife physically, emotionally and challenge her spirituality too.

The Cycle of Lupus Chart

You will not find the chart below anywhere else. So don't look for it on the Internet. I created it to describe the stages your wife will transition through over time. The chart indicates key milestones your wife will experience on her medical journey. I might add that you may as well. I will expand upon each milestone and hope that by the time you end this book, you have a pretty good idea of how lupus, or most other systemic autoimmune diseases, will affect your wife now and in the future. Probably the most difficult challenge your wife will face is dealing with how her identity as a person changes over time as she progresses through the cycles until she accepts her new norm and adjusts. It is not easy, and it requires a positive attitude and a focus on her faith. That is true for you too!

Your wife has been given a bad hand in life and you need to help her make it the best that she can under the circumstance. Life, as Tom Hanks said in the movie Forest Gump, "is like a box of chocolates." That is exactly what living with lupus is like, because as you bite into a bar of chocolate you do not always know what you are going to get. Lupus can masquerade as other diseases and one reason why it is so difficult to diagnose. In many respects, lupus is an acronym for many other diseases too, such as kidney and heart disease that can develop from having lupus.

1. Symptoms: How does one know they have lupus?

Fatigue, swollen joints, fever, hair loss, rash and so on. Your wife's doctor will look at your wife's symptoms to make a diagnosis or make a referral to a specialist, such as a dermatologist or a rheumatologist.

As noted, it can take years before lupus is diagnosed. Because fatigue is so prevalent as a symptom in lupus, it is very difficult for those around your wife to understand what is going on. As we say many times in this book, "she doesn't look sick." Thus, something else is going on and no matter how much she sleeps she always feels a level of fatigue that is minor to major. This period is very difficult because the caregiver is watching any change in behavior that was not expected and more often than not accepted. The dialog ultimately leads to anger, frustration, concern, and so on. At some point, the level of concern and denial of symptoms leads to a doctor.

The following are the eleven medical symptoms that can lead to a diagnosis of lupus:

1. Extreme fatigue

2. Headaches or muscle aches

3. Painful or swollen joints

4. Fever

5. Weight changes

6. Anemia (i.e., low numbers of red blood cells or low total blood volume)

7. Swelling in feet, legs or hands

8. Puffiness around eyes

9. Pleurisy (i.e., pain in the chest when taking a deep breath)

10. Butterfly-shaped rash (Malar) across the cheeks and nose or a rash that is patchy and bumpy (Discoid)

11. Sensitivity to light or sun

There is a 12th diagnosis too, and that is if your wife's kidney is biopsied it can be determined that she has lupus nephritis.

Additionally, if your wife has Raynaud's phenomenon (i.e., fingers turning white or blue when cold), or is experiencing hair loss or mouth/nose ulcers; these are other indicators above and beyond the top eleven that your wife might have lupus. Remember, one disease can beget another and it is oh too often with lupus. Often a definitive diagnosis can be made through a biopsy, but that is not something that is normally done unless your wife is in an emergency situation and the doctors suspect lupus or other circumstances. That is exactly how Patty was diagnosed through a biopsy on her nose that was thought to be cancer and turned out to be a non-specific systemic autoimmune disease that is treated as lupus.

According to Johns Hopkins Medicine, 4 out of the 11 criteria used to diagnose lupus by the American College of Rheumatology are skin conditions. If your wife has fewer, the diagnosis could be considered borderline, incomplete lupus, undifferentiated or non-specific lupus. It all means the same thing. "We are not

sure what you have, but we will treat it as lupus as if it is a non-specific autoimmune disease," the doctor will explain.

You can read more at:
http://www.symptomfind.com/diseases-conditions/recognizing-symptoms-lupus/#jWEc2BxO4R6JplR0.99

2. Diagnosis: How Is Lupus Diagnosed?

A lupus diagnosis can be made immediately, up to six years or more. Some autoimmune diseases are easy to diagnose. Others, such as lupus, are not and often require expertise above that of your PCP (Primary Care Physician) for a definitive diagnosis. Normally a rheumatologist. In some cases, a diagnosis may not be specific, but the treatment will often be the same.

When Patty and I were dating in high school I remember taking her to a doctor. She did not tell me what was wrong, because 1) she didn't know and 2) she didn't want me to know. She was good at masking what was bothering her. Back in the 60's lupus was not well known by the family doctor, and today that pretty much still holds. Having said that, in recent years there has been more attention paid to research and diagnosis. In hindsight, what we didn't know when Patty was 18, was diagnosed when she was 26, which may seem like a long time, but even today it can take six to eight years for a diagnosis. On the other hand, a bad sunburn that refuses to heal results in a trip to the dermatologist where the doctor suspects lupus and refers the patient to a rheumatologist for a definitive diagnosis. A severe kidney infection results in a trip to the emergency room where the doctors suspect lupus and discover the patient is on a downward spiral toward death due to lupus. These are real situations, but for the most part, diagnosis takes months if not years depending on how proactive the patient is in seeing a doctor and how well educated their doctor is about lupus.

Primary doctors are getting better at diagnosing lupus, and part of this is due to better awareness education within the medical community. Like everything else, it takes time and resources to develop and spread the word. Thus, awareness, or the lack thereof, is a real issue and opportunity.

Lupus mirrors many other abnormalities and thus is known as the "Great Imitator." As mentioned, it can often be difficult to diagnose. Your wife's doctor may treat symptoms, but not identify the overall disease. As a patient and advocate it is important to be proactive and if you feel her doctor is not diagnosing, suggest seeing a rheumatologist and ask for a referral. I will talk about this more in Chapter 17 - The Referral.

Over time your wife's symptoms will become evident that something is wrong. This can become very emotional when you, other family members, even friends who think she is always tired, unable to participate in life the way she did before, is perceived to be faking, not wanting to work, not wanting to do things. Know that while everyone else is thinking all that, your wife is thinking, "why don't they believe me, why don't they believe me?" It can become a constant replay in your wife's mind and thus lead to greater stress and progressiveness of her lupus.

Why does diagnosis take so long?

First, your average primary doctor has probably had less than one hour of study on the disease during medical school and thereafter. It is not the disease de jour. It is difficult to diagnose and difficult to treat. Having said that, there is more lupus research going on today than ever before, and one would like to think that doctors are more aware of these efforts and thus the attention the disease is currently receiving.

Second, there is no definitive blood test to determine if one has lupus or not, but a lot can be discovered, i.e., is there infection in the body; kidney and liver function, and one's general overall health along with the eleven symptoms (See page 132 & 133).

If your wife's primary doctor senses there is inflammation, such as joint or swollen organs, he/she will order an ESR test (erythrocyte sedimentation rate test). Depending on what that shows, her doctor may order an ANA blood test (Anti-nuclear antibody test). This test is looking for a particular antibody that is seen in at least 95% of people with lupus. Unfortunately, one can still have lupus without this anti-nuclear antibody and often, even with this antibody present, the test can result in a false positive, thus making a definitive diagnosis harder to make. Kim Kardashian in 2019 thought she had lupus after a positive ANA. Fortunately, the diagnosis was not definitive for Ms Kardahian. Imagine the anxiety and stress all this brought on her and would bring upon your wife in a similar situation. The stress is immense.

Of course, time goes by waiting for results, getting another appointment that will last 8 to 15 minutes on average and possibly another blood test known as the Anti-DNA test. If one does have this antibody, which approximately 70% who have lupus do, it is a pretty good bet that lupus is the diagnosis.

Because lupus can affect one's internal organs, you should get accustomed to your wife having blood tests to ensure liver and kidney function, etc., are within safe parameters. Adverse effects from medicines can cause concern too. Again, this is frustrating and exhausting for someone who is living with lupus that is undiagnosed at this point.

If it looks like a duck, quacks like a duck and walks like a duck, it's a pretty good chance it is a duck . . . but not always. When this occurs, the diagnosis may

become a non-specific autoimmune disease. No big thing, because as much as it would be nice to have a definitive diagnosis, one's treatment and quality of life is more important than the name it is given. As mentioned, many autoimmune diseases are pretty much treated the same way. Our rheumatologist has told us that there is no consistency to diagnosing lupus. Ten people all having different symptoms can ultimately be diagnosed with lupus or any other systemic autoimmune disease, such as psoriasis. That is what Kim Kardashian was ultimately diagnosed with psoriatic arthritis, an autoimmune disease that comes and goes and is not as severe as lupus can be. Obviously, she was relieved, but the emotional trip she was on in regards to her health, career, life was enormous. Imagine how your wife must feel?

Keep in mind, vital organs such as lung, kidney and heart involvement in systemic autoimmune diseases are common. Unfortunately, there are limited treatment strategies. Patty, at this writing, was in the hospital with pneumonia. Her ankles and legs were swollen and water had accumulated in her lungs. Tests indicated that she had pneumonia, but also revealed that she had Stiff Heart Syndrome (Cardiac amyloidosis). Now another medical issue was on our plate to deal with. The treatment initially was to use a diuretic to flush out fluid and reduce swelling and the effects of pneumonia. After five days in the hospital, Patty was released to go home. A couple of weeks thereafter, here creatinine went from 1.7 to over 4. Five is kidney failure. It turned out that the diuretic she was on was causing the kidney issues. It is now a balancing act between hydrating, minimizing the salt intake and watching her weight. Building our team of doctors has been critical to the success we have had in managing Patty's symptoms and her overall health. Obviously, we do not know your age and where you are in this journey, but age and the damage inflammation can cause over the years become a reality.

3. Building Your Team of Doctors

Take control of your lupus or autoimmune disease versus allowing it to take control of you. Proactively build a team of doctors. It is critical to your wife's health. Patty has her primary doctor, a rheumatologist, dermatologist, nephrologist, cardiologist, pulmonologist, endocrinologist, neurologist and more. We ensure that they all communicate with one another so our visits are not about the past, but rather the present and future. Building your team of doctors is probably the most important thing anyone living with lupus can do because quality care will extend life and hopefully the quality of life too.

Your wife's primary doctor is her gateway to other doctors. Make sure that all records from other doctors are sent to your wife's primary doctor so he/she knows all that is going on with her diagnosis. Simply tell her other specialists, if they are not in the same network, to forward the records.

Secondly, your wife must be honest with her doctor about all her symptoms. When I first found myself in this position of caregiver/advocate, I would go with Patty to her doctor visits. Sometimes Patty was not being truthful about her symptoms, and I would speak up. This initially did cause some issues between Patty and I. Though my intentions were admirable, I was not the one who was sick. Patty was emphatic that I butt out. She would control her doctor and the visit. Visit after visit, even though I was told to say nothing, I spoke up when I felt it necessary because I knew it was important that the doctor had as much information as possible to help. Over time Patty came to realize that I was there for her, that we were on the same team and that we both wanted the best for her. Having said this, I know of one husband who is banned from his wife's doctors office by the doctor. A high controller is not what you want to be. Depending on your relationship and demeanor, it becomes a balancing act of emotions and input.

It will take time to build your team of doctors . . . especially a team that your wife is comfortable with and trusts. We have fired our fair share of doctors over the years simply because of their bedside manner, or we felt that they were 'going through the motions' and not paying attention to what Patty's needs were. Our one consistency has been her PCP. He is the gatekeeper, especially when it comes to any changes in her medicine. With Patty's newfound issues with her heart, a cardiologist has come on to our team. We have made sure he is connected to all of Patty's other doctors, especially with updates. Patty's nephrologist only sees patients in her office twice monthly. When Patty was in the hospital with kidney issues, a cohort of our nephrologist stepped in to help. On our first visit with him, after being released from the hospital, we presented him with a list of Patty's doctors and reenforced that her primary doctor is her team's gatekeeper. Our cardiologist was delighted that we were as proactive as we are and able to provide other information, such as a daily record of her weight, blood pressure, pulse, oxygen, etc. He wishes all his patients were this good at keeping records. You may not be at this level of concern and documenting, but keeping that record and a daily journal really helps the doctor and helps the caregiver providing information that is often forgotten and/or not documented in other doctor's records. Your wife's team of doctors will not be built overnight. i.e., she may not require all the doctors and other services listed below:

Rheumatologist, Nephrologist, Dermatologist, Gastroenterologist, Pulmonologist, Perinatologist, Psychologist, Hematologist, Gynecologist or Obstetrician, Cardiologist, Physical Therapist, Marriage Counselor. The list can go on and on!

4. The Five Stages of Acceptance

The Five Stages of Acceptance: Denial; anger; bargaining; depression; acceptance is real. Real too is that at any given time your wife can fall back from one stage to another. Why? Because her disease may well continue to challenge

her in ways she never considered or experienced. It's not until she takes control of her life that life will no longer control her getting through these stages. There is no time limit, there is no silver bullet. Each reacts differently through their own uniqueness and ability. However, she must become strong and that is where you as a caregiver can play an important supportive role.

Also known as the Five Stages of Grief, it is all about how one handles the process of "accepting" their situation. Easier said than done when you are the one dealing with significant health issues. But "grief" is a natural human emotion that manifests itself in anger, intense sadness and for many with lupus, loneliness. "People do not believe me," and "I don't want people to know!" are constant replays in your wife's mind. But that in the end just brings more grief. There is no switch to flip that says: "I accept my illness," nor should there be one. No one changes their old ways to seek the new until they personally find a reason to do so, and unfortunately, that is something that most often evolves overtime to the awareness of the obvious. Rather than looking back at what could have been, it is important to look forward to what can be and that is where the process of "Acceptance" becomes beneficial to your wife and you too as the caregiver.

How one gets to the point of "Acceptance," is different in everyone. It is certainly coming to grips emotionally with one's situation; being willing to take care of one's self versus allowing depression to take away one's life; making sure that doctor appointments are kept and finding others who are in a similar situation, not to gripe and bitch, but rather to be able to support one another through experience, comfort, and bonding. I have yet to meet a person living with lupus who has not benefited from being part of a support group. See Chapter 21 for "Support Groups."

Everyone knows someone with lupus!

That may be a surprising statement to you and it was to me too. However, I have found that when I talk about lupus I learn that just about everyone knows someone with the disease. When checking out at the grocery store I am often asked, "would I like to donate to this cause or that cause," I always say, "No, all our donations go to the Lupus Foundation of America North Carolina Chapter. Do you know anyone with lupus?" Inevitably they do. And, because I carry information packets in the car on lupus, it is not uncommon to share with that person to give to a personal friend. The packet includes information on our LFA chapter in North Carolina, general information and information on support groups in the area.

My work brings me in contact with a lot of different people. At some point in the conversation, I always find a way to insert lupus into the conversation. It might be they have someone ill in the family, or in one case I mentioned that our Lupus Golf Tournament was being canceled due to the weather. In that instance, it turned out the person I was talking to had just learned that his sister had been diagnosed with lupus. Small world, isn't it! I made sure he had our state chapter's website address and contact information so that the office could send his sister a packet of information that would help her, especially at this point in her lupus journey. When it comes to finding people in a similar situation, your wife needs to know that she is not the only one, that she is not alone, and if there is not a support group in her area that she can attend, to search out others to start one or at least identify others go to coffee or lunch together. It brings greater understanding and knowing that she is helping others too as she is receiving the same.

5. The Storm

The Storm clouds of physical, social and emotional and financial health constantly pop up. Expect strong winds, rain with possible hail. Tornados are not unexpected, but rare in most circumstances. If financial storms arise, one's faith must be weighed upon to weather the storm. Caregiver support and the community of like individuals become her umbrella from the storm. Search out cover! That is normally the headline of the day.

At some point you will begin to realize that you are in a storm, constantly pushing up against the winds of emotions, family, friends, neighbors, work, your own physical and financial health depending on your situation and wondering what the future will bring. It can become overwhelming, result in overwhelming stress, anger, depression, (sound familiar) and grief that your life has changed . . . not for the better. Unfortunately, acceptance of your circumstances, like that of your wife, are initially settled in hope rather than the reality of the circumstances. The song, "You'll Never Walk Alone!" from the broadway play Carousel by Rogers and Hammerstein brings some understanding and solace.

Patty's reaction to this passage was, "Gee, it sounds like lupus is a wonderful thing!" It is not, but I like to see that in every adversity lays the seeds to success, and to that end maintaining a positive supportive attitude I believe is important. But you know as well as I do that a positive attitude can only last so long unless it is supported by a positive action that you can become passionate about. That's why I encourage you to get personally involved in any way that you can with respect to funding research and supporting programs and services that help those living day to day on the ground whether Lupus, Alzheimers, Cancer and so on. With the advent of the internet, access to awareness training and participation in online events should not exclude anyone from resources and guidance.

The key here is to get through the storm to "acceptance," so that you and your wife can truly make a difference in your particular situation and hopefully others too. I know that you probably do not see that now, but it is certainly a worthy destination.

6. The Rest of Your Life

The level of your wife's disease will either remain the same, go into remission or progress in severity. Be thankful for the latter. As she gets older, the autoimmune disease she has can manifest itself into other ills that make her life more complicated; your life more demanded upon to provide caregiving services (cooking, cleaning, being Uber Boy, washing, shopping, and so on).

To grow is to progress and finding that avenue in which you and your wife are uniquely adept is a direction worth taking. Your wife will hopefully go into remission and everything thing you have read in this book will become nothing more than a bad dream. However, remission is an undefinable term, other than what one once had they no longer have. Lupus and other begotten illnesses may never fade away. However, because symptoms can often be confused in diagnosis, what your wife has may not be lupus and really could go away. How wonderful would that be!

What are the chances of it not being lupus?

Whether it is lupus or not, it is something that is not specific, but never-the-less has specific symptoms that need to be treated. This is normally referred to as a mixed tissue disease - undefined. Regardless of the diagnosis, you are dealing with an immune system that is working against the health of your wife's body. Most drugs used for one disease are often used in managing another. We also know

people who have gone into remission to which they would like to put the tag 'complete' on the front end, but we also realize that there are no guarantees and that the one thing consistent about lupus is its inconsistency. Never-the-less we remain positive that 'complete remission' is more than a dream and is a reality for some. That's how crazy and mysterious lupus is.

The key understanding at this level of awareness of the lupus conundrum for your wife and you are to live the best possible life together - i.e., knowing your wife's limitations and working within those limitations to live your life to the fullest that you can too.

The problem of writing a book like this is that other ideas are always falling into my mind that I want to share. Patty and I rarely go out to dinner, because the cost of *energy passes* is just too great. However, when I take her to doctor appointments she goes through the exercise of getting ready and because she is dressed for her doctor's visit I will suggest that we go out to lunch afterward. I know that sounds simple, but for Patty what was once normal is not now and to sit down in a restaurant, even a greasy spoon is a wonderful thing that most take for granted.

Patty has a Support Group meeting tomorrow, as I write. It usually gets out around 3:00 P.M. I will attend and afterwards we will go to a nice restaurant for an early dinner around 4:00 PM. It's my birthday, so there is no way she can turn down the idea! Thinking ahead does not always work out, but it is still worth the effort to enjoy every moment we have together.

As we go to bed tonight, Patty's energy levels are very low and she feels that she may not have the energy tomorrow to be able to go to the Support Group even if I take her. That is a simple reality tonight. We will see what tomorrow brings.

CHAPTER 15

‘Til Death Do Us Part

Whether marriage vows have been said or not, it is not out of the question that your loved one could leave this earth unexpectedly because of her disease. In fact you could too if you do not see a primary doctor on a regular basis and or get hit by a Mack Truck.

What if I die before she does or she dies before I do?

This chapter is about living wills, advance directives, power of attorney, and so on, but let me tell you a quick story. A golfing buddy, who was only a couple of years older than I was a very conscientious caregiver to his wife, who had had multiple strokes and needed someone to be with her at all times. We talked one day about his biggest fear, which has crossed my mind from time to time. I am pretty sure that Patty will go before I do, but then too did my friend Don think his wife would go before he did. That way, we would know we had done the best to their end here on earth. I'm pretty sure you feel the same way. On a shopping trip with his daughter, Don suffered a massive heart attack and died three days later. The day after the funeral, the kids put Don's wife, their mother, in an assisted living facility and put Don's house on the market. No one wanted to take care of Mom as Dad did. The best laid plans of mice and men do not always work out the way we want them to. So make sure that you and your wife have your affairs in order. Your wife will be asked about this by her primary doctor, and any time she finds herself being hospitalized (let's hope not). Aretha Franklin, the American singer-songwriter, died with an estate worth 9 million dollars, and she had no Will. Imagine what headache and heartache that caused her family.

Having said this, even though you are living within your wife's limitations, and possibly your own, too, it does not mean that you cannot find those moments to enjoy the things you enjoyed doing together or individually. Life goes on, and so

too should you both. Who goes first is in the Lord's hands but under the circumstances, take as good of care as you can of yourself and, of course, your wife too.

If your wife is rushed to the hospital, you should have the following in place:

1. A Durable Power of Attorney gives you the authority to legally speak for her (manage her finances or other legal needs) if your wife is incapacitated.

2. A Release-of-Information form allows your doctor to share your medical records with other doctors if they are out of your medical system network. A Living Will, God forbid that lupus takes your wife's life, is critical to the end-of-life decisions because it defines what your wife wants regarding the degree doctors go to saving her life.

3. Her passwords. This is one that no one talks about. Make sure that you have a record of all her online accounts and associated UserIDs and passwords. If she dies and you try to cancel online automatic renewal subscriptions or ACH withdrawals, etc., know that without her UserID and password, you will spend hours trying to unwind this web, no pun intended, and get approvals to cancel. So write her UserID and passwords down, yours down too, and keep them in a safe place. You may want to consider getting a password manager, a software application that you can keep on your computer. The best way to do this today is to use a password manager that uses the cloud. Encrypted, these applications allow you to access your password manager from any computer. I would recommend one, but technology is changing so rapidly. Search for the best password manager on the Internet if you elect to use technology to save your UserID and password record.

4. Avoid Probate. Every state seems to handle Probate differently, so check with an estate planner. This can become a very expensive process to work through or a no-brainer depending on her assets. Preparation in advance is important. "Wow, I am beginning to sense that my wife might die earlier than expected from this disease!" you exclaim. None of us know when our last breath will be taken. We have seen children die due to lupus complications; a young teacher with so much promise dies early because of lupus complications. Individuals living with lupus today have a greater chance of longevity than ever before if they see their doctors regularly, eat appropriately, get their rest, and exercise if and when they can. But, we have also seen too many individuals with lupus leave us way too early regardless of these efforts.

5. Consider setting up a trust. This will certainly minimize the risk of Probate because your trust, upon your death, goes directly to your heirs without going through Probate. Again check with an estate planner because laws are continually changing in our states and at the federal level.

6. Key things, known better as stuff, No one expects to die, and it is a good idea to determine who is going to get what when you or your wife dies. In most cases, it is left to the surviving spouse, but there might be certain things your wife wants to leave to someone other than yourself. You may think that these bequests would be in her Will, but as time goes by, additional items may want to be included. Ask your estate planner or lawyer who is preparing her/your Will to note that a separate list of bequest items is mentioned. That way, you do not have to keep paying for your Will to be updated.

7. Finally, what are her end-of-life wishes? Does she want to be buried or cremated, where, and to what extent? i.e., think about prepaying funeral expenses and what are her memorial wishes

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I know that this all sounds grim at best, and if you are young and have never thought about all this, I would at least consider doing something about 1 thru 4 a must. We have been in the hospital wondering if Patty would live, and of course, the older we get, the more we become aware of our longevity. Having said this, Patty has lived with lupus for over 50 years. Lupus is not a death sentence, but it does have more risk than the average healthy person unless one gets run over by a truck or struck while jaywalking. You know what I mean. As mentioned earlier in this book, it is why we do not take "No,' for an answer. We not only want a cure but to spend as much time together as we can before one of us is no longer.

CHAPTER 16

Dealing with the Medical Community

The next step is how you will deal with the medical community. Your wife will be spending a lot of time in the doctor's office and seeing specialists. How you prepare for this will make a big difference in her care and health. As Patty says, "Ignorant patients get ignorant treatment!"

Doctors work in practice, and that is what they are doing - practicing and learning. We have talked about your wife's primary doctor as her gatekeeper to other doctors, normally specialists in their field. For example, a rheumatologist is far more educated on Lupus than your primary doctor, but recognize that they are in practice too. Depending on the level of lupus activity your wife is experiencing, you may become concerned with the level of treatment she is receiving. Of course, this is your wife's decision, not yours. But, if she is not pleased, know that she is the owner of her own care. You are an advocate unless she is incapacitated. There is no harm in searching out another specialist. Being referred to a teaching hospital where the doctors are involved in lupus research and care is not out of the question. This, of course, applies to any other autoimmune disease too. Doctors take each of their patient's medical issues seriously, but sometimes their level of experience is not enough to address the issues at hand. This does not mean you leave one doctor for another, but rather adding one more medical member to your team of doctors. Your PCP or Rheumatologist will need to recommend you.

Chances are your wife already has a primary doctor, and if she has a rheumatologist, all the better. I will assume that she does not, as she probably does not have a Nephrologist (Kidney disease), Cardiologist (Heart disease) and Neurologist (Brain and Nervous System) doctors either. Of course, all of these doctors may not be needed at present, other than your wife's PCP and a rheumatologist. I mention in the last chapter that we have nine doctors on our team. Let this not scare you, but as your wife goes down this angry trail, hopefully, she will not need a complete complement of doctors on her team. However, if she does, there are a lot of specialties that can help her manage her Lupus and systemic medical issues.

Doctors are godsends, but they are also human. Your eight to fifteen minutes with your primary doctor's office visit goes by quickly, often with little or no results. "Let's try this," or "I'm recommending you see . . ." Lupus manifests itself in so many different ways that it is difficult just to say, "Take two a day, and you will be feeling better in a week!" This is often the bread and butter service a doctor provides. It's not their fault. It is the level of individuals they are presented with daily, which for the normal PCP is twenty a day. The amount of paperwork, emails, and phone calls take up the additional time in their busy daily schedule. They are trying to do the best they can under the circumstances.

The better prepared you are for a doctor's visit, the more your wife will get out of it. Most importantly is your wife's honesty with her doctor(s) in respect to identifying her symptoms as best that she can, taking her medicines, and following a good nutritional balanced diet. To not can lead to misdiagnosing underlying medical issues and prescribing medicines that can cause additional problems versus helping the situation. So let's take a look at how you can help your wife during this process of doctor visits.

Write down the questions you have before the visit

How often have you walked out of a doctor's visit and forgotten to ask an important question? As they come to you or your wife's mind, write them

down in a journal (see page 159). Review these questions before the time of the doctor's appointment to confirm they are valid to ask. Your wife will become more involved in the visit than you from the standpoint that you are taking notes, and she is the main attention of the doctor. If a question you both wanted is not covered, bring it up at the end of the visit. Always ask the most important question on your list first because your doctor only has a finite period of time with you. So prioritize the questions you have. If you do not get to them all during this particular visit, save for the next visit if need be. If your doctor has a portal for sharing information and tests with you, send the question if it is something that can not be put off until the next visit.

The importance of keeping the same doctors

Researchers in Exeter, England, have shown that the chances of living longer are greater if you keep the same doctors. The study site's continuity of care is very important, and Patty and I can attest to that. Her doctors know her, know her medical issues, and are up to date on all her medical care from other doctors. The study also shows the opposite in some cases where the mortality rate "actually doubled when people did not have continuity of care," according to Denis Pereira Gray, lead author of the study. Having a comfortable and trusting relationship with your doctors is a very important benefit to your wife's care and apparently longevity. It is important to have one primary doctor through which all records funnel to ensure continuity of care. Your PCP is the one who will recommend other specialists if and when needed, and thereby why it is important he/she clearly understands your wife's medical history and issues.

We ran into this situation when Patty had a cardiac issue that required hospitalization. After getting out of the hospital, we called our heart doctor for a follow-up. He could not see us for a month. To us, that was too long. We were set up a week after Patty was released from the hospital to see our PCP. At that time, we indicated that we wanted to switch doctors because our heart specialist could not see us for a month. As noted in the previous paragraph, we were encouraged by our PCP not to change doctors. Not only that, but he also said: "Wait a moment. I'll call him and see if we can get you in today!" In a few minutes, our PCP came back into the room and said our heart doctor would see Patty within 30 minutes. If this issue ever happens to you, do the following:

As mentioned earlier, most doctors have a portal. If you need to see your doctor ASAP and their scheduler gives you a date way out . . . send a note through the portal. Doctors do have control of their schedules and will accommodate you. If they do not, maybe it is time for a new doctor.

Doctors never tell you what to do!

If you notice, doctors never tell you what to do. They ask you or suggest what they want you to do based on their information unless you are in an acute situation. As a patient, one is looking for guidance. Yes, there are some simple fixes and the average patient's guidance results in a prescription. But for your wife, it will always be a conversation. "We can try this and see how it works or that. What do you think?" or "Do you want to try that?" This may not be a fair comment, but the word "try" seems to come up a lot. "Try" this, or "Try" that. In most cases, under most circumstances dealing with the run-of-the-mill illnesses they see, "Try" this or that is what works. And there are some things one must do that simply make sense, such as getting a flu shot. I get a flu shot every year, as does Patty. Patty wants to make sure that she does not get the flu, nor that I am the one who gives it to her. With lupus, what a doctor "tries" does not always work, but that is part of the discovery process and why they are practicing medicine. I do not mean

this paragraph to be condescending. The reality is that most doctors are great at what they do. The problem is that they do not always know what to do, and that is why a specialist is brought into the picture.

Second opinion

We trust our doctors because we want to trust them. After all, they have spent years being educated to deal with exactly what your wife has. Your wife's doctor will do everything he/she is capable of doing based on their education and experience. But sometimes, that is not enough. For example, we have found ourselves in situations where the doctor does not know what to do. Normal tests have resulted in normal results that do not provide guidance as the symptoms persist. We have also experienced diagnoses that, through the second opinion, have turned out to be false or not as severe as first thought. This is not a knock on the medical community. They are doing the best they can. The key is that your wife and you need to do the best you can as you traverse these medical issues knowing that a second opinion can possibly bring you better results. At least you will know. Do not rest the responsibility on your doctors when it rests in you and your wife's hands.

An example of this is when Patty was having severe pains in her arms and back. Our primary doctor wanted us to go see a specialist on fibromyalgia. His thought was to eliminate that diagnosis, and subsequent testing proved negative. The specialist sent us to a neurologist. The neurologist performed an Electromyography test known as an EMG. It looks for muscular abnormalities. The machine emits sounds, and the sounds the doctor was hearing made no sense to him. He wanted us to see another neurologist who performed the same test.

Her eyes were bulging out of her head as she listened to the same sounds and looked at the monitor displaying erratic rhythms. After a year with this

neurologist, other tests to determine if Patty had Muscular Dystrophy, etc., the neurologist indicated to us that she simply did not know what was going on. Because she did not, she recommended medicine to cope with the pain, and there was nothing else she could do.

As shared earlier in Caregivers Wear Plaid, and deserves mention again, we then asked to be referred to Duke. If you are not familiar, Duke has an excellent research medical hospital. Not unlike John Hopkins and others, it is world-renowned. Our neurologist was so indignant that she exclaimed, "Duke will not find anything!" We insisted and she finally made the referral. On our first trip to Duke, Patty was diagnosed within four hours with Statin Induced Acquired Myotonia. Our PCP had put Patty on a statin as a precautionary step and took her off of it immediately when she started having arm muscle pain. Unfortunately, 10% of individuals with Statin Induced Acquired Myotonia do not see a significant improvement once they stop taking the statins. So though we have not found total success at Duke, we know we are contributing to science in the hope that others will have better recovery results in the future. We found out several years later that the neurologist who did not want to initially refer us to Duke died at the age of 55. We just never know, do we!

The Gatekeeper

Your primary doctor will become your gatekeeper to seeing other doctors. Lupus patients MUST see a rheumatologist to get the best care possible. They are trained to deal with autoimmune diseases. It can take up to a year to get an appointment with a rheumatologist. One reason is that there are not that many rheumatologists in the United States, and many are not taking on new patients. The number of doctors continuing their education to become rheumatologists is not keeping up with the number of rheumatologists retiring every year. So get hooked up with a rheumatologist as soon as possible. It will make a big difference

in how your wife's medical treatment goes forward. He/she will become part of your medical team as possible others as previously mentioned.

Building a good doctor/patient relationship

As a caregiver, you are the advocate for your wife when she is seeing a doctor. I have yet to be thrown out of a doctor visit, yet I know someone that has. The doctor wants to listen to the patient and what is going on with her. This is her time. You are there for taking notes and listening, clarifying what is said so that when you leave the appointment you and your wife have a complete understanding of what was said and what she is supposed to be doing next steps.

If your wife does not feel comfortable with her doctor, there is nothing wrong with finding another. However, we encourage you to stay with your primary care doctor, because he / she is your wife's gatekeeper to other specialists and most importantly her medicines. However, if your wife is not comfortable with her doctor there is nothing wrong with searching out a new one. We have done it on several occasions with specialists when we have felt the doctor was not meeting our needs, and or we did not care for his / her bedside manner. We call this: *Firing your doctor!* If you feel this way, the doctor probably does too. Having said that, most of our other specialists have been on the team for a long time. however, as the years have gone by and Patty's medical issues have become more complex, we have been referred to doctors who have come back and said: "We don't want to see her. Her medical issues are too complex for them." And thus, we search out another specialist as either referred or discovered through other persons living with similar circumstances.

"Really!" you exclaim. You would think that doctors would relish the opportunity to work with Patty and hopefully really make a difference. Most of Patty's doctors do feel this way, but you can tell the ones who don't. When a doctor

does not want to take on the challenge, that speaks volumes to the medical issues facing many who live with lupus or any other life-altering medical issues. In almost all cases there is no silver bullet to correct or cure the circumstances. This can become frustrating and I am sure stressful to doctors too.

Pass the information around

There are times we find ourselves out of network. i.e., one hospital provider is closer to our home in an emergency than the one our primary care doctor is associated with. We always remind doctors we see to forward their notes to our PCP. If you are within your network's hospital system, that update will populate where your other doctors (specialists) can review notes before visits with them. You want them up to date on whom you are seeing and what the results of those visits were. So, we always remind those doctors whom we have out of network to do so. If x-rays, MRI's, CT Scans are performed through an out of network provider, ask that they be forwarded to your PCP and or you are given a copy to provide them.

Why would one have doctors outside of their medical systems network?

Depending on where you live, not every area in the country, especially rural areas, have large medical institutions that have electronic centralized record-keeping for doctors to update one another at the stroke of a key. If this is the case, make sure you get copies of records and provide them to your other doctors. In our case, almost all of our doctors are within one system. Duke University Medical Center has reciprocal access to our hospital system, so our primary doctor and others can see those notes too. We always make sure that all Patty's doctors are aware of updates and facilitate communications when needed. i.e., verifying that the right hand is talking to the left hand.

Making that first appointment

Let's step back for a moment. Making the appointment is normally something your wife is going to do unless she is incapacitated or otherwise unable.

If your wife is not familiar with the doctor and his / her location, she should verify the address and the easiest way to get there . . . parking, and so on. You can always Google Map it. Simple stuff, right?

Special Instructions

Your wife should ask if there are any special instructions she should know about for her visit. For example, if she will be having blood drawn, then she should not eat on the day of her visit. If transportation is going to be an issue, you or your wife should arrange it in advance. Is there paperwork that needs to be filled out? Have the doctor's office send it to you before the visit so that 1) there is time to fill it out completely and 2) that your wife can look up names and phone numbers, etc., requested on the form. It saves time and is appreciated by the doctor and staff that you have come prepared for the appointment.

Blood test:

If your wife has time, try to get blood drawn the week before your doctor's appointment. This way, your doctor will have that information in hand when you visit him/her. This could expedite the prescription of new medicine as well as identify other potential issues, such as low Vitamin D, an increase in white blood cells, which would show an infection in the system, and physical or emotional

stress. A lot more can be learned from White Blood Cell counts, both high and low.

Co-payment:

When calling to make the first appointment, let the doctor's office know what your insurance is and whether there will be a co-payment, and the amount that will be. Normally you will know this from previous experience with your insurance, but no harm in asking to be sure.

Medicine List:

Make sure again, as we have covered, that your wife brings the list of all the medications she is on (See next page). That list should have the medicines she is taking from all her doctors and the dosage amount, frequency of use, and so on. Make sure that the list is in alphabetical order because it makes it a lot easier for the nurse to update your wife's records on their system. Bring two copies so that the nurse does not have to go and make one and thereby can keep one. If you or your wife do not make a list of the medicines she is taking, then pack the prescription bottles up in a bag and bring them with you to the appointment. This idea of a list, however, is very important, especially if you find your wife being rushed to an emergency room. The first thing the doctors will want to know is what is going on and what medicines is she taking. The emergency room nurse and doctor will appreciate a list as it speeds up the process of examining your wife and identifying issues or non-issues.

Your Wife's Name

SSN - Last 4 digits DOB: Last updated: 8//19/2019

EMERGENCY NOTIFICATIONS:

List your primary person to notify, relationship, and phone number(s)

Doe he or she have your Medical Directive, Living Will, Power of Attorney

Secondary notification: Name and phone number

Primary Care Physician: Name, address and phone number

Does your primary doctor have a copy of your wife's Medical Directive, Living Will in patient's file

CURRENT MEDICATIONS:

List all the medicines your wife is taking in Alphabetical order. The nurse or pharmacist will appreciate. List by name, how many mg. And how often taken. Include all medicines prescribed. If your wife is rushed to the hospital, the nurse and emergency room doctor will love you for this list of information.

DRUG REACTIONS:

List medicines your wife has had to certain drugs. I she allergic to Penicillin, Cipro, Codeine. If she was tested for same, list the date or date of reaction (month and year).

ALLERGIES:

List all the allergies she has to medicines and other items such as Latex bandages, etc. Again list in alphabetical order.

MEDICAL HISTORY:

List any diseases, conditions, or illness. Does your wife have Asthma, Renal Insufficiency? Has she been hospitalized (for what and when)?

SURGERIES:

List surgeries and dates as well as any hardware implanted for corrective surgery. If you know the metal of the implant, such as titanium, and the manufacturer, list it.

Do not make your list any longer than two pages. It's easy to create in Excel, Word, Numbers, we use Pages as a MAC user. Keep a copy in your car's glove compartment and any other medical journal / calendar you keep so that it is easily at hand if needed in an emergency. Every nurse on every doctors visit will update your wife's medical record.

Water:

Probably the best thing your wife can be doing is hydrating herself. In the Marines, they expect every soldier to pee clear once a day. Water, water, water. She should not forget to bring a bottle with her to her doctor's visit. If your wife is on water restriction due to a medical issue, such as heart issues, consider those directions.

Loose-fitting clothing:

If your wife shows up in Spandex to her appointment, it will more than likely be difficult for the doctor to give an exam. The wearing of loose-fitting clothes makes it easier for testing blood pressure, giving shots, and whatever body parts the doctor wants to check, such as knees, shoulders, etc. The easier you make it for the doctor and his staff, the smoother your visit will go. If you or your wife thinks she is going to need a chest x-ray, make sure that she does not wear a bra with metal bands. This way, she does not have to completely disrobe for the x-ray, and obviously, she will be more comfortable under those circumstances.

Some women have doctor appointments so often that they have one or two appointment outfits, so they do not have to think about what they are going to wear. This may sound stupid, but the simple act of getting dressed for someone living with lupus or another autoimmune disease can often be a major waste of energy, cause stress, and can put her in other than happy mood. Remember the Energy Passes. She only has so many each day, and some days she may have none.

Take pictures:

I have Gout, and when I have a flare and my medicine is not working the way it should, I know, that I know, that by the time I get to the doctor that my worst moment of Gout will have subsided. So, I took a picture with my iPhone so that my Rheumatologist could see how serious the Gout was. For lupus patients, any symptoms, such as bruises, swellings, rashes, and so on . . . take a picture of your wife just in case she gets to her appointment, and the symptoms have dissipated.

Recognize that your doctor does not view your appointment as a social visit. Niceties are O.K., but scrolling through her iPhone and showing pictures of the kids, etc., until she finds the one she wants the doctor to see is not a good use of her short time with the doctor. So, make sure you or your wife knows how to easily find a picture of her symptom(s) that she wants the doctor to see.

We noticed over time, as Patty's lupus and other medical issues progressed, that our doctor was taking more time with us. We thought we were becoming special. There is what is known as Value-Based Care in the insurance reimbursement business. A patient is rated based on the complexity of their disease and medical care needs (the episode) and the additional compensation to the doctor's practice to provide the best quality of care and hopefully a better patient outcome. Thus, if you find your wife's doctor is spending more time with her, then her doctor has more than likely determined a higher score (medical issue rating) that will result in his office receiving higher remuneration from the insurance company for additional appointment time provided. This is dependent on the level of your wife's disease activity and other medical issues that will determine the amount of time your doctor can and will spend with you. The focus of Value-based Care is on the quality of the visit, and the outcome, versus reimbursing healthcare providers for the number of patients they see (quantity) daily. Our PCP is good with his time, and we try to be respectful of his by being prepared for his visit as we do with every other doctor visit we make. He also lets us know when he is out

of time (he needs to see the next patient) unless the appointment is just before his lunch break. We have never felt rushed, which is an important experience to have with your PCP.

Other stuff:

Of course, when you arrive for your doctor's visit, the first thing they will do is check your information (address, phone numbers) and then insurance. Make sure you bring your insurance cards with you. Second, know what your insurance plan covers. This is important for you and your doctor to figure out what is the best course of action if he wants to refer you to another specialist who may not be covered under your current insurance plan.

On the way to the appointment

Exercise patience. Do whatever you can to reduce her Stress. The word Stress comes from the Old English word "Distress," and means hardship, adversity, and pressure. If your wife wants to get stressed by lashing out at you, don't add to it. I know it is easy to get angry, but she is going through a lot more than you could ever imagine. So take the time to think first when she tells you that you are rolling through a stop sign, and she admonishes you for doing so!

Every wife has a certain way that can stress out a husband. I firmly believe that it is a control mechanism that was learned in the Dark Ages and has been handed down from mother to daughter. Take a deep breath and let her win the battle. The less Stress she has in her life, right, wrong or indifferent, the less Stress you are going to have in yours. Agreed, there are limits, and you need to respond in your defense when necessary, but not automatically. There are also times when you are just the whipping boy. If not deserved, it tells me that something else is going on

with her health and that I need to be more observant of what that might be. Often it just fades away.

Arrive early to her doctor's appointment

Why early, you might ask? There's a good chance you will be taken early, especially if your appointment is just before or after lunch. At least that has been our experience. The last thing you want to do is miss an appointment, especially with your Rheumatologist. Getting another appointment in a reasonable period of time can be difficult. Having said that, if it is an emergency, the doctor's office often will find a slot for you the same or the next day if possible.

Of course, most times, the doctor is running behind. So bring something with you to do. That can be games on your cell phone, a magazine, or a book you are reading. If you are into adult coloring books, not offensive; bring that along. Many doctor offices today have a television in their waiting room to give you something to do. Above all means, don't get frustrated. This is just part of the process. Stress is a big issue with health, and you want to minimize your wife's Stress as much as possible, and thereby yours too. So don't be a jerk. You have a job to do while you're there. Remember, the time the doctor is spending with someone else is just as important to that person as the time the doctor will be spending with your wife is to her and you.

If you have to cancel an appointment, just do not show up. It is like using a service provider at your home, such as a carpet cleaning company, who has asked you to be at the house at a certain time, and then they do not show up, do not call. Would you do business with the carpet cleaning business again? Most likely not. Well, your doctor may not want to see you again because you failed to call and cancel so he/she could adjust or schedule an appointment with another patient. There are always valid excuses, but you want to maintain a good relationship with

all your doctors. Remember that doctors and their staff are part of your wife's medical team. If you and your wife take an interest in her health; come prepared for her appointment as discussed earlier. Going forth, the doctor will be more inclined to take a greater interest in your wife's medical needs. It's just human nature. By being prepared, you show respect for yourselves and the doctor and his team. It can go a long way.

When your wife is called in by the nurse, stay with her. Remember you are now the advocate . . . those additional eyes and ears she is relying on.

Second Stage of the Appointment

The first stage was signing in and then going to the waiting room to be called. Stage 2 is when you are called. The nurse will get your wife's weight and vital signs. Again, note them in your wife's journal. Because Patty is now in a wheelchair, we will let the nurse know what Patty's weight is so that she does not need to go through the painful exercise of getting out of the wheelchair to be weighed. Then the nurse will take you to an exam room for your doctor's visit and update your wife's medicine list on their computer system. Here is where your list of medicines, what she is allergic to, becomes the hit of the day for the nurse by making her job so much easier. The nurse will also ask if anything is bothering your wife that she wants to note for the doctor. We always keep an updated copy of Patty's medical information in her journal and glove compartment of the car for unforeseen emergency trips to the hospital. I keep a copy in my car too. It has come in handy, and the examining doctor will know that you and your wife are conscientious and take her medical issues seriously. We have seen patients show up with a binder containing medical records, etc. That might be a little overkill since almost everything today is computerized on your doctor's computer system. Nevertheless, do what works for you. We prefer to use journaling because it is a quick way for us to go back and see the key points discussed during a doctor's visit. Often, your doctor will ask what another doctor said, and again, the doctor

appreciates the notes we took and that we are prepared and serious about Patty's health issues and needs.

DATE	TIME	Blood Pressure	PULSE	OXY	Weight	COMMENT

This is probably one of the best things we have ever done. I apologize for being repetitive, but how often do you get to a doctor's office and forget to ask that all-important question? You know the one. It was so important, so clear, and you forgot to ask it! That's what stress can cause, so write it down in a journal. If your wife is experiencing new symptoms that she wants to talk to her doctor about, she should write it down in her journal for that upcoming visit. We keep it in chronological order by date so that we can easily go back and see what was discussed or done. Write down the questions you will have so that you do not come out of the visit wondering why you forgot to ask. As in anything, prioritize your questions and ask the most important question first, as your doctor only has so much time allocated to you. Unfortunately, that is the medical world today, so maximize that time by getting your most pressing questions first. If a question comes to your mind during the doctor's examination of your wife, write it down as a reminder. It's amazing how easy it is to forget. If your wife is in the hospital, do the same thing and keep a record of her vitals too. We created the form below to capture Patty's blood pressure, pulse, oxygen and weight every morning and additionally as needed.

This form is easy to create in Excel (Microsoft) or Numbers (Apple) on your computer. All of Patty's doctors really appreciate it. It allows us also to check

our readings against that of the doctors to know that Patty's blood pressure is close to their numbers. Being off 10 or 15 points can be critical.

I also note in the comment section what Patty had for breakfast, lunch, and dinner. Additionally, if Patty is supposed to take a drug "as needed," I will indicate it too and highlight it with a yellow magic marker. This gives the doctor an idea of what is going on.

The "Systems Approach"

The "Systems Approach" or theory is the study of the systems of the body. Systems, like processes, are not always finite. For example, your body is a system that is physical, emotional, and mental. It is susceptible to disease, allergies, other maladies, and the daily stress of living. Your primary doctor's challenge is to think through what is going on in your body and your mind to determinate what the right course of action is needed for the best outcome. This is where your wife's journaling becomes important because it documents what is going on with her in chronological order and provides a tickler for discussion to express her issues with her doctor. Conversely, when your doctor is viewing your "Systems," what you are speaks so loudly he/she can hardly hear a word you are saying as the receptors tell the doctor that something is wrong or more so than what he/she is being told. Doctors are very good at observing.

Your health issues may seem very simple to understand, diagnose and prescribe by your doctor. You have a cold or the flu, and your doctor will prescribe medicine and maybe get a quick blood test on the way out just to cover bases. But it is often like looking for a needle in a haystack, especially if

your wife has not yet been diagnosed. It always seems that one issue begets another when it comes to lupus and other autoimmune diseases.

Your wife can help her doctor work through this thought process of discovery of what is the best course of action. There are no magic bullets here. It's not "Take two aspirins and call me in the morning" medicine. With lupus, it is an ongoing discovery as the body reacts and changes to its environment . . . and it will. So you not only need to be her advocate, but she needs to be her own advocate too. What I mean by that is that we tend to trust what our doctors are telling us is true. They are hunting mentally for an answer on how to help, and not all ideas, suggestions, and practices work. Thus it can be a discovery process for both her and her doctor. Rest assured, your doctor is probably far more aware of what to do, and that is why you and your wife have gone to her/him in the first place. Again, they do not call it a practice by accident. Here is what the "Systems Approach" looks like. Mind you, some doctors will use a form like this, and others will click off the boxes in their minds as they observe and ask questions.

The first part of your wife's "System Approach" is how she is feeling in general. Does she feel fatigued, and to what degree. Does she get chills, sweats, or has trouble sleeping. As you will notice on the form, there is no room for comment. If need be, your wife should note symptoms in her journal to address the questions your doctor may have around these criteria.

From the neck up

The Second part of your wife's "System Approach" is from the neck up. This is a key system to anyone's body and overall health. It's her brain's ability to think, hear, see, take air in and eat food. Your wife should think about what is going on

with her head. For example, does she get headaches or get dizzy from time to time, has blurry vision, or sinus issues, such as a dry nose or unprovoked nose bleeds? Does she periodically get a sore throat? These are all potential signs of issues for someone living with an autoimmune disease like lupus.

Again, encourage your wife to write down in her journal when any of the above or other symptoms occur in the head or neck occur. She should especially note in her journal any emotional or mental health issues she thinks she may be dealing with. I know this is not always something your wife may want to share or expose, but as a caregiver/advocate, if her emotional and mental health is an issue, you should make the doctor aware. This is not easy and can cause consternation between the two of you, but your doctor will positively support the input and make it easier for your wife to discuss, admit and accept a course of action. Other concerns from the neck up will be handled with the what, when and where, and how long did it last questions. For example, difficulty in breathing can become an issue. Breathing is an involuntary bodily function that you do not have to think about. Doctors will tell you that anxiety can disrupt breathing patterns and cause one to think about breathing . . . not being able to get that full breath. So the problem is not necessarily in the lungs but rather the anxiety your wife has. Breathing is a very important subsystem of your head and lungs. So you can see that systems can interact with one another, as teeth do with the stomach, kidneys, the heart, and so on.

A side note: The word "Breath" comes from the Latin, "spiritus." It's a very important vital sign because, without it, you are dead! I told you this would be basic. Those who spoke Latin saw breathing as your spirit and if your breathing is distressed, then so is your spirit, which can lead to anxiety and, for lack of a better word, depression.

Respiratory System

As I noted, air goes through the nose down into the lungs, and all of this is part of the system that allows us to breathe and oxygenates the air in our bloodstream and thus allows us to live. So if your wife has shortness of breath, wheezes, coughs, or has pain when she tries to take a deep breath, make sure she notes in her journal for her doctor's visit. When does it happen, what time of day, duration, etc. If her breathing issues are severe, an emergency, call 911 and get her to the hospital. The faster she gets medical attention, the better off she will be. I have rushed Patty to the hospital with the result that she had pneumonia, was dehydrated, and in the process, other medical issues were discovered. In a way, that was a good thing because we had no idea that she had the beginnings of a serious medical problem.

It should go without saying that if your wife smokes, it is time to quit. If she is not willing to follow her doctor's advice, then she is violating the covenant of "First Do No Harm To Yourself," which oddly enough is that of her doctor - "First do no harm!"

Cardiovascular

The doctor is always going to check your wife's lungs and listen to her heart. Beside her head, there are two other main systems that must work to keep one alive. So, if your wife has been having chest pains or palpitations, or high blood pressure, make a note. As mentioned before, we keep a record of Patty's blood pressure and pulse . . . the date and time it was taken. We take it every morning. Do not skimp on the price of a home blood pressure unit. We ended up with the OMRON brand, which is available at any pharmacy. Note that these home units cannot be calibrated. The one in your doctor's office can be calibrated. You can bring your blood pressure unit to your doctor's visit, and as the nurse takes your

wife's vitals, you can then take them with your home unit. If there is a significant difference, keep a note of it. Having these readings can help your wife's doctor know what is going on over a period of time. Regulating blood pressure medicine is not always the answer to high blood pressure. Again, anxiety and other medication can be contributing factors too. Of course, if your wife is not having blood pressure issues, there is probably little need to go through this exercise regularly. If she is not feeling well, or dizzy, it is always a good thing to check to be on the safe side. Again, we check Patty's blood pressure every morning and note it on our form.

Swelling

Water retention is an issue most women deal with. The taking of diuretics (medicine designed to eliminate water from the body), such as Furosemide, should be monitored by a doctor in that reducing too much water can lead to undue stress upon your wife's kidneys. One issue can beget another issue. If your wife's ankles or legs are swelling beyond what is normal for her, have her touch base with her doctor so that 1) the issue is documented in the doctor's office and 2) that she is prescribed versus playing doctor and prescribing herself. Remember, lupus is a systemic disease, which means it can affect the internal organs such as the heart and kidneys. The two are intertwined systemically.

Fifty percent of individuals living with lupus have what is called Lupus Anticoagulant. Lupus Anticoagulant, according to Johns Hopkins Lupus Center is an antibody that can put your wife at great risk for blood clots. This can lead to strokes, heart attacks, and even miscarriages. Symptoms to be aware of are swelling or redness in the leg; shortness of breath; numbness, pain or pallor in one of her arms or legs.

Blood Clots

There is a test for this, which is called the Activated Partial Thromboplastin Time Test or a PTT. Other tests can be taken if the PTT test is normal and there is still a concern or need to learn more. What is important to know is the possibility and what your wife can do to reduce the risk of blood clots due to the anticoagulant properties of her blood.

First, your wife's doctor may prescribe a blood thinner, which makes a lot of sense. Normally it is baby aspirin. If your wife notices that she is not feeling well with the aspirin, it normally takes three days for it to process out of her system. So taking aspirin once every three days is better than not taking one at all if that is what her doctor prescribed. Again, before changing any medicine dosages, check with your PCP first. Your wife's doctor may also recommend steroids. Of course, they can have unwanted side effects.

Secondly, sitting around all day is not good for your wife. She should exercise as much as she can, even if that is just walking around the house for 5 minutes every hour. Maintaining muscle tone and her blood circulating is important. Of course, one cannot get past laying down and sleeping all night.

Third, Patty sits a lot, but she moves her ankles up and down to keep the blood flowing. Simple to do.

Fourth, if you are traveling long distances in your car with your wife, stop periodically. Those stops are very beneficial in respect to keeping blood flow, but what you will also find is that even though your wife is just sitting in the car, and possibly sleeping, the process of getting from one place to another can be exhausting even though she is not physically doing anything. It often amazes me

that I have driven the whole day, and if anyone should be exhausted or tired, it is I. But, more often than not, it is Patty.

Fifth, if your wife is on birth control pills, estrogen-based, or hormone treatments for menopause, she should check with her doctor. In most cases, these should be avoided.

Gastrointestinal

SKIN:
Bruising
Rash
Psoriasis
Sun Sensitivity

This is the area where everything you put in your mouth gets processed. If things are not going to be well in this system, then your wife should make sure that any symptoms she is having are conveyed to her doctor, such as abdomen pain, nausea, vomiting, heartburn, constipation, diarrhea, etc. It is also important to note if she has had any changes in her bowel habits or sees blood in her stool. Diarrhea can lead to dehydration, and dehydration is one factor that can get your wife into the hospital fast. So, if she mentions she has diarrhea, encourage her to drink more water. Again, balance, counter-balance, in that if she has swelling in her ankles or legs, etc., it can be water retention. When in question, always contact your PCP because her lupus can lead to other systemic issues. The idea is to keep things under control and not out of control. It can be a real balancing act depending on the level of severity your wife is experiencing with her lupus or another systemic autoimmune disease. Once things get out of wack, it can take time to get her health back on track.

Skin System

As you can see in the "Systems Review" form, your wife's primary doctor and Rheumatologist are not necessarily looking for cancer or other skin abnormalities. That is for a Dermatologist to do. However, skin issues associated with lupus and other autoimmune diseases are bruising, rashes, psoriasis, and sun sensitivity. Rashes, for those with lupus, can come in many different forms, but Discoid lupus, as mentioned elsewhere in this book, is probably the most prominent.

Neurologic System

This system deals specifically with your brain and nervous system. Headaches always seem to be an issue with people living with lupus. Hearing loss, weakness on one side of the body, seizures, tremors, abnormal sensations or lack thereof, such as no feeling in the feet, anxiety and having senior moments where it is difficult to recall or remember certain things are all signs that you want your doctor to be aware of. This is when your wife's doctor uses the "follow the finger" with your eyes, pushing and shoving legs and arms, and observation comes into play.

Musculoskeletal System

This system deals specifically with your musculoskeletal system, which means the skeleton, muscles, cartilage, tendons, ligaments, joints, and even connective tissue. Together or individually, these components support specific body parts that, when out of sorts or enflamed, can cause back pain, joint pain, joint swelling, morning stiffness, neck pain, etc. Again, whether or not your wife's doctor has her fill out a "Systems Form" before her visit, rest assured her doctor is observing her and asking questions about each category during her appointment/examination.

Stage 3: The Appointment

After stages one and two comes stage 3, the actual appointment with the doctor when he walks into the room. Remember, this is your fifteen minutes of fame, or at least to get your questions answered. Do not be concerned about how much time you take versus being given. Most doctors will stay with you until all your questions are answered and/or will request that you make another appointment to continue the questions you may have. That may sound weird, but it has happened to us. It was the last time we used that specialist. Know that the doctor does have other patients waiting, and you and your wife should be respectful of that. However, how many times have you had to wait for the doctor because he was running behind? If it is O.K. for one, it is O.K. for you too. We have fired a doctor for consistently being at least 45 minutes to an hour late. We are not recommending that you do this, but we found another specialist who is just as good and more considerate of our time. We understand there is always the potential of an emergency with another patient, but when it happens over and over again, it is time to find another doctor who is more respectful of your time. If your doctor is more interested in "quantity," the number of patients a day, and your desire is "quality," what is accomplished during the appointment, then there is a major disconnect.

Keep in mind that stress is a real Energy Waister for people with an autoimmune disease such as lupus. Some can handle waiting, and for others, it can become a stressful situation. The energy used to shower, get dressed, and the trip to the doctor's office can be more than enough stress for your wife on that day. Remember, she has only so many Energy Passes for the day. It is a lot more than any of us can imagine accepting for those living with the disease. So play it as you see it, always be respectful, but if it is not working out for you, ask your primary doctor for another referral.

Your wife's doctor will ask some questions about how things are at home, such as "have you fallen recently; do you need support getting around the house. Has this guy been pretty good to you?"

Patty fell once, resulting in bruising near her eye. Of course, it became black and blue on the way to the hospital. When we got to the hospital, we started getting questions, such as "Is everything all right at home?" Patty said, "Everything was fine." In today's world, it is a normal question for medical professionals to ask, so don't get your nose bent out of shape if you react that way to the question. No one knows what goes on behind closed doors other than those who are behind them. The hospital wanted to make sure that Patty was not a battered woman looking for a way out. I wouldn't be surprised that they didn't have a way in the emergency room to listen to us after the nurse left the room just to make sure nothing bad had been going on.

Your doctor will also want to know if there is anything different in your wife's eating habits. Prednisone will increase the intake of food, and other medicines can reduce it. Anxiety, depression, and stress can affect eating habits too. So if you have seen a change, it is worth noting. Admittedly, other things can affect someone's eating habits, such as work schedules or going on a diet, but here we are talking about a debilitating autoimmune disease. Many individuals living with lupus have a weight problem either genetically or due to some of the medicines they are on. Your wife may have a variety of clothing sizes ranging from small to large because she will never know where her weight will go. So don't be surprised if your wife ends up with a small, medium, and large wardrobe. There can be a variety of reasons why your wife's weight will go up or down, but a word of caution. Talking about your wife's weight, even at the doctor's office, is not always a popular or smart thing to do. Let the doctor have that conversation.

Take Notes

Going to a doctor's visit is almost like having an alarm system installed in your house. The service technician goes through everything with you. It seems so simple until the technician is no longer there and it's your first time arming the alarm by yourself. "Exactly how did he do that?" you question. The same is true when visiting a doctor. You have limited time with the doctor and, hopefully, a lot of information to gather. When you come out of the appointment, you and your wife will have trouble remembering exactly what was said. It's the nature of the beast. So what can you do? If you have a smartphone, it should have an application to take notes. Input the key statements by the doctor. You do not need to be precise because when reviewing, the note will spark your memory of what was said. As mentioned before, we use a bound notebook to journal the appointment. It is a lot easier to journal and refer back to information that the doctor may want to know about. Such as when did we see Dr. So and So. What did the doctor say? Or, the cardiologist agrees with the nephrologist your wife saw in the hospital. There are a lot of scenarios and what you want to make sure of is that there is consistency in direction and prescriptions. Again, always keep your wife's primary doctor in the loop because he/she is her gateway to treatment.

Clarification

This is a key point. When the visit is ending, always clarify the "to do's." Blood tests and the next visit are not something you would include when clarifying directions from the visit. "We have sent a prescription to your pharmacy, and you will take it every morning with food." Or, "I want you to see XYZ specialist before our next visit? We will set that up before you go!" Think of the things that you are not sure of what you would like clarification on. There is nothing wrong with doing this. You want to make sure that any directions that seem confusing to you are clarified. You do not want to forget anything.

What works for you?

I am semi-retired, owning my own business, and there are days I cannot go with Patty to the doctor. Now, it is difficult for Patty to drive, and I do not want her going by herself. I am part of her team, and I want to make sure I am there for her. So Patty and I keep my work schedule and her schedule, which includes doctors' appointments, on the same calendar. This way, we can block those days out when she has an appointment and needs my help. Fortunately, I have flexibility as long as I do not commit to seeing a client. I also try to play golf with my VFW buddies once a week. That does not always work out, either because of business or the only time a specialist can see Patty is on my day to play golf. So, understands what is important. I'd like to say I play golf, but I don't if Patty needs me. Keep in mind that you need a life, too, so coordinate calendars. As Patty's lupus has progressed, it is more difficult to leave her by herself. So my golf game has suffered considerably. The question is: "Who is more important? You or her?" Answer that question correctly, and life will be a lot better for both of you. And yes, I do get a round of golf in periodically as she feels better. On one day, my group finished the first nine holes, and I called home to check on Patty. She did not answer the phone on three successive phone calls. I dropped out and headed home with visions of Patty being on the floor and not being able to get up. Fortunately, she was on the phone with our son, and she did not know how to use the "Call Waiting" feature. "Next time, please take my call and call him back," I said.

Recording your doctor's session

Audio recording your wife's visit with her doctor(s) is another way to make sure you are hearing the information he/she is saying correctly. Most doctors will not have a problem with you taping the visit. Others may due to legal concerns. Lawsuits in the medical profession represent a significant cost to the industry and your premiums. If you intend to record and not say that you are to your doctor, know that not all states require notifying another that they are being recorded.

You can learn more about this at the Digital Media Law Project www.dmlp.org where you can check your State's guidance - http://www.dmlp.org/legal-guide/state-law-recording. If legal, you can use a small hand recorder or the audio recording feature on your cell phone. Note that any notes you take, video or audio recordings with your doctor (materials) can be discovered if you find yourself in a lawsuit related to that doctor.

Portals

Today, many of the doctors and or the institution they are working through have online portals where your Personal Health Record (PHR) is housed. This portal most often includes one's medical history, medications, allergies, diagnosis, and other issues; notes from clinical visits, imaging reports, and blood test results. There should be an overview of events to refer to. The portal has become a terrific way for your wife's doctor(s) to not only keep her health records online but also to communicate with the patient, your wife, too. It allows your wife to make appointments online, view test results of tests, and have access to the records your medical team documents. What it does not allow you to do is track other physician reports that are outside your primary doctor's network. Patty has several, but it is the one with her PCP that she finds the most important because that is her go-to person (gateway) who is managing her overall health. This is another reason for you, as the caregiver/advocate, to maintain good records on conversations and other health records that may not be in the portal (PHR).

What happens if your wife leaves her doctor's network?

Portability is an important issue. You should be able to download all your information from your doctor's portal (PHR) and transfer it to your new primary

doctor's portal. However, if your doctor does not provide a portal, you need to copy and keep those records. There used to be what is termed "untethered PHR's" online. However, untethered PHRs appear to have not been embraced by or used enough by consumers for online providers to maintain.

The future of personal health care online

It is already here. "I'll see you in six months for a check-up" will be done online unless there is a situation that requires an office visit. The ability to do an EKG online already exists. I am sure you have seen the ads on T.V. It's not far-fetched to think that checking lung capacity and testing blood online is in our future too.

For more immediate non-emergency needs, the Cleveland Clinic has an "Express Care," an online service where you can communicate via video with a healthcare provider using your mobile device, tablet, or computer. It would not surprise me that this service will be provided by all major hospitals and/or doctor networks/offices in the future. Again, these services are provided for non-emergency concerns but can save you or your wife a lot of time depending on your insurance and/or doctors' ability to communicate and the stress of getting back and forth from an in-person appointment. Obviously, during COVID-19, video doctor appointments on Zoom or other platforms, meeting with your financial advisor, and other services became acceptable to use. In some cases, many businesses have changed to working from home (flexible time), and in other industries where less travel and time saved using video technology has become the norm rather than the exception.

With the cost of medical attention going up and the availability of appointments being pushed out more and more, the use of the portal and online care services with PAs (Physician Assistants) or NPS (Nurse Practitioners) will

become more commonplace and affordable. In the case of an emergency, always call 911 or go to the emergency room. Every doctor's phone number has a prerecorded message that says: "If this is an emergency, hang up and call 911 immediately."

Scheduling and Referrals

Stage 4 is the final step in your doctor's visit. If your wife's doctor refers her to a specialist, often the nurse in his/her office will make the appointment for her right there and then. If she cannot, they might say, "I'll get to them, and they will call you to make an appointment," and you leave and wait at home for the specialist's scheduler to call.

Wait not! When you get home, call the specialist's office and let them know that you have been referred. If the specialist's office has not received the referral yet, they will still make the appointment. Make the earliest appointment you can get, and now your wife or you do not have to sit around waiting for the call. This is a proactive move in your health care. Wait not. I know that patience is a virtue, but being proactive is too.

Take it easy on your wife's doctor

I don't know how your day has been going, but your average doctor spends most of their day trying to help people who are not doing so well. Some appointments for them go well, and others do not. How they walk out of one room of circumstances into another and remain focused on the next patient and not the last appointment is a skill in itself. When I see what other people are going through, I say to myself: "But for the grace of God, there go I." Your doctor deals with many medical and office issues throughout their busy day and the pressure to

see so many patients daily. It's a lot to keep up with. It is not inconceivable to believe that many are dealing with M.D. Burn Out. They will appreciate that you take it easy on them and more than likely will give you more time than you need. Realize that you are building a trust relationship, wherein you trust them, but more importantly, they trust your wife and you for conveying how she feels and is doing.

Being prepared for your wife's appointment will help the doctor focus on her and not the last patient or something else that might be going on. After all, doctors are people too and are subject to emotions just like everyone else. So, if the question is, "What can I do for you?" or "How are you doing?" your wife is prepared to direct the conversation where she wants it to go. Your doctor will appreciate that, as will both of you. So, maximize the time you have together with your wife's doctor to get the greatest benefit from the short period of time you will have together.

Medical apps are popping up periodically on the Internet almost as fast as it takes to pop pills. First, we are not making any recommendations because, frankly, we do not use them. But, for those who are younger, living online is part of their daily life. Using these applications can be a great benefit to managing your wife's lupus.

MANGO Health App., is a drug reminder and drug interaction health information application. The application will not only ding your wife when it is time for her to take her medications, but the App says, that if you are successful in taking your medicine correctly, you are entered for a weekly raffle to earn points that can be donated in dollars to a charitable organization or you can receive a gift card.

You can record your weight and check your blood pressure. The application also provides interaction (side effects) of medications, and because it is on your cellular phone, you have the information at your fingertips no matter where you travel.

It's kind of cool because this application encourages one to follow healthy habits with a financial incentive to do so. https://www.mangohealth.com/. Mango Health App has a 5.0 Star Review, but in fairness, to that, they only post their favorable reviews from customers, which are excellent. What makes this App unique is that it is the only health app to point out conflict (negative interactions) with other medications. At least that was true when first published. I surmise there are other applications today that can provide the same services.

The Lupus Companion

The American College of Rheumatology developed this App with input from individuals living with lupus.

The Lupus Companion is Free and provides areas to document your providers, appointments, symptoms, medications, a place to document questions you would like to ask, and information on lupus. The Lupus Companion has only 2.5 Star Review and is only available for IOS Devices.

There are many FREE Apps on the Internet, and if you are comfortable using online applications, try them out. The ones noted above are just two of several that I found, and thus we do not recommend one over the other, if any.

This has been a long chapter, and you, as a caregiver/advocate, are very aware of what has been shared. But then, some are new to this process and have learned a lot about what is going on when visiting a doctor. The next chapter is on "Referrals" to other doctors that your PCP will at some point make.

CHAPTER 17

The Referral

You are about to be introduced to other doctors whom you may have never been exposed to before. Depending on your wife's medical circumstances, the following specialties she may find herself being referred too. You rely on your primary doctor to make that referral, but that does not negate you from finding a specialist that you might be more comfortable with through your Primary Care Provider.

Rheumatologist

If your wife has lupus or another systemic autoimmune disease, then besides your primary doctor, she will need a rheumatologist too. Rheumatology is a sub-specialty of internal medicine. They deal mainly with the musculoskeletal system, soft tissues, autoimmune diseases, vasculitides, and inheritable connective tissue disorders. Though training requirements vary throughout the world, they must complete four years of medical school, followed by three years of residency and an additional two or three years of Fellowship training. It is one of the reasons the number of rheumatologists in the United States is decreasing due to the extensive time to be trained and certified. A medical student simply does not want to take all that time away from going in to practice or research and earning a living.

According to the American College of Rheumatology, in 2015, there were roughly 1.7 rheumatologists per 100,000 persons. Every estimate is that rheumatologists are retiring faster than they can be replaced. That means there will be fewer and fewer rheumatologists per 100,000 persons as time goes by. For someone young, 30s or 40s, the prospects of finding a practice you can get into are becoming more difficult. Thus, getting into a practice is paramount, and you cannot start too early. Once you are in, your rheumatologist will tell you: "You're in, and if you need me before your next visit, just give the office a call, and I will

fit you in!" That is a comforting feeling for your wife and you, too, that your wife has access to quality medical care when she needs it. Also, as covered before, almost all doctors today have online portals for sharing information and asking questions, such as reordering medicine. Hopefully, you can find a rheumatologist who will outlive you and or not retire before your wife dies . . . or you for that matter. The shortage is that serious, especially in rural areas. Knowing the eleven symptoms of lupus, as shared earlier and to your right, will help you prompt your Primary Care Doctor to make a referral for a definitive diagnosis. Ask, "Do you think it is time for my wife to see a rheumatologist?" If the answer is "NO," ask why if the doctor does not explain.

Eleven Symptoms of Lupus

1. Extreme fatigue;
2. Headaches or muscle aches;
3. Painful or swollen joints;
4. Fever;
5. Weight changes;
6. Anemia (i.e., low numbers of red blood cells or low total blood volume);
7. Swelling in feet, legs or hands;
8. Puffiness around eyes;
9. Pleurisy (i.e., pain in the chest when taking a deep breath);
10. Butterfly-shaped rash (Malar) across the cheeks and nose or a rash that is patchy and bumpy (Discoid).
11. Sensitivity to light or sun.

How do you find a Rheumatologist?

Normally your doctor's staff will call over to the referred rheumatologist and set up an appointment for you. It might be nine months out before your wife gets her first appointment, or it could be in a couple of weeks, or they just might say they are not taking any new patients at this time. If it is nine months out, make the appointment. You can always cancel it if you find another rheumatologist. If the referred rheumatologist is not taking new patients, your doctor should continue to call other rheumatologists on their referral list. Again, once they get an appointment for you, take it! It is better to have one in hand than none at all. The

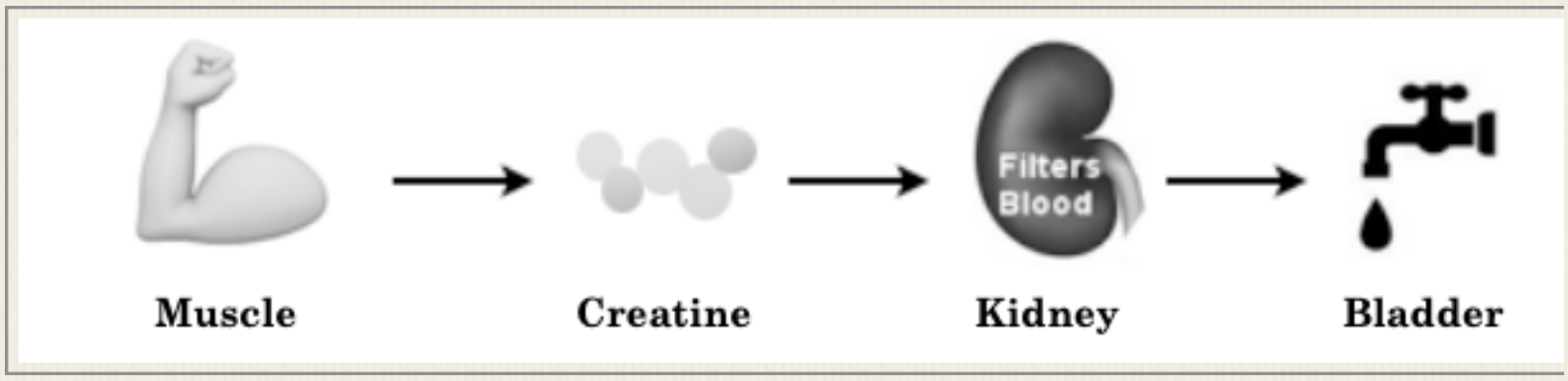
key here is that you want to get into a rheumatologist as soon as possible. It can make a big difference in your wife's health.

Second option: Chances are someone in your family has a rheumatologist. Often family referrals make it easier to get an appointment.

Third option: When you become a caregiver and start talking to others, you would be amazed at how many people you know see a rheumatologist. Contact friends and neighbors. A simple email to them may result in several rheumatologists being recommended. Most would not recommend a rheumatologist unless they liked them. However, I caution you. Your wife may not be ready to have others know that she has lupus. The Privacy of Pain - coming out of the shadows and living with lupus or another autoimmune disease can be very difficult for her to admit and accept, and thereby she is not ready to let the world know. Frankly, that is not a good idea, but very much the norm and understood. You are going to need as much support as you can get, and adding a rheumatologist to your team of doctors is a priority. As a side note, A rheumatologist will tell you that there is no consistency in diagnosis. You initially need a rheumatologist to figure out what is going on. There is no finite.

Fourth: If you have a "next-door neighbor" app or other neighborhood online service, mention the need for "I'm looking for a good rheumatologist" out there. You don't have to say why you are looking for a rheumatologist, just that you are. You will be surprised at how many of your neighbors are willing to help.

Then you and your wife can start making the calls. You might get lucky and find a rheumatologist who is taking on new patients right away or whose staff understands your needs and is taking new patients. You do not need a doctor's referral. However, doctors refer to other doctors they know, and that can be a plus getting in the door.



Other doctors your wife may need to see at some point

Nephrologist - specializes in diseases of the kidneys. The kidney is probably the number one internal organ affected by lupus. As part of the renal system, which includes the bladder, urethra, and two ureters, the kidneys are primarily known for removing harmful waste and toxins from our body through a filtering process of the blood. You cannot live for long without functioning kidneys; thus, if your wife's kidneys begin to fail, there is the potential future of dialysis (cleanse the blood) and or a kidney transplant. Your wife's primary doctor, rheumatologist, and nephrologist will pay close attention to your wife's creatinine. Creatine is a waste product created from the breakdown of muscle. It processes through the bloodstream into the kidneys to filter the waste and other toxins out of the blood and then exits the body through the bladder.

Doctors can check the level of creatine in the kidneys to determine how well the kidneys are functioning. It is estimated that 60% of people with lupus will have kidney function issues. In children, it is estimated to be higher.

A Key Understanding

Lupus, with organ involvement, does not cause the infection that results in the medical issue. It is the medication that suppresses the immune system that can. Needless to say, your wife needs to stay hydrated, stay away from NSAIDs (steroidal anti-inflammatory drugs), and talk to her doctor concerning her immediate medical issue and how to treat her symptoms. I'll talk more about NSAIDs in Chapter 25 - Medicines.

Neurologist - specializes in diseases of the nervous system, which means the brain and spinal cord. With lupus, there is the possibility of what is called "Brain Fog." It is not a disease but rather a symptom of lupus. To a neurologist, it is known as "cognitive dysfunction." It is a common occurrence for people living with lupus, i.e., being overly confused, forgetful, unable to concentrate, and constantly feeling fatigued. The treatment of migraine headaches and problems with smell, touch, and vision fall into the neurologist's bailiwick, as well as muscle and coordination issues such as one would find in Parkinson's disease. Remember, the only thing consistent with lupus is inconsistency, and like other lupus symptoms, "Brain Fog" affects each person differently.

Dermatologist - Dermatology and rheumatology are two specialties that do overlap. A dermatologist evaluates and treats diseases of the skin (cancers, moles, and other skin manifestations associated with infectious and systemic diseases) such as cutaneous lupus. Lupus is one of them, but dermatomyositis and scleroderma are others often associated with lupus. 70% of people with lupus will, at one point or another, will develop a rash.

Gastroenterologist - This is the infamous GI doctor who specializes in diseases from the esophagus to the rectum. For individuals living with lupus, medications can cause GI issues. There is also the concern of viral or bacterial infections. Your wife's doctor will recommend a colonoscopy (through the rectum and beyond) and possibly an endoscopy (down the throat to the stomach) normally every ten years unless there are issues to be concerned about. These procedures and the preparation for these procedures are no big deal and nothing for one to shy away from unless there is a medical issue of concern. i.e., the cleansing process before the procedure is a lot easier than it was years ago.

Endocrinologist - treats hormone imbalances. The most common conditions an endocrinologist treats are individuals with diabetes, thyroid, and adrenal insufficiency. The chronic use of steroids, such as prednisone can reduce the natural production of cortisol in the adrenal glands. It is one reason why stopping prednisone abruptly can result in adrenal suppression. By gradually reducing the amount of prednisone, adrenal glands will begin to function normally over time. If you have ever been on a Methylprednisolone Dose Pack (Z-PAK), you now know why the dosage is tapered over the five-day protocol. It is used to reduce inflammation in many different conditions, such as arthritis, lupus, psoriasis, ulcerative colitis, allergic disorders, and gland disorders treated by endocrinologists.

Pulmonologist - If your wife has asthma or other lung issues, this is the doctor she will want to see. Pulmonologists are specialists who deal with diseases of the lungs. According to the Johns Hopkins Lupus Center, 50% of people living with lupus at some point in their life will experience some sort of lung issues. If your wife is experiencing any chest, lung, or breathing pain, she should let her doctor know. Often when issues are caught early they can be treated. If not caught early, scarring of the lungs can occur, which may lead to more problems down the road.

For more information, go

to: https://www.hopkinslupus.org/lupus-info/lupus-affects-body/lupus-lungs/

Patty has dealt with pulmonary issues over the years that have led up to her being hospitalized with pneumonia. Often tests done in the hospital can uncover other underlying issues. In Patty's case, it was discovered that she has "Stiff Heart Syndrome," or cardiac amyloidosis. In simple terms, it is the hardening of the diastolic heart muscle whereby it does not pump as much blood out of the heart as it should, thus not delivering enough oxygen to other vital organs. One problem can lead to another as diuretics are used to reduce unwanted water and salt in the kidneys and thus make it easier for the heart to pump. This ultimately caused the creatinine level in her kidneys to go up, which resulted in another hospital stay.

Unwanted water and salt are something that can creep up over time and potentially lead to heart failure. Shortness of breath, foot swelling, coughing, confusion or memory loss, rapid weight gain, and feeling tired and fatigued are the symptoms of potential heart failure. Fatigue always seems to be a constant with lupus, but we have experienced every symptom. It was not until Patty was really having trouble breathing that we called 911. In this case, you do not want to hesitate to get her emergency personnel to start an IV and stabilize your wife while being transported to the hospital. With all of the lupus-related medical issues we have personally experienced over the years, Patty's pulmonary, heart, and accelerated kidney issues have been the most concerning. A couple of years later, Patty was rushed to the hospital (during COVID-19) and underwent emergency surgery for a blockage of an artery. She had a stent installed and miraculously was home within a couple of days, feeling like a new person.

Physical therapist (joints) - We can't say enough about how much physical therapy has helped Patty, especially with her Myotonia. As a non-invasive treatment for chronic pain, having effective treatment and learning how to stretch and exercise should improve your wife's health. This is dependent on your wife's physical needs and whether or not it warrants her doctor prescribing that she sees

a physical therapist. But if you ask Patty what has helped her most throughout her journey with lupus and other health issues, she will tell you physical therapy has been the best. Why? Because she can feel the results of each session almost immediately. Do the results last? It all depends on the physical issues your wife is dealing with. Exercise and stretching are always good for anyone's health.

What do doctors say is the most important thing a person living with lupus should remember to do?

I stuck this in here because I have had the opportunity to speak with many rheumatologists, and bar none . . . they all say the most important thing for a person living with lupus is to remember to take their medicine every day! I am sure this is true with any other systemic autoimmune disease or any disease for that matter. The stake in the ground is that she MUST take her medicines as prescribed, even when she is feeling better or excellent. Otherwise, some very serious, up to including death, medical issues can occur. So don't fool around with the meds and follow the advice of your wife's doctors . . . period! You will see this warning mentioned elsewhere in Caregivers Wear Plaid. It is that serious!

What if you cannot afford the prescribed medicine. I'll talk about this more in Chapter 25 on medicines, but know that there are options to receive discounts and/or receive medicines at little or no cost. Assistance programs do exist. Unfortunately, many who qualify for assistance either do not know about the programs or give up too easily in the discovery process. Ask your doctor if she/he knows of any programs available if you find yourself in this situation. Your pharmacist can be of help too. See Chapter 26: Your Pharmacist Love You.

Health Apps to Track Lupus Management

Under this theme of taking medicine for lupus and other autoimmune diseases, the number of pills taken daily (morning and night) can be extensive. Applications to manage medicines are popping up periodically on the Internet almost as fast as it takes to pop pills. First, we are not making any recommendations. Frankly, we do not use them. But, for those who are younger, living online as part of their daily life using all sorts of applications. Here is one that can be of great benefit to managing their daily medicines: The MANGO Health App

The MANGO Health Application is a drug reminder and drug interaction health information application. The application will not only ding your wife when it is time for her to take her medications, but the App says "that if you are successful in taking your medicine correctly, you are entered for a weekly raffle to earn points that can be donated in dollars to a charitable organization or you can receive a gift card."

You can record your weight and check your blood pressure. The application also provides interaction (side effects) of medications, and because it is on your cellular phone, you have the information at your fingertips no matter where you travel. Your pharmacist will also be able to give you the same (interaction) information.

It's kind of cool because this application encourages one to follow healthy habits with a financial incentive to do so. https://www.mangohealth.com/. Mango Health App has a 5.0 Star Review, but in fairness, as mentioned before, most websites only post favorable reviews from customers, which are normally excellent. What makes this App unique is that it is the only health application to point out conflict (negative interactions) with other medications.

The Lupus Companion

The American College of Rheumatology developed this App with input from individuals living with lupus. The Lupus Companion is Free and provides areas to document your providers, appointments, symptoms, medications, questions you have for your doctor, and information on lupus. The Lupus Companion has only 2.5 Star Review and is only available for IOS Devices.

There are many FREE Apps on the Internet, and I suggest that if you are interested in using them, download and try them out. The ones noted in this chapter are just two of several I found, and we do not recommend one over the other. The key is to use what works for your wife. If one of the above works for you, or you find another App that knocks your socks off https://www.laptopmag.com/articles/best-lupus-apps, let us know at info@caregivers-wear-plaid.org. We just want you to know that applications are out there, and new ones are created on a regular basis.

CHAPTER 19

Your Child Has Lupus

This chapter is about perspective, because it is hard for a husband, a father, to understand and come to grips with his wife or child having lupus. It is probably even more difficult to adjust to your child having lupus because this simply is just not suppose to happen.

WARNING

If your doctor suspects or has any hint that your child may have lupus, insist on getting to a pediatric rheumatologist immediately! Why? Early-onset lupus versus being an adult has many differences.

Lupus in children is rare. Statistically, 1 out of 4000 children will develop lupus. Compare the statistics in adults that 1 in 123 plus women will have lupus. Remember, in adults, 10% of those with lupus are men, and 90% are women. It is extremely rare to see children under the age of five with lupus. Having said that, we do know of one child who was diagnosed at birth. Dr. Thomas Griffen, Levine Children's Hospital in Charlotte, North Carolina says, "In children, there is a higher percentage of lupus seen in boys than in girls under the age of 10."

F:M 4:3 in years under the age of 10.

F:M 4:1 in 10-20 years of age

F:M 9:1 in 20-50 years of age

F:M 5:1 in 50 years or more of age.

Female Children and teens are more inclined to have lupus than males, but in young children, boys seem to have a higher activity under 10 years of age than in

later years. "In children (with lupus), kidney and brain disease are the two that doctors worry about the most." Dr. Griffen also states, "multi-disease symptoms, such as arthritis, rash, joint pain, are red flags, which makes lupus easier to diagnose versus just having one symptom."

Let me go off track for a moment and tell you the story of a young man, and I'll call him Billy, and the story of a young lady, whom I'll name Emily. Both stories are based on true circumstances. I tell them to provide context to what you as a Dad, as a family, are dealing with in a child who has been diagnosed with lupus or another debilitating autoimmune disease. Billy's circumstances were under his control. Emily was not!

Billy's story

Billy was a model student, a model child, raised diligently by parents who adored him and the prospect that they had raised a wonderful young man. And, by all accounts, they had. When Billy turned sixteen, he got his temporary driver's permit, and Mom would let him drive to school with her beside him for practice. Billy completed the student driving course and practiced enough to pass the driver's test and get his permanent driver's license. To any parent, there is a sense of apprehension that the day will come when their child will drive by themself. "Will Billy follow the rules of the road, stay out of harm's way?" Mom thinks. Of course, he will. He is a good, responsible kid. You have all the reasons to think, not otherwise. You've raised your only child to what you believe to be a good, conscientious, valued member of society, and now he can drive himself back and forth from school by himself. He is becoming an adult with adult responsibilities.

When the call came that Billy had been in a horrific car accident on his way home from baseball practice, his Mom raced to the scene to find him being put into an ambulance. The officer on the scene told her that her son was traveling at

a high rate of speed, crossed the white line, and hit the other car head-on. The officer suspects that Billy was doing over 90 miles per hour as he entered the corner and overcorrected, losing control of the car. The people in the other vehicle died within hours at the hospital. For the grace of God, Billy only had a superficial cut on his forehead, a bruised arm, and a concussion. Billy does not remember anything that happened. In a single moment, a life tragically changes not only for Billy but for Mom and Dad, and yes, the lives of the other family too.

As a parent, you sit back and thank God that your child is going to be O.K., but that is not what occurs. Having no recollection of the accident, Billy pleads guilty to the judge and is sentenced to probation, community service, license suspension, and an unbelievable level of guilt and grief. An "A" student in school becomes a C/D student. All because of one moment-in-time of making a poor choice to speed around a dangerous corner, lose control of the car and smash head-on into a vehicle resulting in the death of two people. Billy, to this day, does not remember a thing about the accident other than the remorse he had come to accept when it was clear to him that he was at fault and that two people had died due to his actions. Billy was racing a teammate back to their neighborhood. Who could get their first? There was no intent, just who could get home the fastest.

When the lawsuit came, insurance would not come close to covering the demand. Dad was older than Mom and had retired with a small pension. Mom continued to work, though she wanted to retire. They offered their life's savings, but that would not be enough for the loss of two lives. Billy lived in an upscale neighborhood that had taken his parents years to achieve, and now it would all be gone. The savings, the retirement, the house, because the jury could not see past the fact that two people had lost their lives. How bad can it get! It got really bad and will take years to overcome, if ever, and years for Mom and Dad to get back on their feet financially, if ever. For Billy, he is fortunate. Mom and Dad love him and remain in his corner. He's a good kid who screwed up. A 'once occurrence' that will affect him for the rest of his life. Why do I tell you this story? Because Billy had a choice, wherein your child did not.

Emily has lupus through no fault of her own, and yet her family is facing the same emotions very much and possibly financial issues too. The only difference is that the two people did not die.

Emily's story

Emily is your child. A good kid, good grades, friends, involved in the community, church, someone you are very proud of raised in a manner that any parent would take pride in. And then, one day, Emily finds herself feeling a level of fatigue that she had never really felt before. It crept up on her. It was hard to notice at first, put the finger on it, but you saw it in her sleeping longer, less interested in things, not seeing her friends as often, or being involved in church gatherings as enthusiastically as before. Something is wrong, and before you know it, you feel that your child, for some reason, has an attitude problem. "Is Emily on drugs? What the heck is going on with this kid?" you ask. You take your child to the doctor. A blood test shows nothing to be alarmed about. It's probably the stress of growing up. "I'll give you this medicine or that, and let's see how you feel in a couple of months," says the doctor. Your primary care doctor has always been excellent, so if he can't figure out what is going on, then there is nothing going on that could be too serious. The medicine will work, you think. Over time, Emily continues to get worse and withdraws more. Is it something at school, with friends, and so on? Emily feels she is the only one who understands how she feels and what is happening to her.

"No child of mine is going to slough off," says Dad. He sees his daughter withdrawing into a secure, comfortable, cozy place to curl up and rest the day away from the fears of whatever is happening. Again, it can take up to six years for lupus to be diagnosed. It depends on many different things because rheumatologists will tell you that no two individuals have the same symptoms. Imagine how much time passes; how much angst between the daughter and family members because they do not believe their daughter is sick. Finally, the family

doctor suspects that Emily might have lupus. "What is that?" you want to know, but you, Dad, do not make an assertive effort to find out. "I'm sure there is a medicine out there that will make my daughter feel better," you think. "No daughter of mine is going to become sick because of my genes!" you exclaim. Said like a true man. "What about Mom's family?" you question. "Yes, it must be on her side, but I can't accept that. My child is perfect!" Hopefully, we all feel that way about our children, but as we all well know, that is not always the case health-wise and in their personal life.

If you are like most people, you have never heard of lupus or any other autoimmune disease for that matter. But Emily has one. Emily knew something was wrong, could not express it clearly, and only knew that it was getting worse, not better. She did not have the energy to do the things she used to, the ability to always focus clearly, nor the energy to always be with her friends.

Emily's Dad is wondering what happened to her and is pulling away slowly because he does not understand why this gradual change has now become an issue. She tries to express what is going on, her feelings, but Dad thinks it is all baloney. But not unlike Billy, who had a sudden event in his life that tragically affected his family and life, you see your daughter as lazy, not realizing she is far sicker than you could ever imagine. You think this cannot be happening to your kid. This is not her! And so Dad becomes frustrated, angry, and concerned, a list of emotions that only a father can feel under the circumstances.

Billy, in this story, had a choice. Your daughter did not, as her lupus is a product of her genes and some proteins hidden in the family tree somewhere. Two different situations, two different outcomes. But with the support of family and acceptance of circumstances, Billy and Emily can live a good life. Turn their circumstances into a positive, knowing that their life will always be different because of their life experience. It's all about acceptance, adjustments, and getting the help needed to progress the best one can as one lives their life.

In your daughter's life, you play a very important role in her success. She needs to feel that she is loved by you. That you accept her lupus even when she does not by supporting her emotionally and financially if need be as she gets older.

Emily has learned a lot over the years about her lupus. Mom had the foresight to come to a support group meeting and realized how important being around others in a similar situation was. Like most with lupus, Emily doesn't look sick, but she is, and when they go to family gatherings, Mom asks Emily if she would like the wheelchair. Moms can be moms. As Emily says, "Absolutely not! I want to be as normal around others as I can be!" she exclaims. And that is a key that both Mom and Dad need to accept. To treat their daughter, their child, as if she is normal and respect her need for quiet time when she is not. In other words, let their daughter manage her disease and not the disease, or her parent manage her.

Here are some tips for Dad to consider:

You, Dad, cannot be all things in all situations. I know we want to be, but when dealing with a life-altering disease, such as lupus, it becomes a team effort. The support Patty gets from others is unbelievable. Support that I cannot give her because it takes a team. Fortunately, we have a team around us made up of others in a similar situation. The group provides understanding and moral support when the need arises. I recognize this is a difficult bridge for most guys to cross, but with the help of Mom, your child, the medical community, and everyone else, there will be less stress in everyone's life.

The first question is, how do you go about developing the right attitude towards lupus or any other disabling autoimmune disease? The answer is simple: Get educated! You may very well be the solution to your child's disease by learning as much as you can and getting involved with the community surrounding your child's particular medical issues. That may seem a little far-fetched right now to

you, but Patty and I know that we have improved the lives of countless individuals through our involvement in the lupus community. This book is just one effort toward helping others. You may never know when you will come in touch with someone who is living in a similar situation. Your words, experience, and compassion may very well help that individual cross the bridge to greater understanding and hopefully better circumstances.

Mom is not the only shoulder your child needs to lean on or rely on. Of course, depending on your child's age, the demands and needs will vary. The younger the child, the less likely they will understand what is happening to them. However, as they get older or are older at the inception of the disease, they must have some understanding of why certain behaviors are important to their overall health, such as taking their medicine as prescribed. Obviously, there is a difference between a three-year-old and a teen in regards to their awareness and understanding.

Know that lupus just doesn't go away. It is something that your daughter will live with varying degrees for the rest of her life unless a cure is found or she is fortunate enough to go into remission. Your child is going to need all the support he/she can get from you; involved mentally, emotionally, advocate, and simply being there for her. This is true for Mom as well. Siblings will learn to adjust. The impact on them can have adverse effects even though they do not have an illness. The vacations missed, or not being able to enjoy the beach with her siblings, and so on. A child with lupus needs a team effort from her family to live and adjust in a positive way to her lupus. This can bring undue pressure on the family as everyone tries to find a sense of normalcy in what otherwise is a level of chaos and concern that is not easy to deal with for all.

If you have other children, they need not be ignored. Children can become jealous and feel left out. Dad must spend equal or balanced time so that one child's lupus does not become a negative, but rather a positive to the family . . . bringing

you closer as a family. Hopefully, your child's siblings will become closer and more supportive by helping out when they can. You're a team. Have those open conversations; understand and respect the feelings of your other children and be there for them just as you are for your child with lupus or another disabling or otherwise autoimmune disease.

Siblings should not feel guilty or encumbered by their brother/sister's lupus. Their honest feelings should not be ignored because there could be negative emotions and concerns. "Could what has happened to my sister happen to me?" a sibling asks. "Can I possibly die?" These are a few honest thoughts that require conversation and positive support from both parents.

Normalcy is what you, your wife, and other children want. Your child may feel left out of certain aspects of family outings, such as a day at the beach, but are your other children unable to participate in activities because of their sister's circumstances. The answer is "No." You can take the kids to the beach while Mom stays with Emily or vice versa. "Yes," it does require acceptance and understanding of the circumstances, and "yes," it can become life-altering if allowed. Living with someone with lupus, regardless of age, is living within the limits that the disease allows in respect to participation outside the comforts of home. Common sense goes a long way. Unfortunately, what is common sense to you and/or a sibling may not be to another. Thus communicate, communicate, communicate.

Communicate, communicate, communicate with your child's daycare provider or teachers and the school nurse so they are aware of your child's circumstances. As your child progresses in school, they should not be penalized when dealing with a non-communicable illness. i.e., does your child need a rest break during the school day? If so, can a study period be scheduled in place of math or a gym class? Is a gym class too much for your child to handle physically? Talk to school administrators about the special needs that your child may require to participate

as normally as possible in school. Remember, growing up can be a very emotional time in any child's life. Does he/she like me? Gossip. Friends who do not understand. It's a time to think of others, and many friends will do just that. The young lady who is the Homecoming Queen relinquishes her crown to a special needs child who has always dreamed that one day she would be like others: be a Homecoming Queen too. Good friends will understand.

In one case, a young adult in college has friends who love to go out on the weekend and party. Of course, our young lady cannot drink because of her lupus. So she became the designated driver for her friends and enjoys the evening just as much as they do sans alcohol.

What about you?

Amor Vincit Omnia (" Love Conquers All"). Love your kids, love your wife, embrace the circumstances, be supportive, and know that when frustration and emotions are well inside that, it is your love of your child, children, wife, and the family that will bring you through these circumstances. Yes, those who died in the car accident are a tragedy that Billy's family needs to deal with. It is simply tragic. The son who made the bad choice has brought upon his family a hardship that hopefully will allow the sun down the road to shine again through their faith, understanding, and desire to come out on the other side in a positive way. It will be a long journey for sure. "Yes," your child's disease, lupus or any other debilitating autoimmune disease, has upset the nuclear family's vision. However, going down this path together will make you all a lot stronger. Your child will age to adulthood and, by all accounts, will live a wonderful life with some limitations; marry, have children and raise a family you will be proud of. If anything, you will find that lupus will make your daughter a lot stronger as a person, and more focused on her life, because she knows how fragile it can be.

Living with a child who has an autoimmune disease, such as lupus, can be very challenging. Your emotions are confused at best on what to do and how to handle certain situations. As a working Dad, it is not always easy to come home to a sick child knowing that your time, thoughts, and needs will press upon your time and emotions when all you want to do is have a beer and relax. We are all dealt hands in our lives, and learning how to play the cards and adjust is an important key. This is not unlike living with your wife's disease and all that is required of you when you get home.

If you find yourself having negative thoughts about your situation, i.e., guilt, anger, frustration, do not judge yourself. These are normal feelings that will arise from time to time. Talk to your wife because she has the mother instinct, and she also has the common sense to see the situation that you may not. So, be open-minded. An honest conversation can help a lot, especially with your daughter/son. They need to know that their lupus is not their fault, and you need to accept that it is not your fault either. Remember that actions and words count. Unfortunately, your child's disease was the role of the genetic dice. Remember, too, that "it's your attitude towards life that will be life's attitude towards you." so says John N. Mitchell. That is something you, and only you, control. If you find yourself in denial, cannot address the situation, or come to grips with it, find a trusted friend that you can talk to, or seek medical help through your Primary Care Doctor.

Learn everything you can about your child's illness. Lupus is not something to be hidden but rather understood. Have conversations with your child that are supportive and understanding, and be that advocate. Conversations should be kept simple. A child will know when something is wrong, and they are looking to you as a parent for their security and guidance. Let her/him be all that she/he can be, i.e., do the things she can for herself, but be quietly there to help out when she needs support. Her knowing that you are there to support her is a powerful therapy. And, if Mom cannot take time off to get your child to a doctor's

appointment, jump in and take her. Your child must know that you are supportive of them. You are your child's security blanket.

You and your wife should have a life too. Your daughter can participate in most family activities, such as going out to dinner and going to indoor events, as long as she has the energy passes to do so. Your daughter will learn to balance her energy and adjust to her circumstances. What is most important is her understanding of not only her physical circumstances but the mental side of living with an autoimmune disease. Support and understanding from you, Mom, and siblings provide that safe, loving, and understanding environment. She wants her life back, and this is a very difficult adjustment for anyone, whether a child or an adult. Your daughter or son will learn quickly who their friends are. Having said that, your child will try to be as normal as possible around their friends. Sometimes easier said than done. Education/awareness is important in these relationships, and depending on your child's disease activity, he/she will adjust. Talk to her friends' parents to ensure they understand that lupus is not contagious and ask for their support too in keeping things as normal as possible. It's hard for a child who has a discoid rash as it's not much different than pimples to their psyche.

If you have other children, know that siblings will react in different ways. "Why can't big sister play with us on the beach?" one exclaims! Many different emotions can arise: anger, fear they may catch lupus, or the fear that their sister may die. Depending on a child's age and his/her siblings, it can be difficult to understand. Thus, not only do you need some coping skills but understand that they do too. If a child starts acting differently, withdrawing from the family, or simply spending more time to themselves, have that open discussion of understanding. If it continues, talk to your primary care doctor or rheumatologist for advice.

Stay in tune with your child whether they are six years old, fourteen, or older. If they are in school, make sure that their teachers understand and what accommodations they can make if need be. Also, make sure that the school nurse

is well aware of the circumstances, medications, and any other needs, as well as emergency contact numbers if the school needs to get in contact with you or your wife. The more you know that those around your child understand, the easier it will be for you to get through your day. This is a new normal for your child, you, and the family too. Your child will need to put on sunscreen and protective clothing, and a hat when she is outside during recess, and that can be uncomfortable on a hot sunny day. Staying in the shade is not always easy, and UVA rays find easy ways to get around protection. Coolibar (www.coolibar.com) has sun protective clothing for kids, babies, and adults too.

The Teen Years

Whatever happened. How fast my little one has grown up and is transitioned from a child to an adult. So much goes on in the human body physically and mentally as children grow into their teen years. Somehow, we go from parent and provider to provider and annoyer as your child struggles with his/her identity, emotions, the outlook for the future. If the inception of your child's disease occurred in their teen years, the challenges to normalcy could become much greater than if active earlier in their life. It takes time to understand and adjust to the circumstances one lives. Peer pressure, whether real or not, is a perception that is hard to remove from one's mind. And we are back to communications as a solution to resolve these issues with friends, family, siblings, and parents too.

As your child reaches the age of responsibility, i.e., for their health insurance, make sure that you have included them in any conversation in regards too what they need to be adequately covered. Realize that once a child reaches the age of 18, you as a parent no longer have the right to their medical information or visits with them to the doctor under current HIPPA laws. What is most important to a child in retrospect as they grow into adulthood was their parents' understanding, support, and love as it remains so always.

CHAPTER 19

What's the Outlook?

Research, hope and some good stories to be told, and some not!

Lupus Research

This is a hard segment to discuss because "The Cruel Mystery" continues to perplex researchers. Why? You would think in this era, with all that is known about the human body, DNA, stem cell research, etc., we would be closer to understanding this disease. The problem with lupus is that researchers cannot define the exact problem with the immune system because it is so different in patients. It is like a moving target that makes it difficult to hone in. That is what researchers are trying to do as new medicines, such as Benlysta, are developed and new therapies, such as mesenchymal stem cell therapy, are being researched. Since the initial writing of Caregivers Wear Plaid, two new drugs have been approved by the FDA for lupus. SAPHNELO, which for adults with moderate lupus (whatever that means), comes with some serious side effects, so check with your doctor before considering. This drug, according to its literature, indicates it is "not for severe active lupus nephritis or central nervous system lupus. SPHNELO is the first medicine approved for lupus since 2011 ten years after Benlysta. So check the FDA on the Internet for more information.

Prior to these efforts, medicines used to treat lupus suppressed the immune system, which helps to alleviate symptoms. However, these medicines, such as prednisone and Plaquenil, have been compared to trying to kill a fly with a

cannonball. There can be a lot of collateral damage and side effects associated with taking many of these drugs over time.

Today, researchers are looking more at the molecular structure of the immune system. Sooner or later, an answer will be discovered, but in the meantime, your focus is on being a caregiver. Just know that over the years, the average lifetime of someone living with lupus has significantly increased due to better focus on the disease and how it is treated. Primary Care Doctors are more aware of lupus today than they ever have been. At this writing, there is a clinical research study on a new blood test to determine diagnoses of lupus, which would be wonderful if it proves out to be successful. This in itself will significantly reduce the time between the onset of symptoms (the anxiety, frustration, what's going on inside of your wife and you, too) and diagnosis. Knowing what you are dealing with through diagnosis is a great relief. That certainly gets you focused on the next stage of accepting and dealing with lupus or the autoimmune disease your wife has.

Let me not sugarcoat this!

Lupus can kill, and I have seen too many people go before their expected time. How much time you and your wife will have together will vary. Patty has lived with lupus for over 50 years since being diagnosed, so we know it is not a death sentence. However, others have seen their life end unexpectedly and abruptly. A lot can be attributed to the disease's level of activity in the body and how well your wife takes care of herself; taking her medicine, eating properly, managing her energy, keeping a positive attitude, and so on. However, everyone is different, and no one seems to react to lupus symptoms in a uniform, tightly knotted package. There are different levels of severity.

In an October 2016 report from the National Institute of Arthritis and Musculoskeletal and Skin Disease entitled "The Future Direction of Lupus Research," it is noted that "Fifty years ago, survival was 50 percent after four years. Today, thanks to advancements brought about by research on the mechanisms of diseases and aggressive therapy, it is 97 percent at five years, and 90 percent at ten years." Over the last twenty years, greater research and understanding of the immune system is showing promise for new treatments and therapies.

Clinical trials

Today, clinical trials seem more the norm than the exception. The Lupus Foundation of America is a good resource for knowing when and where clinical trials are being conducted. Additional websites to check out are www.clinicaltrials.gov and www.centerwatch.com.

Advancements in Stem Cell Therapy

Stem cell therapies with embryonic cells have shown great promise. Mesenchymal Stem Cell therapy (MSC) has been studied over the last decade for use in the treatment of patients with severe lupus. These cells are not embryonic stem cells but rather derived from bone marrow. What makes this therapy exciting is that the immune system does not see these cells as an invader because the immune system does not detect these cells as foreign. Thus, there is no fear of rejection nor the need to find a match, as with kidney transplants. There also seems to be far fewer side effects or adverse reaction to the therapy. However, this therapy continues to be understudied through trials. For more information on MSC trials, go to www.lupus.org.

Just such one story of these trials

In 2018, Barbi Manchester and I were honored by the Lupus Foundation of America's North Carolina Chapter as Queen and King of their Annual Mardi Gras Gala. Barbi was also the keynote speaker for the evening. Patty and I have known Barbi and her family for years through the foundation and their efforts to raise funds for a cure. Barbi is an exceptional person, as are those in her family, who have rallied around and supported her every effort to bring awareness to lupus, raise funds for a cure, raise her son, and regain a semblance of health.

I use the term "semblance of health" because that is what it is. Good days and bad days, to the extent that Barbi, with all her efforts and fortitude, was losing the battle with lupus and knew that she did not have much time left here on earth. She was that sick, but she never gave up!

I had not seen Barbi for a couple of years when she came on the stage at the gala to give the keynote speech that night. This was not the Barbi I had seen in decline over the years. She was not gaunt-looking, tired-looking, defeated looking. She was vibrant, with a glow on her face that was exemplified by her enthusiasm and the results of the mesenchymal stem cell therapy trial she was participating in. As Queen and King of the Gala, we had the first dance of the evening. Holding her in my arms, I could sense this young lady's renewed spirit and strength. Barbi had endured so much, given so much to others as an example of fortitude and conviction to not let lupus define her. Mesenchymal stem cell therapy seems to show great promise in discovering an answer to controlling this cruel mystery we call lupus. Only time will tell as funding for stage II control testing is conducted. As a book gets older, research of the past does not always clearly define the progress that has been made. Talk with your primary care doctor and rheumatologist about the use of Mesenchymal stem cell therapy and its current viability.

Some personal stories

A neighbor up the street from us was diagnosed with lupus. She called the Lupus Foundation of America's North Carolina Chapter for help. To her surprise and ours, they told her we lived three houses down from her and that we would be happy to help with information, etc. She had kidney involvement at the time but had not shared that with us. We told her we would always be there to help if she needed us for anything. At the age of 45, she died of a blood clot while on dialysis. She had two high school-aged sons and a husband who had just been laid off from his job.

A school teacher diagnosed with lupus and engaged to be married is rushed to the hospital. The doctors, after several days, are not sure what is going on but do get her to the point where they feel comfortable letting her go home. The doctors tell her finance and mother to go home and get a good night's sleep . . . and that she would be going home in the morning. The next morning her fiancee comes to the hospital to pick her up, only to find out that she died during the night. She was only 28 years old.

A lady who lives across the lake from where we live and who we had never met fails to wake up one morning from her husband's call. We learned later that she had lupus and died in her sleep at the age of 45.

And then there is our Shellee to whom we dedicated this book. These are but a scant few of the sad losses to this disease. On the other side of the coin, there are good stories of remission, excellent reactions to the medicine, kidney transplants, and so on. You just never know what each day is going the bring. Remaining positive is always important.

But there are good stories too!

One young lady who needed a kidney transplant due to lupus became so desperate that she put a message for help on Facebook. A total stranger, who turned out to be a match, donated a kidney, and our young lady's life has improved significantly to the extent she travels, loves her job, is healthy enough to work, and volunteers for every lupus event that she can. Now her donor is a sister in more ways than one.

What is sad, and I know to be true in our community of lupus and other autoimmune diseases, is that most prefer to live in the shadows of life and not in the light of the day. It's the privacy of pain that one does not want others to see or be known to have. It affects one's identity, personal, professional, and social life to extremes that are hard to understand. Whether one is sick with a potentially life-threatening disease or not, we should all embrace life the best we can to live and contribute to the needs of others. Thereby we become one and at peace within.

SECTION 3

Strategies

Life truly begins when you are living with someone who has a debilitating autoimmune disease. As I have said before, no person changes there old ways to seek the new until they personally find a reason to do so. If you ever needed a reason to do so, it is now. Otherwise, I don't think you would be reading my book. Because we are creatures of habit, you might think this is a hard thing to do. But, we can change if we have the purpose and courage to do so. In section 3 I will share some strategies that may very well be out of your comfort zone. But realize this, your wife needs a committed partner in this journey she is on. Chances that her disease will go away for most is hope. Her fears are well-founded. "I need you, but why would you stay?" she thinks. It's what love is all about, and there is never a better time to show it.

CHAPTER 20

Counteracting Fatigue

Fatigue, no matter how much she rests, does not go away!

Can something be done to counteract fatigue?

That's an excellent question and something we will touch more on in this book, but the answer is "Yes." Here are some things both she and you can do.

1. Exercise: The lack of exercise can lead to fatigue and conversely lead to greater energy. The key is to find what works for you. For some, walking helps a bit. For others, it might be riding a bike, swimming, or doing yoga. What might work for your wife may not work for someone else. By exercising, one's cardiovascular function will improve. That leads to better oxygenation and circulation of blood to internal organs and hopefully less fatigue. How often, when, and where your wife will discover what works for her. If she cannot exercise, she should talk to her Primary Care Doctor about a rehabilitation program. Patty goes once a week to physical therapy with a wonderful therapist who "Works wonders for her!"

2. Medicine: I have always wondered if doctors truly know the interaction of the medicines they prescribe. The answer is: Sometimes, my opinion. In their defense, everyone's system reacts differently to medicines. Some medicines or a combination of can cause fatigue. I recall Patty's Primary Care Doctor indicating at one point that he feared he had overmedicated her. It's an interesting game that is played. Medicines that have worked for years no longer work as well because

tolerance has developed over time. Then too, there can be an interaction of drugs or misprescribed. Medicines that often are godsends can also create additional problems, such as fatigue. So if your wife finds her fatigue higher than normal, don't self prescribe, but encourage her to go see her doctor before it gets worse.

3. Use of your subconscious mind: This is more than mind over matter. Yoga, for example, can encourage relaxation and thereby reduce anxiety and even resolve physical, mental, and emotional issues. Again, I am not a doctor, but I have used my subconscious mind for the past 50 years of my life to relax and sleep. Patty will tell you that when my head hits the pillow, I am out, but that is by a mental choice developed over the years and reinforced every night through a simple mantra. If this is for you or your wife, discuss it with your doctor. Physical and mental yoga can be very beneficial.

4. Diet: A good anti-inflammatory diet is important to one's overall health. This is very true for those with a systemic autoimmune disease. We have had more than one doctor recommend the Mediterranean Diet to us as well as a vegan diet. Each doctor indicated that they didn't know why it works, but it does work! In 2018, Dr. Fred Tabung, a visiting researcher with the Department of Nutrition at Harvard's T.H. Chan School of Public Health, said in a Harvard Medical School health news article that "diet is also one of the best ways to reduce it," referring to systemic inflammation. He mentions The Mediterranean Diet as a good diet to follow in his article. The diet is full of whole fruits, nuts, legumes, dark green leafy vegetables, and whole grains. Many of these foods are also rich in micronutrients that can support a healthy immune system. Conversely, "a poor diet can alter your immune system," says Dr. Tabung, which can contribute to inflammation. I know . . . who wants to eat such a diet, but the alternative is a lot worse than the help your wife can receive from the Mediterranean Diet. Something to consider. Remember, inflammation is one cause of fatigue.

I know it is difficult to change eating habits. After all, we do love foods that are not necessarily good for us. Moderation is probably a keyword. That saying, "you are what you eat," has a lot of truth when it comes to systemic inflammation. Ask your doctor to recommend a nutritionist or his feelings about the Mediterranean Diet. Systemic autoimmune diseases require adjustments, and that seems to be a constant.

5. Time management: Your wife, because of the limited energy passes she has, will quickly learn that she needs to manage her time wisely when she is out shopping, appointments, and so on. She will learn when she has the most energy and when she does not. Some will take a nap every day at a specific time because they know that will re-energize them for the rest of the day, or at least a portion of their day. Your wife should consider what's important that day and what is not. And then, do the more important things first while she has the most energy, the less crucial when she does not, or at another time when she feels well enough to focus and accomplish the tasks.

6. Stay Hydrated: There are plenty of studies out there that indicate that dehydration can cause fatigue. Our nephrologist recommends four regular bottles of water a day. For some reason, my pallet wants something more than plain water, so I put about 1/3d of diet tea in each bottle or glass of water that I drink. Sipping water throughout the day will maintain blood volume making the heart work less to push oxygen and nutrients throughout the body. At www.truelemon.com, 20 Reasons to Reach for Lemon Water Every Morning, having a "cup of warm lemon water first thing upon waking . . . has incredible ways it will benefit your mind, body, skin, heart and overall well-being." Check it out. Unfortunately, fatigue is a constant with most systemic autoimmune diseases. However, reducing fatigue a little bit is better than not reducing it at all. Ask your Primary Care Doctor what he/she would recommend. Not only their medical training but experiences with their patients can often bring good advice.

CHAPTER 21

The Power of Support Groups

No one likes to think they need help. They believe they can handle their issues by themselves. Oddly enough, in time, you will come to know that your best friends are those who are living their lives in a similar situation. No one better understands this than those who have come before you and your wife.

"You were missed at Support Group last week. We had a couple of new ladies who were so interested in everything we talked about. You know that feeling when you FINALLY find people who can help you and know you're not nuts for feeling so badly. It's a huge relief for them. It's why we do what we do year in and year out." A message from Patty to a Support Group member who could not attend one of their monthly meetings.

What we more often than not hear from a woman who has been diagnosed with lupus is that they do not want to become part of a support group because 1) they think it is a gripe session and 2) they do not want others to know. i.e., wearing the mask of anonymity. What we have found is the exact opposite for most when they join a support group. "I wish I had come sooner" is often the retort. They embrace their new friends, learn from them, and share with them too. Life begins to be seen in a totally different perspective. Members become a resource to one another. The medical profession does not provide this kind of support. Yes, if things get difficult at home, your doctor will more than likely recommend a counselor or social worker. But from our viewpoint, many issues at home are related to lupus, and we assume other autoimmune diseases too are derived from a lack of understanding, support and the disease they are living with. Who can better support your wife and you than those who are living in a similar situation? Those who have learned over time how to cope and live the best quality of life possible under the circumstances. And that is what a support group can provide: Awareness, friendship, confidentiality, and purpose.

Not every state has a lupus chapter. You can find LFA State Chapter Support Groups at: https://www.lupus.org/chapters. These LFA Chapter meetings are most often led by someone living with lupus who the foundation has trained as a facilitator. Simply call the chapter and they will give you the particulars.

What if you live in a state that does not have a chapter? What can you do?

Individuals who lead lupus support groups are volunteers. Patty helped start a support group at a local church in our community. At first, there were only three or four members. They usually met on a Tuesday night, and though the group was small, it really did help. As mentioned, it served as an opportunity to get together with like others, share experiences, ask questions and build friendships. The group would have family cookouts, lunch together, and support one another however they could. Here are a few ideas on how you can start a support group if there is one that does not exist in your state or area. You might be surprised at how many others in your community may want to become involved.

First, your wife needs to decide if starting a support group is something she wants to do. Not everyone is cut out to take on the challenge. Reaching out to others with a similar autoimmune disease can start by having coffee together. A support group can be as simple as that. Two people with a similar situation get together to share and support one another. Though Patty is in a formal support group here in North Carolina, we have lupus friends who are always thinking of us and what they can do, such as bringing dinner over or driving Patty to a support group meeting. In the lupus community, friends beget friends. This is important because your wife needs someone to reach out to other than you, and we know there are others with lupus or other autoimmune diseases who need to reach out to. Your wife coming out of the shadows of her disease is an important step to coping with her disease. How do others handle this or handle that? What's new with lupus? What one thing do you wish you could improve upon in dealing

with your disease? Question and answers that bring insight. So, if your wife is thinking about starting a support group, the following are some things she needs to consider.

The five keys to a support group

1. Who is going to lead it? (Leadership)
2. Where is it going to be held? (Logistics)
3. Where to get materials for the meeting? (Materials)
4. How to run a support group meeting? (Discussion)
5. Where do you find the people to attend? (Awareness)

Leadership

With lupus, the leaders are primarily women who have lupus and want to take on the leadership role of communicating, organizing, creating handouts for discussion, and making sure the location is left as it was found after the meeting is over. It is not a bad idea if someone in the group wants to step up, to be a co-leader of the group. They can help with these duties and also fill in for the leader when she is unable to attend.

Logistics

This is more than what and where. In the lupus community, meetings are normally held once a month, either during the day or evening. That really depends on the leader's availability. There is no reason why meeting times cannot vary from month to month. Some groups may meet more often, like every other week. What we have found is that individuals with lupus tend to keep in contact

between meetings online, phone calls, or catch coffee together at a local bistro. If your wife is comfortable hosting a support group meeting at your house, that is always an option too. However, doing so may cause more work and effort at your house that can exhaust, use up Energy Passes, and be more difficult to manage than going to a facility that can support the meeting with little or no effort.

You will find that churches, community centers, and libraries are great places to meet. Schools or colleges in your area may be able to provide space free of charge too. If you plan to show a video or need projection, often the above venues have the equipment and assistance to operate (Free). Meetings are normally scheduled for two hours, such as 1:00 to 3:00 or 6:30 to 8:30, and are normally held mid-week. However, there is no rule. Where ever the meeting is held, attendees should feel safe and comfortable attending.

Materials

Materials for Support Groups are everywhere. One of the best resources is contacting the Patient Services Manager at any state chapter and tell them what you are planning on doing and could they provide materials for the meeting. You more than likely will need to make copies, but it is an easy resource. It will also open up for dialog on what other groups are doing. The chapter will more than likely want someone in the group to go through facilitation training but they will be excited that you want to get involved and will support your effort in every way possible that they can.

Size

One may have concerns that if this group gets really big, how does one manage that. In reality, the ideal size for a support group is between 8 and 10 members.

This allows members to talk about individual issues, especially someone who might be new to the group. The group could have up to twenty or more members, but historically not everyone shows up due to how they are feeling or other work-family issues.

Often materials to be handed out are never used because the group gets into a conversation that leads to other questions, concerns, sharing of information, and so on. That is O.K. because keeping the discussion going is an important role of the facilitator and this type of interaction is important and often better than a formal presentation. Videos and articles can be found at lupus.org as well as others on the Internet. Having said that, don't believe everything your read about on the Internet. There is a lot of misinformation.

Discussion

A support group is not designed to be a "Bitch Session" but rather a help and sharing session. Whether it is two people getting together for coffee or a formal group, no one must place a burden upon another by sharing their grief. Grief can be exercised from the mind through stimulating conversation, learning new things, and helping others who are in a similar situation. In essence, everyone needs comfort, to learn anything new, and how others have learned to adjust to their circumstances and live a better quality of life. It's easy to fall into the "Why me" attitude versus "Why not me," and how can I help others. Oddly enough, when helping others through a situation or concern, the one who learns the most is the one who is helping.

Do not be concerned about other people's schedules. What I mean by that is people with autoimmune diseases work and have busy life schedules, and you may think they do not have the time in their day to attend a support group. Patty's

group meets during the day, and the group is made up of all ages and all different circumstances. Many of the ladies in Patty's support group do hold down jobs, but their employers allow them to take some extra time off, other than a normal lunch break, to attend. Their bosses understand the importance of a support group to their overall health and performance. It is a small token of support since the meetings are held normally once a month. Other support groups will meet in the evening because it is convenient for their group. There are always options. It's important to know that a support group cannot be all things to all people. That's just the nature of people. Respecting their needs and concerns should always be a consideration of any group. You will find that those who do not become comfortable will just start not showing up. But that's when the leader should follow up personally or by email to check that everything is O.K., provide information shared at the meeting, and so on.

It's common in support groups that medications prescribed for treatment are discussed. This is good and bad, because what one person is on getting good results, another at the meeting may not. Or, one wonders why their rheumatologist has not prescribed the same drug that some others are taking. With lupus and other autoimmune diseases, what necessarily works for one does not for another. There is no standard protocol other than what one's doctor is prescribing. But every once in a while, a new drug comes on the market or a trial that a support group member may be interested in. Awareness of what is new should be a focus so that members can at least discuss it with their doctor(s). When Benlysta was developed and approved by the FDA (Food and Drug Administration) to treat lupus symptoms, many doctors did not recommend the drug immediately, and for a good reason. Any new drug can have side effects, and your doctor does not want you to be the trial case. However, if trials come your way, that could show promise, and depending on your mindset, you may talk your doctor into supporting your desire—more discussion about this in Chapter 25 - Medications.

Like any meetings, support groups are better attended when attendees know a specific topic will be discussed. The support group facilitator can also ask the

group what they would like to know more about; search-related disease website's for what's new to ascertain a topic for the meeting, and then do some research on who, what, and where that information is being discussed. Any information that is to be shared at a support group meeting should be sent to members before the meeting so that those interested can read beforehand and formulate questions in their minds.

One of the things we learned at the annual lupus summit we hold here in North Carolina is that during lunchtime, staff wanted to have a program and a speaker to make a presentation while everyone was eating. What we came to discover is that people attending wanted time to speak with each other. Meet and greet one another, learn from each other and make new friendships. Socializing is a key component of uplifting one another. So having an agenda for a meeting is a good idea, but if socializing becomes the need of the group for that day, let it ride.

Periodically I attend Patty's support group meetings, and I encourage you, men, to attend your wife's meetings. At those meetings, I normally try to keep my mouth shut and listen. But, there are those times that I can't help myself and will share some insights. I have been into personal development throughout my life and how to use the subconscious mind to improve one's life; I have even written a book of prose that expounds on life principles. What I have found in groups is their interest in coping with their disease. The day-to-day life they are forced into living. When that opportunity arises, I will share a thought or two, and I am always encouraged by those who stop me after the meeting or sometime after to thank me for the impression it has made on them. I'm sure you have many insights, too, and when appropriate, I encourage you to share them. You never know how what you say positively affects another.

For discussion, if there is a local foundation chapter supporting your area, they are always willing for someone to come from their office and speak. Patty's support group often has someone from the LFANC chapter come, not necessarily to speak, but to let everyone know what is going on in the chapter and what is new, if

anything, from the national office. From a presentation and social aspect, those working in nonprofits are always looking for opportunities to speak and share.

Awareness - How do you find other Lupies?

There is a term I have not used before in this book. I hate giving people names that identify them or their disease, but people in the lupus community often refer to themselves as Lupies. Go with it if you feel it fits.

You would think that your doctor would love to connect others with similar circumstances, but that does not fall into their realm of service and HIPPA (privacy) laws. Your doctor focuses on getting your wife healthy and not helping her cope with the social, personal, and emotional issues associated with lupus unless she reaches out to him/her. The one question the doctor will ask your wife is whether or not she is feeling depressed if he/she suspects that may be the case. Otherwise, the doctor is primarily managing medicine or making a referral recommendation. But one's quality of life is critically important to the process too. This is not to say that if you do start a support group in your community that you cannot ask your primary doctor, rheumatologist, etc., to hand your card out with contact information, meeting dates and times, and so on. That is at their discretion whether to do so.

So, where can you reach out?

1) If your state does not have a chapter, reach out to the state next to the one you live (if they have a chapter) and send them an email indicating that you are interested in starting a support group in your area. Many individuals with lupus do cross state lines, often attending fundraising walks, workshops, and summits. Someone else in your community may very well have started a group in your area, and this is an easy way to connect.

2) If you are a churchgoer, talk to your minister and find out if he/she is aware of anyone within your church community whom she may reach out to who has lupus. Placing a note in the church bulletin. Even if you do not go to church, go and talk to the minister in a neighborhood church and tell them what you want to do. 1) They often have space for a meeting, and 2) they have a congregation where I guarantee you others are living with lupus or know someone who does.

Churches are always looking for new people to add to their fold.

Put cards out on bulletin boards at the local coffee shop.

It seems that every major retail food store is raising money for this nonprofit and that nonprofit. Each time I am asked, I indicate that "all my donation money goes to the Lupus Foundation of America's North Carolina Chapter. Do you know anyone with lupus?" Just about one out of three do, which tells me there are a lot more people in America and the World living with lupus who have not been diagnosed included in the numbers. Often it is an aunt, a family member, or someone they knew in college. If they are open to receiving information, I make sure that they get it. The issue is about awareness and awareness to action that hopefully will improve someone's life who thought their circumstances were unique. There is a very large audience out there waiting to reach out and be touched by someone who can help with the day-to-day and emotional issues associated with lupus or another autoimmune disease if that is your circumstance.

Talk to people in your neighborhood. You will be surprised how many women living with lupus have yet to come out of the shadows and need the comfort of another to talk to, share, and learn. No one with lupus or any other autoimmune disease should find themselves alone or only in the care of their doctor. Socializing with others and other lupies will improve your wife's feelings of well-being and reduce feelings of depression. If you or your wife talk to friends, neighbors, and relatives, they very well may know someone with lupus. A friend, someone they

work with, and so on. 1 out of 123 + women who have lupus may very well be sitting at home in the privacy of their pain. It's finding them and offering an easy, not intimidating, friendly, supportive environment where they can ask questions, share concerns, help others and make new friends.

Former and current Navy Seals held a swim in the Hudson River to raise funds for GIs in need. Pete Hedseth, from Fox News, was challenged to swim with the group, which he did. Before the first leg of the swim, each participant did 100 sit-ups and 100 chin-ups. Then they all jumped into the Hudson River and swam their first leg to the Statue of Liberty in the Harbor. Pete, during that leg, began to tire and one of the Navy Seals shadowing him said: "Grab my trunks and hang on!" With that additional help, Hedseth, who is in great shape himself, was able to finish the first leg. Before continuing the second leg of the swim, each Seal did another 100 sit-ups and 100 chin-ups and then splashed back into the water as a team. Pete was able to sidestep that requirement as he made live commentary on Fox News and then got back in the water with the Seals. With additional assistance from his Navy Seal buddies, he was able to make all three legs, which ended up at Ellis Island. That's very much what support groups are like. Grabbing on to someone's trunks (talking, sharing, helping) and being pulled into understanding, new mindsets, and insights into how to live with lupus or as a caregiver too. It's the support team needed when things are not going as well as one would like. No one understands better than another woman in a similar situation who has gone before and knows the road a little bit better to travel. It is no different than another caregiver who has walked in your shoes before your journey. That is why we are here. To make the journey a little easier.

Online Support Groups

Facebook (META) and Google have group meetings, as does Zoom. There are other meetup applications online to provide connectivity with other like-minded people regardless of where one is located. This is good, especially for those who are in remote areas where an established support group does not exist or your wife

is unable to get out as often as she would like. In-person meetings are always preferred as there are fewer distractions and better interpersonal communication.

A point in case: I had the opportunity in my professional career to design and implement the information security awareness program for the enterprise at Bank of America. This was no easy feat, but I did it through an awareness program designed to change employees' values with respect to safeguarding sensitive information properly. It took seven years to change that value proposition. We hit a 94% employee awareness quotient, for lack of a better term. We started at under 40%. The program was designed under a simple premise. Communicate with employees seven times in seven different ways over time. We incorporated every component available at the time to communicate, communicate, communicate. It's the same with support groups. It's why you cannot get disconnected from your wife versus what is going on in your life. The more you know, the more you get involved, and the more you learn. The more you learn, you realize that you can make a difference in her life as a caregiver and that too in others by spreading the word, spreading awareness of the services, the Q&A's, and the opportunity to participate.

Where can your wife hold a support group meeting?

Starting small, it can simply be lunch . . . sitting around a table and having your meeting. Many lunchtime restaurants would love to have your business and are very supportive. Coffee shops are the same, but as your group grows, you will probably need a larger space, and that is where the church comes in. Churches are often willing to give space for meetings such as this. It is part of their community mission. If you have a mall in your area, you may find them willing to donate space for your meeting. The good news about lupus support groups, at least in our experience, is that they may have twenty or more members, but not everyone makes the monthly gathering due to not feeling well or other commitments. Usually, there is a core group of ten or so, and that is with a well-run support

group that has been around for years. The group meets monthly on a Wednesday at a church, and twice a year, they gather for a luncheon at a local restaurant. We have made many dear friends in our lupus community. Yes, many look to Patty for guidance and wisdom, but I guarantee you she learns as much, if not more, from them too. As mentioned before, support groups are a safe place to share one's fears and frustrations and reinforce the hope that tomorrow will be a better day through awareness, compassion, and, yes, hope. During COVID-19, support group meetings were held online, but as COVID declined, in-person meetings were held in conjunction with Internet meetup technology. Not always easy to manage both methods of communication at the same time.

Annual Summit

Many state lupus chapters hold an annual Summit, which is a great event to meet others and learn from doctors and specialists who work with lupus patients. The summit is normally one day and held on a weekend. Always well attended. Every summit, one or two husbands' or fathers come to the event with a level of skepticism. By the time the event is over, they leave with a commitment to do the best they can to be a caregiver and an advocate for their loved ones. This does not happen because of a "Come to Jesus" presentation. It happens because they begin to understand that lupus is real and that countless people have it. They now understand the severity of the disease and want to become involved in a positive way. This applies to workshops and local support group meetings too.

The LFA holds teleconferences throughout the year presented by doctors and other professionals on various subjects that are related to living with lupus. If you wish to participate, you can go to www.lupus.org/northcarolina. Events are listed on their HOME page.

Finally

There are always legal concerns when a group gets together under the impression or the fact that they are representing a national organization. That is why facilitators are trained and approved for conducting these meetings. It makes sense to contact the chapter or organization you wish to be involved with prior to starting a group. That does not negate a group of people getting together of their own volition. However, suppose you start a support group, and it begins to build in size. In that case, you should consider adopting criteria and support from the State Chapter or National organization and in no way indicate that an outside organization approves it unless that is actually true. That means being officially approved. Not to be repetitive, but during COVID-19, for obvious reasons, the Lupus Foundation of America did not want formal Support Group meetings held. The obvious fear was that it could be a venue where COVID-19 is spread and result in severe illness or death to a participant. Thus, no official meetings were held. That did not negate us as friends and supporters to one another to get together unofficially on Zoom and even have lunch together as COVID abated. The above is my personal advice as I am not a lawyer, nor am I any longer on the Board of Directors of the North Carolina Chapter of the Lupus Foundation of America or otherwise affiliated.

CHAPTER 22

What If Your Wife Can No Longer Work?

This is a very important question for you and your wife. What if she cannot contribute to the family income as she has done so in the past? We know individuals wherein this circumstance has completely altered their lives, and there is no way to get around the fear and worry other than to have each other, family, and friends support your wife's emotional concerns and yours too. Chances are your wife worked hard for her education and job position, and to think that she may not be able to continue to work is a major shift in her life and yours too. Hopefully, your wife will be able to continue to work for many years. Depending on the active level of her lupus, at some point, her lupus will become an issue that will require accommodations; elevate to the level that she is unable to work anymore. That's one heck of a way to start a chapter, but you must begin to think of the future, what your wife's income means to the financial stability of your family, and the adjustments you are going to have to make to keep it all together if she can no longer contribute to the family finances. Right now, your wife needs some accommodations. What do you need to know, and what does she need to do?

The COVID experiment

Rarely does it happen in one lifetime, but when an event occurs, that is life-altering, such as COVID-19, finding alternative solutions arise. Imagine the last epidemic in the early 1900s when there was no internet. COVID-19 allowed millions of people to work from home, and employers discovered that productivity went up in most industries. My business, which required being present in person,

evolved to Zoom, wherein, over time, the benefits of all participating became relevant. This allowed me to stay home with Patty and still have my business. To that extent, COVID has been a good thing because we were seriously thinking of shutting the business down for Patty's needs. If your wife can work from home, just as easily as being present at the job, she should ask her employer for the accommodation. Most larger companies have their own portal. Every time I call for support, the individual is working from home. So, if your wife needs accommodations and others in the company are working from home or not, she should ask after expressing her health issues.

Additionally, companies in this year 2022 are having trouble finding qualified candidates. This may not last forever but certainly in the foreseeable future. This is the time for accommodations unless her boss is

First, get educated on your wife's rights!

Lupus falls under the EEOC (Equal Employment Opportunity Commission) Act of 1991 and the amendments thereto of 2008. Having a conversation with her boss in regard to accommodations on the job should not be one to fear. Companies today are required under the Americans with Disabilities Act to provide reasonable accommodations for their employees who are disabled. Lupus falls into that category. Because I do not know what your particular situation is, the size of the company you work for, the temperament of management, and her boss, there are resources that you can consult before such interaction.

The US government has an online free service called JAN (Job Accommodation Network). It is supported by the US Department of Labor's Office of Disability Employment Policy. Go to: www.askjan.org. A consultant from JAN will contact your wife to discuss her needs and what accommodations work best within her personal situation. JAN also provides coaching on how to approach

and talk to her employer about her disability.

Workplace accommodations

Normally your wife does not want her employer or other employees to know about her lupus and how difficult it has become to perform at her job. The fear is that she could lose her job and income, and that is a frightening thing to think about. In essence, all she wants to be able to do is to continue to work and live a normal life.

Accommodations that allow her to continue to work are a benefit to the company as is to her too. This should never be considered or looked at as special treatment by the company or other employees. The law gives her certain considerations that must be followed. The Americans with Disability Act of 1991 prohibits employers from discriminating against an employee who has a recognized disability under the law. The law was improved upon in 2008 when Congress enacted the ADA Amendments Act (ADAA). The ADAA further clarified activities that needed to be recognized for those living with a disability. They included: Sleeping, reading, eating, communicating, working, performing manual tasks, standing, lifting, bending, seeing, hearing, speaking, walking, and even breathing. The ADAA also clarified what the word "disability" meant: MS, lupus, cancer, epilepsy, and others in remission or active state.

What can you do, what can they do?

Companies do not want to lose qualified workers unless they need to cut payroll. It makes no sense to keep good talent under normal circumstances., In almost all cases, your boss will make accommodations if/when your wife's lupus becomes a physical issue or other concern. One key opportunity is for your wife to educate her boss about lupus when the time is right because chances are her boss

has never heard of lupus. Before she does this, you and your wife need to know what her legal rights are under the Americans with Disabilities Act and amendments thereto.

The Interactive Process

If your wife needs modification to her job so that she can perform appropriately, she must tell her employer that she has a disability and needs accommodation. This is called "The Interactive Process" under the ADAA law. Obviously, your wife needs to describe the issue she is having for the employer to understand the accommodation requested. It could be as simple as a stool to sit on at the register when she is working at the check-out counter. If your wife works in an office where she sits under fluorescent lighting, a special shield can be placed over the light reducing the UVA rays emitted. If her computer screen is bothering her, there are anti-glare filters that are easy to place over the monitor. Your wife's request must be specific to an accommodation(s) to allow her to be as productive now as she has been in the past.

Suppose your wife has been working for the company for many years, enough years where her experience adds greater value to the organization. In that case, hopefully, her boss will find another opportunity for her within the company. Alternative jobs or additional training for a new job that better suits her circumstances can be beneficial to the company. Remember, most companies understand that their most valuable asset is their employees. The cost to hire and train new employees and get them up to the speed and the knowledge your wife most likely has is an expensive proposition. So, don't be surprised that her boss looks for other opportunities within the company to accommodate her needs and desire to continue to work.

The law also takes into consideration the size of the company your wife works for with respect to providing certain accommodations. For example, if she works for a company that has 50 or more employees, she can request intermittent family leave. Your wife's boss will also need to know that flares can occur, wherein one day she is at work doing fine, and the next day she cannot get out of bed.

Reasonable Request

What one company may think is reasonable, another may not. I surmise that most accommodation requests can easily be resolved with little or no effort on the company's behalf. And certainly, alternative fixes can be agreed to.

However, if your wife's requests are greeted as unreasonable, it is time to get creative. In terms of sales, when the customer says, "No," he/she means, "I want more information!" To that extent, a letter from your wife's doctor outlining her needs and why it is medically sound is one way to support her need for accommodations. It's a way to expedite the process and document it too.

What I am about to tell you may seem a little weird, but don't let the law or the employer get in your way. What's most important, I assume, is that your wife wants to continue to work and feels that she can with accommodations. Every company has its jerks who follow company policy to the letter. But, there are always exceptions; common sense and doing the right thing. For example, the chair your wife sits in at her workstation causes physical stress on her back. What she needs is a chair with lumbar support. The company says that they will not do that.

What's more important? The job or the chair? I would assume the job, so ask your employer if bringing your chair in is all right. I know this isn't right, but there is more than one way to skin a cat. If your boss can bring in an easy chair from

home to put in their office so they can sit back, relax and read papers, etc., then you should be able to bring your chair into the office to sit on. I'm sure you will find one in the President or CEO's office. So you pay for a chair, and your wife gets to keep her job with reduced stress. It also reduces your stress. It's all about choices and working with reasonable people for reasonable purposes.

Little things like asking for an ergonomic keyboard are not out of the question. Most companies do this already and do not want the medical costs and downtime of the Carpal Tunnel. It's common sense, but then some managers do not understand that. If that is the case, go buy a keyboard you like and don't say anything to anyone. They don't cost that much. If the company has a policy of not using your personal equipment (keyboard), ask for an exception under the ADA.

How to ask your employer if you need accommodation

Think about "The end in Mind" and a "Win-Win." Your wife's request for accommodations could turn into a new job and promotion based on her needs and that of the company. Probably the worse thing any manager is required to go through is the process of displacing someone due to business considerations. It is never personal, nor should it be taken that way. It is just the reality, especially in large companies. Companies are like a growing organisms. Some cells die as others are birthed. Jobs are ever-evolving. What was a necessary process and service yesterday may well not be tomorrow! Having said that, when one is displaced, it is difficult not to take it in a personal way. Regarding accommodations, I encourage your wife to think positively when approaching her boss. If your wife is a good employee, there is no way that her manager does not want to accommodate your wife's needs and may well come up with alternative solutions you or your wife has not even thought of.

Patty and I have been associated with the Lupus Foundation of America North Carolina Chapter for over fifteen years at this writing, and what we see more often than not is that the fatigue factor your wife is dealing with is the number one reason accommodations are asked for. More and more companies are providing flextime for their employees today. As mentioned earlier, during COVID-19, companies, out of survival, allowed their employees to work from home. As said, it saves the company the cost of facility space. It provides an extra benefit to the employee, which should result in retention as long as productivity is not impacted. As our world has become accustomed to working from home, it is probably a lot easier today to request work from home, either full-time or part-time. Obviously, there are many jobs that working from home is not a viable alternative, but if it is, there is a better chance of approval. Your wife's energy passes: showering, dressing, and driving to work can wipe her out for the day. Flex-time, working from home, can maximize your wife's energy levels for the day and thus her productivity.

There are some downsides to working from home. If your job requires interaction with other employees in the same office to do your job, that is one consideration. I've seen people who work on flex time and have no idea who their boss is or where they are located. They only find out that someone left the company when they send them an email, and it bounces. There is a lot to be said about being in the office, especially for meetings. Unfortunately, most managers do not know how to run effective meetings, which probably makes paying attention more difficult if you are on the phone. But certainly, being able to work at home and periodically required to come into the office for meetings or just once or twice a week to stay in touch with coworkers is a small sacrifice to the company and your wife if she wants to keep her job.

If the company your wife works for does not allow flex time, they may be able to accommodate a different work schedule. For example, come in an hour later so she does not have to fight traffic and leave an hour early at the end of the day so

she can get home quicker. A shorter workday and maybe a rest break in the afternoon will be all the accommodations your wife needs to stay working. I might add that it is good for your wife's mental health and certainly for the company that they are retaining an employee who has job knowledge, company knowledge, and customer knowledge.

If your wife works outside . . .

Working outside does present a problem because the sun is not your wife's friend. It is suggested that those living with lupus should not be outdoors between the hours of 10:00 am ad 4:00 pm because that is when the UVA rays are at their highest. Having said that, and as mentioned before, there is clothing on the market that will protect the skin against the sun's rays (Colabar for one), and good doses of sunscreen (50 SP or higher) and a hat. If your wife's job is physically demanding, she can ask for a less physically demanding job. If she needs more frequent rest periods, she should ask for them. These are not unacceptable or over-demanding requests under the Americans with Disability Act. Remember, the law says "reasonable accommodations."

Part-time work

Part-time work is also a consideration. Will the company allow your wife to work part-time? Because the law is in place, the fear of talking with one's manager should not enter your wife's mind, though I know it is probably there. Your wife has the law behind her, but most importantly, she is just looking for some common sense accommodations, not confrontation, so she can continue to work and contribute financially to your family and/or her emotional well-being.

Other accommodations

Think in terms of your wife's working environment. When she comes to work, does she have to walk a long distance to the entrance? A closer parking space for her will save her energy from coming and going. Does she have a long way, once entering the facility, to get to her workstation? Can her workstation be moved closer to the entryway so she doesn't have to walk so far when entering or leaving the building? How close is she to the restrooms or break room? What would reduce her stress at work, and I don't mean firing the boss? Encourage your wife to think outside of the box.

Protect yourself

Recognize that your wife needs to protect herself depending on the relationship she has with her manager. If your wife sits down with her manager and expresses her need for accommodation, it would make sense thereafter to send her manager an email clarifying her understanding of what transpired during that meeting—two reasons for doing this. First, to clarify that what was shared was understood by your wife and her employer. Two, that if legal action is in the cards down the road, she has documented her request in writing. Your wife can write a letter outlining her circumstances and the need for accommodation and ask for a meeting with her boss. The manager should respect the need for documentation and not question that.

Be specific with your requests. For someone living with lupus, photosensitivity is a real issue and working flex time ranks high on the request list too. But, be specific about what your accommodation needs are.

If all else fails

If the company your wife works for is not accommodating and well-intentioned and she feels she has been treated unfairly, contact the Equal Employment Opportunity Commission (EEOC) and file a complaint. Of course, she is not going to win many friends at the company doing this, but it is her right to do so. In this respect, it would probably make sense to contact a lawyer and get his/her to review the circumstances before plowing ahead. If discrimination is egregious enough, you may want to retain a lawyer to represent you through the process of filing with the EEOC and the company she works for. If your wife's job is terminated due to her disability, know that she has 180 days from her last day on the job to file a complaint with the EEOC. If the company goes out of business and that is the reason your wife has lost her job, it does not constitute a reason to file a complaint with the EEOC.

Conciliation

If your claim has merit, the EEOC will interact with the company in what is called the "Conciliation Process." If the company and EEOC cannot resolve the issue, the EEOC is empowered to bring suit against the company on your behalf and/or advise you that you have the right to sue.

Disability Insurance

Lupus can be a disabling disease to the extent that your wife may not be able to hold down a job. As a caregiver, individuals living with lupus can, at some point, qualify for disability through the Social Security Administration. The process of application and being awarded disability monthly payments is an arduous process and one that requires a lot of patience.

The Social Security Administration does not do anything easy in the sense that just about everyone who applies gets rejected on the first submission. Do not worry about this. Simply reapply and reapply. Perseverance, as frustrating as it might be, will win for you in the long term. I have met many who have given up on receiving disability after their first rejection simply because they did not know how the process worked.

At some point, you will have the opportunity to go in front of an administrative judge who will decide your case. The process is so difficult because there are so many applicants. So keep pushing if you are not getting awarded disability to the extent of asking to see a judge. The good news today is that the Social Security Administration has a better understanding of lupus, the disease, and how debilitating it can be. If need be, there are attorneys who practice in this area. Most attorneys work on a contingency basis, so you do not have too much to lose if you and your wife decide to go that way.

Additionally, you are not penalized for waiting so long to be awarded disability. From the day you're awarded, your disability will be paid from the time you first applied. So your wife will get a lumped sum settlement from which the attorney will take their fee. Make sure that is your understanding with the attorney if you decide to go that way.

The Social Security Office, as part of their process, may well send you to their doctors for an analysis of your wife's health. It takes time. The entire process can take up to two years or more to have benefits approved or to get in front of a judge. So make sure that your wife keeps good records.

How do you find a lawyer?

Simply Google Social Security Benefit lawyers or attorneys. They know how to fight for your benefits and will save you a lot of angst. It may take several months to get in front of a disability judge, but your attorney will go with you and represent you. If your wife knows someone else with lupus who has received disability benefits, she will learn more by hearing their story and what they may have done differently now that they are through the process of acceptance.

It's all about the medical records

You should know as your wife's caregiver/advocate that having good medical records and a complete record is important in presenting your wife's case for disability. Do not rely on your doctors to provide your medical records to the Social Security Disability Administrators. It's your responsibility. If your wife is on her doctor's portal, she should be able to see all of her medical records. However, if your wife has more than one doctor, your wife will need to go to each doctor's portal individually to download documents. If your doctor does not have a portal, then ask the nurse to make a copy. There may be a fee for this from your PCP, hospital, or another specialist.

Here are some key tips that will help you

First, your wife's doctors are her team, and you do not want to change team members if you can help it. Their records will show continuity and length of time recorded under each doctor, such as her Primary Care Doctor, rheumatologist, neurologist, and so on. Also, have your wife use the same pharmacy because they can easily pull up the record of medicines she has been prescribed over the years.

Second, your wife should tell her doctors that she will more than likely be applying for social security disability benefits because she does not have the energy to perform in her job. This is very important because you will probably notice that doctors today, during your wife's visit, update her record online throughout her visit. So, if the doctor says, "How are you doing today?" and she says she feels great, that will show up in her medical records and could make it more difficult to qualify for benefits. I am not suggesting that she lies about it, but make sure the doctor is capturing your wife's health issues properly, and not that you had a wonderful trip to the Bahamas, enjoyed the sun and fun, etc. In other words, your wife needs to be honest with her doctor with respect to how she is feeling.

Third, your wife should keep all of her medical records in a binder in chronological order by a doctor. This binder tells her medical history story and can expedite the process. If she wishes, she can continue this practice after she receives disability, but there is not much benefit to doing so.

Know that what slows up the acceptance process is the administrators at the Social Security Disability Office trying to get her medical records from her doctor and waiting for the entire record to come in before they look at it and move forward in the process. Good record keeping and gathering practices on her part can pay off in saving time and receiving benefits sooner. When she takes her application and medical history in for an examination, she will be well ahead of the game.

If there is any idea that your wife could find herself medically unable to perform at her job, start gathering those records now from her doctors and build that binder of her medical history. Additionally, if there are certain functions or skills that she cannot perform, have her doctor write a letter explaining the same and make that part of her medical record too.

Another option to consider

So, the career may or may not be over. Most people I know do not enjoy what they are doing for a living! If they could be doing something else, they would do it in a heartbeat. So I encourage your wife to think about what she can do at home to earn income. There are many opportunities to work from home as companies look to reduce overhead (brick and mortar) and increase their employed staff. Here are a few ideas to help.

1. Start your own business. With the internet today, anyone can start a new business overnight as long as they have a product or service to provide. Caregivers Wear Plaid is an exercise in precisely that. It is the next and hopefully last step in reinventing myself as I age out of my current occupation. Retirement is not all that it is cracked up to be. I want to stay active as long as I can, and helping others for me is a great way to do it. So, does your wife have a business idea that she has always wanted to explore?

2. The daughter of a long-time friend, who graduated with my daughter when they were in middle school, has a business building websites and supporting online marketing for burgeoning entrepreneurs and on-going businesses. She has two small kids at home, and the cost of daycare, as you may well know, is just out of sight. So working from home and online has been a very profitable business for them.

3. If your wife is good at writing, becoming a copywriter online is a way to make money.

4. Becoming a customer service representative. Many companies allow their CSRs to work from home. Imagine your wife can work in her jammies, and no one will ever know.

Now, the idea is not to tell your wife to get a job. She is sick, and she no longer has the energy to get up early, prepare for work, make the commute, do her job, run errands on the way home, and wipe the kid's nose when she gets there. But I guarantee you that she has the desire to live life to the fullest and whether it is volunteering or building her own business or an online business together. It can bring a lot of freedom and joy to her and yours. Explore the possibilities in a positive way. There is enough negative stuff going on in your life, so make it positive.

Final thought

Depending on your wife's job position and the number of years she has been with her company, in today's employment environment (2019), it has become more difficult for companies to find qualified workers. Job knowledge and knowledge of company standards, policies, and guidelines. Additionally, the interaction with other employees over time (whom to go to when and where), can take many years for a new employee to come up to speed within an organization. This is a value your wife brings to the table and why companies need to have a positive reaction and action to accommodation requests. Not all jobs allow companies to be so generous, but if a company does not take care of their employees long-term, they might not have a company.

CHAPTER 23

The Sepsis Concern

If your wife experiences a severe flare there is a good chance she will need hospitalization. The risk is sepsis!

This is always a touchy subject to talk about because hospitals and their doctors and nurses are there to help you through an emergency, and they do the best they can. Know that while your wife is in the hospital, her Primary Care doctor is not. Hospitals have hospitalists (doctors) who are responsible for your wife's care while she is in the hospital. What the hospitalist is not is a doctor who is very familiar with your wife's medical history as her PCP would be. Your wife's immune system, or lack thereof, makes her very susceptible to Sepsis, an infection in one part of the body that begins to spread to other parts of the body, such as the stomach, lungs, urinary tract, and so on.

Sepsis is potentially deadly and can be averted if caught in time. I have dedicated a whole chapter to Sepsis because "each hour of delay in antimicrobial administration over the ensuing 6 hrs was associated with an average decrease in survival of 7.6%," as noted in Crit Care Med. 2006 June; 34(6):1589-96 released by the National Institute of Health. This chapter will hopefully help you better understand Sepsis, how to identify it, and why you need to react to it as fast as possible.

What is Sepsis?

SEPSIS means DECAY. Infection in the body leaves behind toxins that start this process of decay. Thus early detection of Sepsis is essential to reduce the amount of potential damage to tissue and organs.

The story I am about to tell you is real. Mr. "X's" wife is having some minor chest pain and some pain in her right arm but was not a complainer, and her husband felt it was better to be safe than sorry and brought her to the hospital emergency room. It was determined that she did not meet the first two levels of the hospital's triage (admitting) system, which I will explain to you in a few moments. She appeared to be low-risk and would not be admitted until a bed was available. 2.5 hours later, she was admitted, but tests did not immediately indicate her condition. It was finally determined that she had an issue with a dissection (a tear within the wall of a blood vessel) that was causing her to go into severe Sepsis. Unfortunately, the hospital did not have a doctor available to deal with the emergency, and rather than waiting for a specialist to come in, it was decided to transfer her to another hospital where she could be treated immediately. Of course, all that took time, and by the time she arrived at the transferred hospital, a total of eight hours from originally coming into the ER, she coded (died) before they could get her treatment. Remember, she sat in the emergency room waiting room for over 2 1/2 hours because her symptoms were not properly observed, nor did her husband (caregiver/advocate) know what to do or express what was going on. Keep in mind that Sepsis is an internal body response to an infection that can cause organ dysfunction, among other things, and lead to death in a very short time, i.e., 24 to 72 hours, if not treated properly.

My Patty had a similar situation wherein we rushed her to the hospital by ambulance. This was during COVID, so you can imagine that is the last place I wanted her to be. People were sitting in the parking lot waiting to get in, and the

lobby area was full of people waiting too. Patty's circumstances were such that she was raced back to a room in the ER where we spent the next four days. The ER had 32 beds, of which had nine patients with COVID-19. The ER doctor came in, and thankfully I had our medicine list and doctor notes with me. It did not take long to discover that the ER doctor's wife had just been diagnosed with lupus. Lupus is a lot more prevalent than any of us can imagine.

The first issue we dealt with was that Patty had no idea about anything. She did not know what a pen was or a TV. It was not until the next morning that our hospitalist caught up with us just after an ultrasound. He went through the same routine. He showed her a pen. She did not know what it was. He pointed his finger at me and said, "Who is he?" She had no idea! That was the first that I recognized she did not know me. A subsequent test showed a small brain aneurysm which was easy to deal with if treated immediately. But, this all started with the concern of Sepsis. The hospitalist also mentioned that he wished every patient arrived with the information I had on Patty. It speeds up the diagnosis process real quickly, and too, I was able to stop the doctors from going down different tracks because of my knowledge of Patty's medical history.

Hospitals are required

The issue of Sepsis is so important that as of October 15, 2015, the Centers for Medicare and Medicaid Services, an agency of the U.S. Department of Health and Human Services, now requires hospitals to check for Sepsis when admitting a patient. Why? If your wife has severe Sepsis or sepsis shock, two of the three classifications of Sepsis, there is a 25% to 50% chance that she will not survive, as the story above relates. One out of three deaths in the United States is due to Sepsis (infection). This has become a significant medical issue at hospitals in America. According to ATS 2014 Abstract 50626 and JAMA doi:10.1001/jama.2014.5804, article, "that of all hospital deaths nationally, as many as 52.0 percent were among patients diagnosed with Sepsis. Sepsis

hospitalizations also contributed to 21.2% of all hospital charges." The earlier Sepsis is treated, the better the recovery. Unfortunately, if a person has had Sepsis before, they are more prone to recurrence. This is important for you to know, understand and be aware of the symptoms. Here is where an advocate inserts themselves if and when needed with emergency personnel, nurses, and doctors. In essence, we lost Shellee (as noted in our dedication) to Sepsis as she was dealing with it more often than not. Her official diagnosis of death was a heart attack, but it was the Sepsis (infection) that led to it.

Understanding Sepsis . . .

First, there are three stages of Sepsis. 1) Sepsis, 2) Severe Sepsis, and 3) Septic Shock. For best outcomes, Sepsis must be treated in the first stage. Thus getting your wife to the emergency room early on is important. This is not a "let's call the doctor on Monday morning and see when they can get us in" conversation. This is a "get your wife to the hospital now and get it checked out" action.

What are the signs of Sepsis?

There is a segment of the population that is at higher risk than others. Certainly, those living with an autoimmune disease, such as lupus, can be easily compromised. Cancer patients, patients awaiting transplants, HIV patients are others that are at higher risk for infection. Having said this, everyone who is sick can theoretically get Sepsis. So what are the signs?

According to sepsis.org, the following symptoms are associated with Sepsis. If your wife has recently had an operation, a cut, a cold, an infection, any combination of the symptoms noted next should send up a red flag.

Sepsis Symptoms

S - Shivering, fever, or very cold

E - Extreme pain or general discomfort

P - Pale or discolored skin

S - Sleepy, difficult to rouse, confused

I - "I feel like I might die" statements

S - Short of breath

If your wife's blood pressure drops to dangerous levels, this, along with any of the other symptoms, can indicate that she is in Septic Shock. You should have a conversation with your Primary Care Doctor with respect to the above and what he/she recommends.

WARNING

It is not easy not to overreact. You need to know your wife and her particular symptoms and history. For example, your wife could have Asthma, and her breathing problem is a normal occurrence. Because fatigue is a constant with people living with lupus, her being "sleepy" is very normal too. Shivering, fever, very cold, extreme pain or general discomfort, pale or discolored skin is a big **RED FLAG** that more than likely warrants action. Your wife will know something is wrong, just not what! As a caregiver/advocate, discuss this with your wife's doctor and follow his/her advice.

What can you do to avoid Sepsis?

There is no way other than to use common sense in being careful; to ensure that you wash your hands, use good hygiene practices at home, do not kiss your wife on the lips if you have a cold or think you are getting sick . . . common sense, which might not be so common in some folks today. If you are against getting the flu shot, get it, as she should too. Vaccinations are important to reduce the chance of getting sick, and normally if the vaccination does not totally work, it often results in a milder case if you had not been vaccinated. Again, check with your doctor on this and any other advice he/she may have.

Admitting to the hospital criteria

If you suspect your wife has Sepsis, you are in the emergency room, and admission to the hospital is taking time, you can usurp their uncertainty. Simply state the obvious: "I think my wife has sepsis!" You know whether this is her first event or not, and you now know the symptoms of Sepsis.

Admittance criteria

Hospitals admit patients based on a criterion called ESL, which stands for Emergency Severity Index. This is a five-level triage process designed to clinically evaluate a patient into one of 5 groups. Group number 5 is the least urgent, and depending on the amount of time one waits in the emergency room's waiting room will give you a pretty good idea of what group you are in. If this is missed diagnosed during admission to the hospital, it can result in tragic circumstances, as mentioned earlier.

Group 1 is heart attack and needs immediate life-saving attention. This is a heart attack, gunshot, severe respiratory distress, acute mental status changes, or the individual is simply unresponsive.

Group 2 asks for three observations:

- Is this a high-risk situation?

- Is the patient confused, lethargic or disoriented?

- Is the patient experiencing severe pain or distress?

Depending on the answer to those three observations, Group 2 requires a determination to be made on how many resources are needed to provide service to the patient. Resources mean labs, IV fluids, medications, simple procedures, etc. In addition, if many resources are required, then the patient's vital signs are important to consider if the patient is to be in Group 2 or not.

Group 3 means there are many danger signs to the patients' vital signs.

Group 4 says there is one resource needed, and

Group 5 means that there are no resources needed. Based on what group you are in depends on whether or not your wife gets the next available bed in the ER.

As your wife's advocate, and caregiver, it is important to express what you know is going on if, in fact, you do. She has had previous episodes, or she got up quickly, and all of a sudden did not feel well and started having chest pains and pain in her right arm. Whatever the symptoms expressed help the triage nurse begin the process of getting a better understanding of what she and the ER are dealing

with. We sometimes think doctors are magicians, and in some cases, they perform some pretty miraculous work. But they do not read minds, and they need to look at every possible datapoint they can get their hands on to make an educated guess on what is going on. This might require a CT scan or an MRI, labs, etc.

The key here is to get admitted as fast as possible. The longer you and your wife sit in the ER waiting room, the greater the potential risk is to her health. So you do not want to be sitting in the waiting room for a couple of hours with your wife going into Sepsis shock.

Tips

This may seem a little obvious, but if at all possible, get your wife to the emergency room by ambulance. Hospital personnel tends to be more proactive/immediate in initial care when brought in on a gurney versus arriving in a wheelchair or walking in.

If you decide to "walk in," know that some hospital emergency rooms are busier than others. Going to a local Urgent Care facility could expedite circumstances. They can check on emergency room availability, can direct you to the ER with the shortest wait time, and alert the emergency room that you are on the way. So think through this. If you think your wife has Sepsis or another medical issue pops up, where are you going to go. Of course, this assumes that there is more than one hospital in your area that you can go to. And if it is an emergency, do not worry about whether it is in-network or not unless it affects your insurance. Time could be of the essence. You should think through these scenarios beforehand to minimize some of the stress associated with such an event.

The Insurance Game

Over time we have noticed that once the hospital knows we have good insurance, the experience and experience of care improves significantly, i.e., more than just Medicaid or Medicare. We have also noticed that just about every test under the sun is run once our insurance has been approved. I know you may find this hard to believe, but most hospitals are dealing with the ongoing management of potential financial disaster. It is an expensive business to run, non-profit or not. It is also a business wherein 45 to 50% of patients do not have adequate insurance to cover the real cost of tests, doctors, nurses, facilities, and supporting staff, and yet the hospital is required to provide service.

Long-term effects of Sepsis

Many will experience psychological and physical effects of having Sepsis. 50% of those diagnosed, the effects are long-term. Psychologically, insomnia, nightmares, panic attacks, poor concentration, cognitive issues, and low self-esteem are probable. On the physical side, the effects of extreme fatigue are apparent, as well as severe muscle and joint pain, weight loss, and breathing effects. This is not fun stuff. Weight loss is of particular concern because if your wife does not have an appetite, is not eating, or only having small amounts of food, sleeping the day away to where she is eating less . . . this can all add up. Often, when Patty is not hungry, I will give her a 1/2 sandwich just so that I know she has eaten something. Food is the fuel required to generate energy, and that is needed for her recovery. So far, her lack of appetite is not sepsis-related, but it tells me something else is going on in her that needs a watchful eye. Individuals with Sepsis can take months to come back to what, for them, is normal. This is serious stuff.

Thus the urgency of care. The quicker the Sepsis is treated, normally the better the outcome. The University of Michigan performed a study in 2012 which showed that Sepsis survivors had a higher risk of developing lung infections as well as kidney and liver involvement. If the doctor suspects your wife's Sepsis is severe, she will more than likely be placed in the Intensive Care Unit (ICU) at the hospital. A 2013 Johns Hopkins study suggests that those with severe Sepsis admitted to an ICU have a much higher probability of developing PTSD.

How prevalent is Sepsis in individuals with lupus?

Individuals living with an autoimmune disease, such as lupus, appear to have a higher rate of infection, such as pneumonia and Sepsis, as well as urinary tract infections, etcetera, than the general population. Some studies show that it can be as much as 12 times higher. Early diagnosis is imperative with respect to getting treatment that reduces the risk of short-term and long-term effects. Mortality in SLE patients accounts for about 13% to 37% of hospitalizations and one-third of deaths. There is an 8% increase in the risk of death for every hour that treatment is not given.

I've probably 'Sepsis'd' you out with this chapter, but the last time I saw Shellee alive, I was walking into a hospital to meet with a client, and she spotted me at the door. She was there for a follow-up with her doctor for her Sepsis. It was the last time I talked with Shellee and saw her alive.

CHAPTER 24

Family, Friends & Neighbors

It is sad to say that many of your friends, neighbors and even relatives, other than direct family, will have a tendency to fade away. "Why?"

Your wife does not look sick, especially when seeing others than you and your children if you have any. It's more than vanity that each of us wants to look our best when we are with other people, going to the store, or visiting with family, friends, neighbors, and relatives. But recognize that often this interaction takes a tremendous amount of effort on your wife's part resulting in another level of fatigue that she will cover up well until you are on your way to or arrive back home. Again, she only has so many Energy Passes each day to use. I'm amazed at how well Patty handles this, and then when she gets back in the car, she is exhausted. It's not for a sympathy vote. She has exerted the extra effort to appear normal to otherwise normal feeling people. Of course, they can be doing the same thing. Everyone in the company of others tries to put their best foot forward, as the saying goes.

Friends and neighbors will begin to shy away from inviting you over for dinner or a party simply because your wife does not have the Energy Passes available on that day to go. "I'm sorry, but I am not feeling well, and we will not be able to come!" The one thing your wife would love to do is go, socialize and be part of the fun, but she is not always capable of doing so. A friend with lupus had a neighbor invite her and her husband for dinner three months out, believing that if she gave them enough lead time, she would be able to come. It has nothing to do with time but how she feels on that particular day. Lupus is really an ordeal when it comes to the lack of energy, which manifests itself as fatigue. It is not uncommon over time that your current friends will begin to disappear under the assumption that your actions, canceling invites, means you do not want to be friends anymore. This can

be very frustrating to your wife and you, but realize that if your "friends" have not been made aware of your wife's lupus, their action is somewhat understandable. If your friends have been made aware of your wife's circumstances and begin to fade away, I suggest that you are lucky. They probably weren't good friends in the first place! Actions, unfortunately, sometimes rule over words of understanding. It is better to forgive than to allow these emotions to eat at you. Easier said than done, and as much as being excluded, other friends will be gained if you reach out, especially to those dealing with similar circumstances. There should be no pity party here. Lupus is not your wife's fault, and the loss of "friends" should not be ignored. It is better to forgive them than to allow them to cause more stress in your life. If your wife has a best friend who sticks with her through thick and thin with this disease, she and you are most fortunate. I may also suggest that your wife's lupus is not something that should be kept from friends. Their understanding of why you and your wife cannot always attend their events will often reduce misunderstandings.

An Extended family is probably the most difficult to deal with. No one wants to accept that someone in their family is as sick as your wife, especially when she does not appear to be sick. All kinds of negative thoughts go through their minds, I am sure, because they do not understand this disease or its consequences. "And after all, how could anybody be this sick in our family. You're too young to be this sick, so it must be something else you're covering up!" they think. It is not like your wife broke her leg and would be in a cast for six or more weeks, and when the cast comes off, she is back to normal. "Can I sign your cast? Can I get anything at the store for you?" Because the injury is visible, it is easy for people to associate the appropriate reaction. But with lupus, your wife does not look sick unless she has Discoid Lupus (Facial Rash), which is visual. To the average person, this is perceived as a dermatologic issue and not a potentially life-threatening disease if it evolves into Systemic Lupus Erythematosus (SLE).

What is the alternative? Over time your/her family will hopefully come to accept the realities of lupus and even get involved in supporting the mission to find a cure.

I know this part of the book has been mostly about your wife. But be assured, I will talk about you and your friends and the importance of living your life, too, especially as your wife becomes more dependent on your role as a caregiver. It is workable. What is important here is that you and your wife live the best, fun-filled, purposeful life you can in the time you have together. When Patty and I got together after 40 years of not seeing one another, we hoped that she would be well enough and active enough for her to reach 65. At this writing, Patty is 79, and though her health challenges are progressing, we are hoping for many more wonderful years together, as challenging as they may be.

It's nice when neighbors come over and ask how Patty is doing. I'll ask Patty if she can take some company, and more often than not, she will say, "Yes." Tucked in her recliner in her jammies with a blanket over her, the conversation becomes a social interaction that she needs. Patty does not see the need to get dressed for these occasions, though it certainly would be her preference. Of course, it does not take long for her Energy Pass to abate, but the interaction is good for her and her soul. Sometimes the impromptu social gatherings are good.

After COVID was less of an issue, I started holding driveway parties for the neighbors. In an old fashion cookout where neighbors would bring a dish, and I would cook hamburgers and hot dogs, Patty would sit in a comfortable chair and enjoy meeting new neighbors and old alike as evening drew its curtain. Everyone seems to want to catch up with Patty and just have a general conversation with her. It makes for a good evening.

Living with someone who has lupus is not a sentence to a lesser life. On the contrary, I profess it is the impetus to a better, more rewarding life. I am a far better person today than I would have ever been if it was not for Patty's lupus and our involvement with this disease. Do I wish she did not have it? You bet! But we are dealing with it the best we can, together, in support of one another. As her caregiver, Patty realizes the importance that I need to remain as healthy and mentally positive as possible to be there for her. I'll talk about what that looks like in Chapter 27 - Don't Feel Guilty.

You need to know that countless individuals are living with lupus who are in remission through the mystical course of this disease or by the medicines they react to positively. There is one special lady who has been so sick with lupus that her parents gave her a trip with friends to say goodbye because the prospects of her living much longer were not good. Today she is back from the brink of death, fulfilling her life and that of her young son, too, all because of a drug trial that she insisted on being part of. So there is hope. Unfortunately, her husband did not have the fortitude, courage, and love to stay around for her or his son. She is fortunate to have a loving and supportive immediate family and boundless friends who know and understand her story, her trials, and living with lupus.

Lessons learned

When your wife asks you do to something, don't complain about it. "Just do it!" as Nike says. Most of what she will ask are simple little requests that do not take much time. It's those little requests that, when not complied with, can result in stress for her and thereby stress for you, if you get my drift.

Use 'moments in time.' So much can be accomplished in small bites of time, such as normal household chores. Dusting, cleaning a toilet. It is a matter of attitude.

When I was a young boy, I was fortunate enough to go away to a private school. All new students had to show up a week early for orientation. Part of that process was being given a job to do. Mine was to clean the latrine on the floor my room was on. If you did a good job, you got dessert at dinner. If you did not, then you watched all those who had done a good job eating their dessert. When I first saw the latrine, it needed a good cleaning as it had been ignored all summer long. It took a lot of work to get it in shape enough so that I got my dessert. I was driven to make a good impression, and I took great pride in cleaning the latrine to perfection. Of course, dessert was on my mind as it was usually the only good thing on the menu. Within a couple of days, I had gotten down to a system that was very easy to maintain every day. Several weeks later, I was taken off my latrine duty and given a classroom to keep clean. I wasn't initially a happy camper, but my desire for dessert overcame my reluctance quickly.

Fast forward many years, and I found myself in basic training in the Air Force. I was always told that if you go into the military, never raise your hand and volunteer for anything. When our Technical Instructor gathered us around and said, "who wants to do latrine duty?" I raised my hand to the chuckles of many around me. I knew how easy it would be and that it was. The rest of my comrades would drag their butts in at the end of the day and race for the showers, exhausted. I had it easy because I made the job a simple process. And that is what I am suggesting to you is to do the same thing. Accept what needs to be done and do it knowing that your wife wishes to dust, vacuum, do the shopping and cooking, make the bed, and, yes, clean the bathroom. You are now living in a 'new normal' that you more than likely have been adjusting to. It seems that that is a never-ending process as your wife's limitations become worse. The other side of

this coin is that you make enough money to have someone come in and clean once a month, but even then, there will be cleanups to do.

When it comes to your friends, if you are a pleaser, then you need to learn how to say "No." It's not easy to do, but sharing "the why" makes it a little easier. In other words, check with your wife before making any commitments.

If you find yourself at a party or event that is being held outdoors, whether it is sunny or cloudy, do not let your wife stay outside too long. UVA rays can easily come through the clouds, sneak under an umbrella, and so on. You do not want your wife going into a flare for a few forgotten moments of where she is and the damage it can do.

Whether your wife wants others to know that she has lupus, friends, immediate family, and other relatives need to know what is going on. Why? There is a genetic component to lupus, and if others in the family are experiencing similar symptoms, even though their health has not totally upended their world, they have an inkling of what might be going on in their body. The earlier the diagnosis, the better the outcome? We hear that, but with lupus and other autoimmune diseases, one never knows. Inflammation leads to a breakdown in whatever is inflamed. So it makes sense to reduce inflammation quickly, as expressed in the chapter on Sepsis. Additionally, the more your friends, family, and relatives know, the more they are inclined to understand your wife's limitations. The other issues pertaining to your wife and your decision not to share your wife's disease with others should be honored. However, you may very well find that both of you will rapidly withdraw into a negative place that neither of you wishes to be.

Little things can make a big difference. When we go out to shop or travel in the car, Patty sits on a cushion from one of the chairs in our breakfast nook. It makes

her more comfortable. We also have a foam padded pillow that she uses with her wheelchair when we go see a doctor or go shopping at a department store, and so on. Talking about wheels, when Patty is not using her cane and needs to get around, we use a walker with wheels (Rollator). It's a lot easier on her back. We have found a travel chair made by "Drive," which is easy to fold and put in the trunk of our car and easy for her to navigate. It also comes with a seat, so if she needs to sit down and rest, it is right there for her to do so.

As her lupus and other co-morbidities progressed, Patty stopped using her cane and became reliant on the Rollator (walker with wheels) and the travel chair when she went to physical therapy, the doctor, and her hairstylist, out to dinner, etc. As mentioned before, it does not take much for most living with lupus before fatigue sets in. For example, it is a ten-hour car trip when we travel to see our son in Alabama. Often we will stop halfway for the night, but the trip is tiring for her. Once in Alabama, Patty needs a full day of doing nothing to regain her strength. Going to physical therapy will exhaust her for most of the day. Thus, expect over time, especially if your wife has been diagnosed with other diseases (remember, one begets another), that her health will decline and require more of your time to be there for her.

In the next chapter, I will give you an idea of the types of medicines your wife will most likely be on. No one pill is going to make your wife whole. The mystery widens as patients learn that what works for one does not necessarily work for another. Of course, steroids always seem to have a positive effect, but they come with a lot of baggage emotionally and physically. Additionally, if your wife has diabetes, make sure that doctors are aware as steroids can significantly increase her blood sugar. A circumstance that can take months or more to get under control.

CHAPTER 25

Medicine

The average lupus patient is taking at least 8 medicines per day.

You will come to learn that most drugs prescribed for lupus were never developed for lupus treatment. In 1948, the FDA approved aspirin as a treatment for lupus. Not far after came Prednisone and then Plaquenil, which was developed for Malaria in 1955. The first drug-targeted therapy for lupus, Benlysta, was approved by the FDA in 2011.

There are different classes of drugs used in the treatment of lupus. In this chapter, we will provide a basic overview of what they are and what they do. Fortunately, these drugs require prescriptions from a doctor, so you just can't run to the pharmacy and fill your cart up. Most importantly, if these drugs are not used under the care of doctors' guidance, the results can become dangerous to your wife's health. In other words, your wife needs to follow instructions.

As previously discussed, any medicines being prescribed by doctors other than her Primary Care Doctor should be routed through her PCP as the gatekeeper. Of course, if her rheumatologist or other doctor changes a medicine, ask them to notify your PCP. If they are unwilling to do that, make sure that you or your wife does it. As suggested earlier in this book, one disease begets another, and your wife may find herself on a large daily protocol of medicines. Medicines can have significant negative interactions and or cause additional medical problems. This is another reason for your wife to keep all her medicines prescribed at one pharmacy because your pharmacist will be able to see these interactions too and possibly

question the doctors' orders. That's part of your medical team working in your wife's best interest.

There are several classes of drugs your wife will see prescribed as her lupus progresses or hopefully goes into remission. They are Corticosteroids, Antimalarials, and Immunosuppressants.

Corticosteroids

Corticosteroids are a group of drugs that are very useful in treating medical conditions, such as lupus. You have probably heard of cortisone, and then there is hydrocortisone and Prednisone.

Prednisone

This drug is magical, but it is also often referred to as the "Devil's Tic Tac" and "Making a Deal with the Devil." Prednisone is usually the initial go-to drug of choice for doctors. 1) it suppresses inflammation, 2) lowers an out-of-control immune system, and 3) it is a very inexpensive drug if you do not have insurance.

So what does Prednisone do?

Prednisone suppresses inflammation due to an imbalance of hormones in your wife's body. These hormones are produced naturally in her adrenal glands. When Prednisone, which mimics the effects of hormones, is introduced in an amount that exceeds normal body production, the resulting effect will decrease inflammation and reduce the symptoms of lupus and other diseases such as

Arthritis, Asthma, Addison's, and many other diseases. It's an amazing medicine, but it definitely has some serious side effects.

Why is Prednisone referred to as "The Devil's Tac Tac" or "Making a Deal with the Devil"?

The side effects of Prednisone can be significant, and probably the worst for a woman is weight gain. Extreme anxiety, depression, fluid retention, high blood pressure, a racing heart, mood swings, energy bursts, and trouble sleeping will create chaos emotionally, mentally, and physically. These are by-products of medicine that should not be ignored and why your wife should follow doctors' orders and prescriptions guidelines. Most importantly, you need to know what you can expect when your wife is on Prednisone. She will have an energy boost, and you might think that she is going a little crazy sometimes.

So why is the drug magical?

It can save your wife's life and significantly reduce symptoms. However, it is not a drug one wants to be on for long periods of time. Using Prednisone over an extended period can result in osteoporosis, the loss of bone mass that leads to a weaker skeleton, and thus potential injury. This is not hyperbole. We know individuals who are dealing with this issue.

WARNING: Do Not Stop Prednisone Suddenly!

Everyone's body reacts a little bit differently to drugs. It's the mystery of our body, so when your wife's doctor prescribes Prednisone or any other drug, it may take time to adjust the dose to the desired results. If this process occurs and

becomes frustrating to your wife, the statement: "I'm just stopping prednisone now!" is not a good course of action. Prednisone needs to be weaned off; otherwise, it could cause a serious medical issue. So make sure she contacts her doctor before any action is taken.

WARNING: If your wife is on Prednisone, she should not receive a "live" vaccine. It can present serious reactions, including death. Make sure your doctor knows what medicines your wife is on prior to prescribing. On the face of that, the last statement may seem a little ridiculous, but your wife's doctor should also know what over-the-counter medicines she is on as well as medicines prescribed (new) by another doctor. Another reason why your wife's PCP is her gateway. If your wife starts exhibiting severe symptoms after taking a "live" vaccine, such as shortness of breath, stomach pain, or a significant change in her personality, contact her PCP immediately.

- **Hydroxychloroquine** (Plaquenil) Hydroxychloroquine is a drug that was originally developed to fight Malaria. What this drug may do is reduce the risk of a lupus patient contracting a serious infection. Because it has relatively few side effects in comparison to Prednisone, most persons living with lupus prefer this drug as the alternative.

- **Cyclosporine** (Gengraf, Neoral, Sandimmune) is an immunosuppressant medication

- **Azathioprine** (Azasan, Imuran) is another immunosuppressant medicine normally used in conjunction with other medicines to suppress the immune system in transplant operations. Since your wife's immune system is an enemy to her health, using immunosuppressant drugs helps reduce the risk of flares and the progression of the disease. These drugs also work on blocking heightened immune responses to tissues that can affect the heart, kidneys, and bone marrow.

- **Cellcept** is another immunosuppressant drug.

Monoclonal antibodies

• **Benlysta** - In 2011, Benlysta, a Monoclonal Antibody Therapy, became the first drug in 50 years to be approved by the FDA for lupus. It is not a steroid but rather a biologic therapy that can reduce certain cells, most notably Blys, in the immune system, thereby reducing the occurrence of lupus activity. Benlysta is given by infusion or injection and is very expensive. For those on Medicare, 95% of the cost is covered under Part D. Of course, there are deductibles, the donut hole, and other considerations. Benlysta is not considered medically necessary if a lupus patient has severe active lupus nephritis (kidney disease) or severe active central nervous system lupus.

• **Saphnelo** - was approved in 2021 for systemic lupus erythematosus (SLE). There are a lot of "Don't Use" warnings with all medicines. And Saphnelo is not used for severe active lupus nephritis or central nervous system lupus. So again, check with your doctor and, more preferably, your rheumatologist for guidance. There is no way a book like Caregivers Wear Plaid can keep up with new medicines and options to treat the various forms of lupus. We recommend the Lupus Foundation of America atat:https://www.lupus.org/resources/medications-used-to-treat-lupus

Talk to your doctor and rheumatologist about Benlysta and Saphnelo. If the cost of treatment is a consideration and/or your insurance company will not cover it, know that most pharmaceutical companies today have assistance programs for their product.

If your wife does not have a rheumatologist, have your doctor refer immediately. A rheumatologist is primary to your wife's care.

Doctors are always careful with what they prescribe because there are always potential adverse effects that can cause more issues than intended. So again, follow your rheumatologists' guidance if your wife's lupus becomes severe enough to be this proactive. Your rheumatologist has many more years of experience than your PCP, which you and your PCP will rely upon for proper guidance.

NSAIDs - Non-steroidal anti-inflammatory drugs

NSAIDs include over-the-counter medicines, such as aspirin, ibuprofen (Motrin), and naproxen. There is a whole list of prescription NSAID medicines that are made up of names that neither you possibly nor I for sure I can pronounce.

WARNING: It is important to note that if your wife has kidney involvement with her lupus or other autoimmune diseases that, NSAIDs are not recommended. Again, she should check with her PCP first.

It is also important to note also that as new drugs are developed and considered for the treatment of people living with lupus or other diseases, most doctors do not like to be "first in!" In other words, they do not want your wife to be the test case for the drug and deal with the side effects. The drug may be far less beneficial than its original intent. Pharmaceutical companies do run trials, and they are always looking for persons to participate. That is a personal choice on whether to participate and whether your wife qualifies specifically for what the trial is looking for. For example, if your wife has been on one particular drug for her lupus the trial may use that as a differentiator with her qualifications to participate.

Rituximab

Rituximab, or Rituxan, is a drug that causes us great concern because though it can decrease joint pain and swelling, it is more of a cancer drug. It is used in conjunction with methotrexate. Unfortunately, the risks associated with this drug have potentially severe side effects, such as problems with vision, speech, and walking, which are all related to the brain. And Rituxan can also cause severe skin rashes and mouth sores, which are symptoms of lupus. So why take a drug that is going to cause these types of symptoms in the first place? The answer is that one's lupus is so severe that other therapies are not working; this is a last-ditch effort. Keep in mind that your doctor is trying to do the best they can for your wife, and in doing that, they look to all options in their toolbox. Most doctors are very cautious because there is always the possibility of unintended consequences. Patty's Acquired Statin Induced Myotonia (ASIM), a very painful condition that is characterized by the tensing and stiffness of skeletal muscles, is an example of that. Being put on statins due to heart problems in Patty's family history led to (ASIM), which has added another dimension to Patty's health issues. So there are unindented consequences. Patty's doctor removed her from statins after she complained about muscle pain. The damage had been done, and it took over two years before we got to Duke University, where a diagnosis was made in one day. Unfortunately, Patty fell into the 10% of people who do not respond to treatment or naturally get better from getting off statins. The last effort to help Patty would be Rituximab, which she refused to take. One other person with a similar situation elected to take Rituximab with the result that her disease activity worsened. Whether it was due to Rituximab or not is another question.

There are also good reasons that your doctor will suggest Rituximab as a lupus treatment but consider it carefully. Again, Patty and I are not doctors but know that the ultimate person responsible for your medical care is your wife and you as her advocate. So get educated on this and other drugs, Know what you are dealing with in respect to the good, the bad and the ugly.

What is the alternative to medicine?

The key is to reduce risk!

As mentioned before, no person changes their old ways to seek the new until they personally find a reason to do so. The Five Stages of Acceptance (See Chapter 12) often justify emotionally and mentally not doing what is in one's best interest. A key to your wife living a better, more normal life is to change those habits that are not in her best interest when dealing with a systemic autoimmune disease. It takes only 21 days to change an old habit into a new habit. Obviously, that is easier done than said, but when the mind is ready, so too will be the action. We see it with people who go on diets and lose 50 pounds, and we see it in people who are sick and will benefit from changing or adjusting their lifestyle to improve the possibility of getting better or remaining better. Here are a few things your wife can do to maintain a balance in her disease. However, realize there is no finite, but a lot of common sense.

If your wife is a drinker, know that when mixed with medications, it can result in a cocktail of unintentional medical issues. She should get enough rest, exercise on a regular basis, eat a balanced diet, stay out of the sun as much as possible, quit smoking, follow her doctors' advice, and treat any medical issues that pop up, especially a fever. The process of reducing stress is something that you as the caregiver can help with as well as your wife, by attending a support group for caregivers but also a support group for the disease you are dealing with. There is nothing wrong with asking for help from others with like circumstances. You will learn a lot and feel better about your circumstances.

Current Medications

Medication Name	Sig Desc	Last Refilled
Tumeric	take one daily	
tramadol 50 mg tablet	take 1 tablet by oral route every 6 hours as needed	
Synthroid 75 mcg tablet	take one at night	
Prednisone 5 Mg Tablet	TAKE ONE TABLET BY MOUTH PER DAY OR AS DIRECTED (MAX 4 TABLETS PER MD)	06/25/2018
Plaquenil 200 Mg Tablet	TAKE 1 TABLET BY ORAL ROUTE 2 TIMES EVERY DAY	07/06/2018
Pilocarpine Hcl 5 Mg Tablet	TAKE ONE TABLET BY MOUTH THREE TIMES A DAY	07/03/2018
omeprazole 20 mg capsule,delayed release	take 1 capsule by oral route every day before a meal	
OMEGA-3	take 2 daily	
multivitamin tablet	take 1 by Oral route every day	
lovastatin 40 mg tablet	take 1 tablet by oral route every day with the evening meal	
loratadine 10 mg disintegrating tablet	Administer LORATADINE 10 mg PO pre-infusion (BENLYSTA).	
Lasix 20 mg tablet	TAKE 1 TABLET BY ORAL ROUTE EVERY DAY AS NEEDED AS NEEDED	07/31/2018
Hydroxyzine Hcl 25 Mg Tab	TAKE ONE TABLET BY MOUTH THREE TIMES A DAY AS NEEDED	07/31/2018
Folic Acid 1 Mg Tablet	TAKE 2 TABLET BY ORAL ROUTE EVERY DAY	02/08/2018
CellCept 500 mg tablet	take 1 Tablet by oral route 2 times every day	
BROMELAINS	take one daily	
Benlysta 400 mg intravenous solution	Administer BENLYSTA 10 mg/kg in 250cc NS IV in 250cc NS over 1 hour every 4 weeks	
BD Pre-Filled Normal Saline injection syringe	Administer NORMAL SALINE FLUSH 100 cc IV with infusion (BENLYSTA).	
amlodipine 10 mg tablet	take 1 tablet by oral route every day	
ALBUTEROL SULFATE HFA 90 MCG/ACTUATION AEROSOL INHALER	inhale 2 puff by inhalation route every 4 - 6 hours as needed as needed	06/07/2017
acetaminophen ER 650 mg tablet,extended release	Administer ACETAMINOPHEN 8 HOUR 650mg PO pre-infusion (BENLYSTA).	

Education

You and your wife need to get educated about her disease as much as you can. Following the suggestions in the previous paragraph can reduce inflammation and thereby the level of the disease. On the next page is a sample list of medications

one lupus patient is taking to control her disease. It is through no fault of her own that her lupus is this severe. The good news is that she is doing better. There is no assurance that following the aforementioned will result in a better quality of life, but it is pretty well recognized that if a person with lupus follows their doctors' advice that their overall health will be a lot better than if they did otherwise. We assume this is true with any disease.

The average medicine cost for a person living with lupus who does not have good insurance can exceed $2,000 monthly, and that does not include Benlysta or Saphnelo. On the next page is an actual printout of a lupus patient's medicine list. Keep in mind that the list for your wife will change as her medicines are adjusted.

Immunizations

WARNING

It is amazing how we pick up things when talking to others about lupus and other autoimmune diseases. We are at a Fall Festival in the Village we live promoting our book, Caregivers Wear Plaid. A lady comes up to our table and, while talking to her, mentions a friend, who has an autoimmune disease, given a live-virus Shingles shot. As mentioned before, most all live-virus vaccines should not be given to a person with a suppressed immune system for obvious reasons. One’s compromised immune system does not have the ability to fight off a live-virus vaccine as easily as someone with a normal-acting immune system.

The friend, the lady, was referring to indicated that she now cannot hear out of her left ear due to her live-virus vaccination? I end that sentence with a

question mark because there always can be other factors. Such as, the lady had Shingles in her ear, and the damage was done before the vaccination.

Make sure that your wife and/or yourself check with your Primary Care Doctor before getting vaccinated. Interestingly enough, vaccines are designed to 'teach' one's immune system how to reject germs if they get into your system. One's immune system may very well fight off a germ, wherein another person will have difficulty fighting it off due to a suppressed immune system.

WARNING

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system. One's immune system may very well fight off a germ, wherein another person will have difficulty fighting it off because of a suppressed immune system. There are four types of vaccines.

- Live-attenuated vaccines
- Inactivated vaccines
- Subunit, recombinant, polysaccharide, and conjugate vaccines
- Toxoid vaccines

It's the live-attenuated vaccines that will put your wife at the greatest risk. Attenuated means weakened, and normally 1 or 2 vaccinations of a live, weakened virus are all that one needs for a lifetime of protection for most diseases, such as Measles, Mumps, Rubella (MMR combined vaccine), Rotavirus, Smallpox, Chickenpox, and Yellow fever. However, Flu is a different story. A live-attenuated vaccine administered to someone with an autoimmune disease can have serious repercussions.

The Intranasal Influenza Vaccine, which is a live-attenuated vaccine (FluMist), is a spray form inhaled through the nose. This spray is normally given to young children and not adults. Interestingly, the live, weakened flu virus remains only in the head. "As a precautionary measure, recipients of intranasal LAIV (FluMist) should avoid close contact with severely immunosuppressed persons for seven days after vaccination." (www.clinicalkey.com - General Information on Immunization against Influenza.

Check with your Primary Care Doctor. He should recommend an inactivated-virus product versus a live-virus vaccination. If your wife has not been diagnosed with an autoimmune disease but has the many symptoms of

an autoimmune disease, such as fatigue, headaches or muscle aches, painful or swollen joints, and so on, do not get a live-virus vaccination.

Today the flu shot is being offered at pharmacies, and other retail locations, besides that of your primary doctor. They will have a form to fill out that asks many of the questions that can determine whether or not it is safe for you to get a live-virus vaccination. Do not lie on this form. Doing so can have serious medical ramifications if your wife is severely immunosuppressed.

SECTION B The following questions will help us determine your eligibility to be vaccinated today.

All vaccines

1.	Do you feel sick today?	☐ Yes	☐ No	☐ Don't know
2.	Do you have any health conditions, such as heart disease, diabetes or asthma? If yes, please list:	☐ Yes	☐ No	☐ Don't know
3.	Do you have allergies to latex, medications, food or vaccines (examples: eggs, bovine protein, gelatin, gentamicin, polymyxin, neomycin, phenol, yeast or thimerosal)? If yes, please list:	☐ Yes	☐ No	☐ Don't know
4.	Have you ever had a reaction after receiving a vaccination, including fainting or feeling dizzy?	☐ Yes	☐ No	☐ Don't know
5.	Have you ever had a seizure disorder for which you are on seizure medication(s), a brain disorder, Guillain-Barré syndrome (a condition that causes paralysis) or other nervous system problem?	☐ Yes	☐ No	☐ Don't know
6.	**For women:** Are you pregnant or considering becoming pregnant in the next month?	☐ Yes	☐ No	☐ Don't know

For chickenpox, MMR® II, shingles, Vaxchora®, yellow fever only:
Only answer these questions if you are receiving any vaccinations listed above.

7.	Have you received any vaccinations or skin tests in the past four to eight weeks? If yes, please list:	☐ Yes	☐ No	☐ Don't know
8.	Do you have a condition that may weaken your immune system (e.g., cancer, leukemia, lymphoma, HIV/AIDS, transplant)?	☐ Yes	☐ No	☐ Don't know
9.	Are you currently on home infusions, weekly injections such as Humira® (adalimumab), Remicade® (infliximab) or Enbrel® (etanercept), high-dose methotrexate, azathioprine or 6-mercaptopurine, antivirals, anticancer drugs or radiation treatments?	☐ Yes	☐ No	☐ Don't know
10.	Are you currently taking high-dose steroid therapy (prednisone > 20mg/day or equivalent) for longer than 2 weeks?	☐ Yes	☐ No	☐ Don't know
11.	Have you received a transfusion of blood or blood products or been given a medication called immune (gamma) globulin in the past year?	☐ Yes	☐ No	☐ Don't know
12.	Do you have a history of thymus disease (including myasthenia gravis, DiGeorge syndrome or thymoma), or had your thymus removed? (yellow fever only)	☐ Yes	☐ No	☐ Don't know
13.	Do you have a history of thrombocytopenia or thrombocytopenia purpura? (MMR® II only)	☐ Yes	☐ No	☐ Don't know
14.	Have you consumed and food or drink in the last hour? (Vaxchora® only)	☐ Yes	☐ No	☐ Don't know
15.	Have you taken antibiotics in the last 14 days or antimalarials in the last 10 days? (Vaxchora® only)	☐ Yes	☐ No	☐ Don't know

Inactivated vaccines - also referred to as "killed vaccines," are grown in a culture wherein the virus, bacteria, and other pathogens' infectivity is reduced through heat or other treatment but still provides a level of protection against the virus and so on. This is the normal vaccination given annually for Influenza.

If you are interested in learning more about vaccines, such as subunit, recombinant, polysaccharide, and conjugate vaccines and toxoid vaccines, go to: https://www.vaccines.gov/basics/types.

If your wife is on other medicines that are not noted in our book, certainly, there are online resources, but we suggest checking with your primary doctor and or pharmacist if you have any concerns.

CHAPTER 26

Your Pharmacist Loves You

How to work with your pharmacist. He/she is a key component to your wife's health experience

Your pharmacist is more than someone who just fills prescriptions. Their primary function is to know their customer's medications, and know their medical condition too. Your pharmacist also recognizes that they are the last stop along the dispensing process of medicine to your wife. If there is a potential problem with her prescription, your pharmacist can be your advocate to clarifying with your medical professional on why a specific drug was prescribed. Most doctors only take a few classes in pharmacotherapy and pharmacology in medical school. Your pharmacist has completed four years of training and they are the last step in the process of ensuring what your wife is about to ingest is safe for her to do so. Your pharmacist has also had extensive education in cardiology, nephrology and other medical conditions too. So, don't look at your pharmacist as someone who just dispenses pills. They are medical professionals too. Always feel free to ask your pharmacist any questions.

Also, know that your pharmacist is the most available health care professional to your wife. There is no sitting in the waiting room and waiting for the doctor. The good pharmacist will take the time to listen to your wife's ailments, such as having a headache for the last three days, and can determine whether a drug your wife is on is potentially causing that problem. What may be insignificant to your wife can ring alarm bells in the mind of your pharmacist. Another reason to build that relationship.

There are pharmacists who see their job as the one to count pills and not take the time to know their customers. Good pharmacists want to be part of your wife's support group; to ensure that the medicines she is taking are safe for her to do so. If Your pharmacist does not show interest in being part of your support group, find another pharmacist or pharmacy. So few patients see their pharmacist as a part of their medical support group. So, don't think you are putting more work on them. The good pharmacists want to help and in most cases why they became pharmacists in the first place.

Health care is continually progressing

We see this with medical providers shifting from paper to computers to review and update files; write and send prescriptions. In the pharmacy world, there is a push to put the pharmacist in front of you the patient. It is called: Working to the top of your license. That means to talk to the customer about their medications, their healthcare conditions versus spending time counting pills and putting them in bottles. Of course, checking your wife's medications is part of their function.

Who actually does fills your wife's prescription?

You would think it is the pharmacist, but today most pharmacies use an automated process to fill prescriptions. The order is placed in the computer, which produces a barcode. The barcode is scanned; the bottle with the medication gets scanned, poured into a tray, counted by laser beam and then put into a bottle and placed into a bag with information that pertains to the drug and put on the shelf waiting for you to pick it up. The pharmacist should check the order prior to you receiving it, and that is better done in front of the customer where he/she can have a conversation with the customer and create that relationship and understanding of the customers' needs and concerns.

Does your wife know her pharmacist?

Oddly enough, most people do not know who their pharmacist is. Your doctor prescribes medicine, and you go and pick it up and that is pretty much the end of the interaction. As discussed in the chapter on Disability Insurance, dealing with one pharmacy has distinct advantages, not only to be able to gather records but also to have the support of your pharmacist. Additionally, your pharmacist can see what is going on with your wife from a medicine standpoint. Her Rheumatologist may prescribe one thing and her primary doctor another. If they are not all on the same page, there is the possibility of a negative interaction. If your wife is not using the same pharmacy for all her medicines, there is the possibility of a negative reaction. Many primary doctors (PCP) will at some point, or if your wife comes under palliative care (a serious illness where the only alternative is to keep the patient comfortable from their symptoms), will require that all medicine prescribed go through him/her. The easiest way to handle this is to ensure that your prescribing doctor, if not your PCP, updates your PCP. Another good reason to keep your team of doctors as close together as possible.

The term: "knowing your customer" is critical in the banking industry. It is also to your pharmacist. The better they understand what is going on with your wife the more they can be an advocate and resource for her. Make sure your wife tells her pharmacist that she has lupus and any other medical issues she may have.

Think about this for a moment. Your wife probably sees her rheumatologist once or twice a year. During the intervening time between visits, who in the medical profession is seeing what is going on with your wife. Chances are your pharmacist will see you or your wife more often than her doctors will and if he/she knows what your medical issues are . . . notices there is something different about her, she can intervene with guidance. Your pharmacist is a key support resource on your medical team. Take advantage of their expertise and a listening ear.

The American Pharmacist Association poised the question: Can you truly know your medicines if you do not truly know your pharmacist? Have you ever read the pages of information that come with your prescription to understand potential drug interaction or side effects? Probably not. Again, if your pharmacist knows you and your medical (medicine) history, they can intervene or discuss with your wife any issues that she may have with a specific drug. This works best when a relationship is developed between your wife's pharmacist and you too. When I go to the pharmacy for something I need, the pharmacist always asks how Patty is doing. We have called our pharmacist when a doctor in the hospital was prescribing a medicine we were not familiar with. She called us back immediately and eased our concerns. That probably would have never occurred unless we and she had built that relationship over time. What you want for your wife are professionals who will be advocates for your wife's care. Certainly you, family members, are at the top of the list, but most do not realize how important their pharmacist is to their wife's overall health care.

Give them the list!

It is important that your wife has a list of all medicines she is currently taking when she visits her doctors, along with her allergies, to reduce the risk of negative interaction between drugs. See page 123.

Do not make your list any longer than two pages. It's easy to create in Excel, Word, Numbers, we use Pages as a MAC user. Keep a copy in your car's glove compartment and any other medical journal/calendar you keep so that it is easily at hand if needed in an emergency. Every nurse on every doctor's visit will update your wife's medical record.

Negative Interactions from Medicines

Negative interactions do not happen often, but once is not acceptable. Even though your doctors might be under one medical records system, every time we go for an appointment there always seems to be an error in their records. Imagine if your doctors are not under the same system . . . what confusion could occur! From a medicine perspective, if you use more than one pharmacist, you should make sure that all of them have a complete list in their records of the medicines your wife is taking. By doing so, each will have a clear view and understanding of what medicines your wife is taking and the associated risks/rewards. Consider it as your single source clearinghouse checking your medicines for interactions and other potential issues even if you are using more than one pharmacy.

Is your pharmacist the only check for drug interactions?

Today, most pharmacies use technology to flag potential drug interactions. When processing a prescription, the system will pop up a freeze screen alert if there is a potential drug interaction with the prescribed drug. It then requires him/her to enter their personal password to continue processing the order. If the pharmacy does not have all the medicines your wife is on in their system, then the interaction may not be discovered unless your pharmacist knows your wife's medical history. It's an interaction that could possibly be fatal. Another reason for your pharmacist to know all drugs your wife is taking (prescribed and over the counter).

It would be wonderful if there was a national database that all pharmacists could use to search and update a customer's list of drugs they are taking. Unfortunately, privacy regulations will probably never allow this to happen. So, if you are dealing with more than one pharmacy, make sure that each has a complete list of all the drugs your wife is on.

Over prescribing

Consider this. Your wife, because she is very cost-conscious, sees many different specialists and uses different pharmacies for her medications. Unfortunately, if her doctors do not know all the drugs she is on and her pharmacist does not know all the drugs she is on, this could lead to over medication that can create additional medical problems.

We have experienced this wherein our primary doctor was concerned that Patty had been over-medicated; that it was time to cut back on one or more medicines, or even discontinue a medicine. This process is called "De-prescribing". Our primary doctor knew all the medicines Patty was on. Imagine if he didn't! It's that interaction of drugs that can result in other symptoms that can be very difficult to diagnose.

To that point, in a November 11, 2016 segment on NBC Nightly News, Dr. Anthony Zizza, Beth Israel Deaconess Medical Center, was interviewed about "De-prescribing" medicines. We have often wondered whether our doctors really understood the interaction between drugs. "Most doctors receive little education on medicines". Zizza said, "If a person starts getting over 5 medications, we really worry about polypharmacy and the interaction between those medications." Lupus patients find themselves taking many different medicines because often they are dealing with many different medical issues. It is not uncommon for someone living with lupus to be on eight or more drugs daily. As the number of medications increase, so too does the concern of negative drug interaction. Dr. Zizza noted that "as people get older their physiology changes, their metabolism changes, the way we handle drugs in our body changes." So, what was working well one day may not be working well the next or is causing issues such as confusion, dizziness, and balance issues. Sleep aids, antidepressants, and blood pressure medicine are just a few of the drugs that can cause interaction issues. So, make sure that all your

doctors and pharmacists know what medicines your wife is taking. It is that important.

The Cost of Drugs

At the time this book was written none of us knew where the cost of medicine would be going. Up has been the general direction and there are various reasons why that our government is investigating. We figured out one day that if we did not have insurance, Patty's medicines would cost around $2,000 per month. The average person who has lupus spends around $20,000 per year for their medicines. It's an expensive proposition if you do not have insurance or you have a high deductible. Whatever your wife's medical issues may be, without proper insurance coverage the cost can become excessive to the point that your wife is taking her prescriptions every other day, less often or not all. This is not acceptable medical care, but circumstances can be real.

What if I do not have adequate insurance?

If you do not have adequate insurance or your provider does not provide the brand name or generic drug, consider using "GoodRX" (www.goodrx.com). There you will find pricing and discounts on certain drugs; even financial assistance. Your wife's doctor may have free samples, but that does not solve the long term problem. And yes, there are always generic medicines that normally come at a lower cost. Many pharmaceutical companies will also provide discounts to those who cannot afford their medicine.

The Universal Drug Store

I discovered this resource through my Rheumatologist. If you do not have prescription insurance, the Universal Drug Store, located in Toronto, Ontario, Canada, can be a reasonable cost provider for your wife's medicines, and yours too if need be. Your wife's Rheumatologist, and I presume your doctor, can set you up with this service by sending them a prescription. You can not do this directly by yourself, meaning that your doctor must send them the prescription. From there, you will receive a call within a week to ten days from their call center in the Philippines.

The Call Center will set you up with an account and payment can be made by American Express or Check. The Universal Drug Store provides medicines at a significant discount. For example: Colchicine here in the United Staes costs approximately $186.00 for a 30 day supply. Through GoodRX, it costs $86.00 for the same prescription. In Costa Rica, you can buy 100 tablets over-the-counter for just under $40.00 US without a prescription, but you need to travel there in order to get it. Through the Universal Drug Store, a 100 day supply of Colchicine is $55.00 + $7.00 for shipping. That is a significant savings and it will be delivered right to your door. Medicines should be FDA approved in order to come into the States. This may not always be the case as some foreign pharmacies may be shipping non-FDA approved medicines, and "there are generics available outside of America that have not been approved here," says Jill Magda RPH. As the prescription/quality/pharmacy/distribution system continues to be questioned, with respect to cost, there is a 'beware' that you know the drug you are receiving from a foreign pharmacy is in fact what you thought it was.

Check them out at www.uiversaldrugstore.com

Coupons

Pharmacists can help you with co-pay coupon cards. Many pharmacies have co-pay cards on hand received from drug reps. It's better to ask and receive than not. Also, check online for available coupons on drugs that you are taking or have just been prescribed by your doctor. Your doctor and pharmacist can help you find or give you discount coupons. If you do not have a computer or a way of getting online to check for coupons, ask your pharmacist to look up. If one is available, they can apply it to your prescription immediately and save you money.

Another source for help is possibly the state you live in. Google your state for drug cards. For example, in North Carolina Google: North Carolina Drug Cards. You'll learn information on free statewide prescription assistance.

How do you transfer your prescription from one pharmacy to another?

This is a lot simpler than you might imagine. Simply go to the pharmacy that you want to get your prescriptions from and ask them to contact your existing pharmacy to transfer your prescriptions. It is normally done by fax or electronically. Once received, your new pharmacy will enter the prescriptions into their system and you are good to go.

Additionally, make sure that your wife's doctor is aware of your change in pharmacy. This is easy to do at your next doctor's visit. Your doctor, when prescribing medicine, will always verify whether the pharmacy on file is the correct one and will update accordingly to your instruction.

Over the counter medicines

If you have a medical issue, such as an upset stomach and are looking for an over the counter medicine, check with your pharmacist to see if there are any potential interaction issues. Your pharmacist can pull up your profile and will know if the product is acceptable for you to use.

Remember, your pharmacist can become your best friend. They are local, easy to get to in an emergency, hopefully friendly and most importantly understand the medicines your wife is taking. Having said that, they are not Urgent Care.

One final thought. Because your wife's immune system is so low, make sure you wash your hands every time you get something for her that is food related. When shopping for food I always use the sanitizing wipes they provide to clean the handle and my hands too. Your wife's immune system is compromised and very susceptible to getting a cold, the flu, other bacteria or a virus. Her contracting any of these could be devastating. When I get ice out of the refrigerator for Patty's water I always wash my hands beforehand just to make sure. It's not paranoia, but rather common sense. We also have a portable air filter system that keeps the air as clean as possible in the house. Little things, but it can add up to better health for your wife and you.

Finally, if I have become repetitive in this book, it's oversight on my part or an emphasis on what is really important. As it is said, "repetition is the aide to memory!"

CHAPTER 27

Don’t Feel Guilty

It is easy to feel guilty if you do things away from your wife that are enjoyable and she cannot participate - like golf. This can be even more of a problem when you enter retirement. It’s important to plan the non-financial aspects of your life.

It's easy to feel guilty, as a caregiver, when you are out and about doing things you like to do, and you know your wife is at home not feeling well. Don't feel guilty! It's an easy trap to fall into. You need free time to enjoy life too. You just need to compartmentalize it. Realize that she needs free time from you too. A good caregiver will not become overbearing upon their loved one. But, you will need "your time" too.

Compartment #1:

Being there with your wife watching television, enjoying the evening, having dinner together. It's time to pay attention to what has been going on in her and your children's lives if they are still at home. Grandkids are a great pick-up but will tire your wife out quickly. However, she will endure. It is the price your wife is willing to pay.

Compartment #2:

Join a club or group. Playing cards with the guys once a week is your time away to enjoy. You should not feel guilty. I used to play golf every Wednesday with my VFW friends, but as Patty's health issues have progressed, the opportunity to do that has become less often. Patty has learned to schedule her doctor and physical

therapy appointments around my golf schedule, but that doesn't always work now. That's OK, as she is my priority. It's not golf! There have been times that her health has been so poor that she could not drive, so I affectionately became known as her Uber Boy. Just what I want to be known as, but it is not about me. It is about being with her at her doctors' appointments as an advocate and getting her to physical therapy and other appointments when she is not capable of doing so herself. It is this support that she greatly appreciates. So, when you take time off to do other things for yourself, don't feel guilty that you are taking time away from her. Your wife needs her peace and quiet more than you can imagine. Today, Patty no longer drives, and that brings on more responsibility and personal time for me. However, that is my opportunity to give rather than take.

The dry cleaning company I use knows that Patty is sick, and it is their thought that I should not waste my time driving down to them with my dress pants and shirts. The young lady behind the counter said, "We have a pick-up service for your laundry if you like?" I looked at her and said, "Making this trip down here gives me some time to be by myself and . . . if I am not home, you are assuming that Patty is going to answer the door!" When I have an errand to do, Patty, more often than not, will exclaim, "Where are you going now!" I think part of that is that she does not want me to spend money, but there are a lot of household needs, such as food, things I need to maintain the house, or a project. What she is telling me is, "I really don't want you leaving me . . . I need the company." So, when she falls asleep in her chair, I will leave her a sticky note next to her chair and slip out of the house. Whatever your needs or 'to do's' are, you can find a way of doing them with a focus on her first.

Compartment #3:

If you do not have a hobby that you enjoy, then find one. This is far more important than you could imagine. When you get to retirement age, the one thing that can kill you faster than anything else is boredom. If your wife is too sick to go

and do things with you, then what is it that you enjoy doing to relax. A hobby provides a purpose. A purpose that keeps the mind engaged and interested is one way to ensure that boredom does not become your killer. Nurture your hobby in your working years. It is a great thing to retire too. If travel is your ideal want to do, then you have a problem. For many with lupus and other systemic autoimmune diseases, they are not capable of or excited about using up or having enough Energy Passes to make and enjoy the trip.

Yes, your wife will have some 'honey-do' jobs for you when you retire, but let's face it, you can only clean out or reorganize the garage so many times! While editing this page, Patty asked me to get out the Fall pillows to replace the Summer pillows on the coaches in our family room. Rather than saying, "Yes, Dear" and getting to it later, I took a break from writing . . . got the pillows out of storage . . . replaced the Summer with the Fall, and then sat down to write again. No-fuss, no forgetting, and easing any potential stress for Patty and me down the road when she would have asked again, not so kindly. It has nothing to do with being a "Go For / Gopher." It is simply to reduce stress in the household.

If you really find yourself getting bored, we have the Internet, and nothing is more interesting than the Boredom Therapy website to spend some time: https://boredomtherapy.com/about/. Yes, there is a website for boredom. More retired boomers become bored every day. Think about it. They have worked at a vocation for 35 or 40 or more years, and now they are shipped off to retirement, hopefully in good financial shape, but have no understanding of what they will do. Many will return to work because it is hard to change a work ethic in later years. It is quickly discovered that retirement is not all it is cracked up to be. Most retirees have had no thought about the non-financial aspects of their life. It's not uncommon for retirees to become depressed; they realize they did not have that much in common with their wives and have a fading sense of pride in what they used to do because they are not doing it anymore. Think about what you want to transition to when you retire. As a caregiver, you want to have the

flexibility to maintain some socialization outside of the house that interests you. God bless you if you can play golf daily, but even the pros take time off.

Today, I have my own business that provides me with great flexibility and time to write and be that caregiver to my Patty. Yes, I have had a good career, but I was able to turn a hobby into a business. It was time to reinvent myself, as I suggest to you. More and more retirees will find themselves starting their own businesses. 25% of new businesses in 2016 were created by people between the ages of 55 & 64. When COVID hit, many found themselves working from home, and many decided to retire early. The Internet allows almost anyone to start their own business or little money. My business provides me with enough work to keep me actively involved, interested in life, and a feeling that I am contributing to other people's success. Caregivers Wear Plaid is an extension as I age out of one business and segue into a preplanned life of sharing with others what Patty and I have learned over the years as a care receiver and caregiver. Retirement is only retirement when you have nothing to do. Think about it . . . I'm just saying.

Another thing you can consider is getting a part-time job. There are a lot of employers who need part-time mature workers. For me, I just never wanted to be a Walmart Greeter, but for others, that is a great gig. Go back to school and take courses of interest at your local community college. If you are thinking of going into business, there are always continuing education courses you can take before you make the dive.

Compartment #4:

If travel is your ideal want to do, then you have a problem. There are things you will or will not be able to do. For example, I recently had to go to Costa Rica, and Patty could have traveled with me as she has before, but her health at this time does not make traveling easy. Additionally, if she needed medical assistance in

Costa Rica, besides the fact that our medical insurance would not cover her there, she would not be comfortable. They are not her doctors.

We would love to go to France. She has always wanted to go to Paris. Again, her health, energy, and ability to get around and do all she and I would like to do are not impossible but certainly weighs on our decision on whether to go or not. Of course, COVID and travel restrictions to other counties during that time had us hunkered down at home. Lupus is not a disease that you go to the hospital, get checked out, and go on your way to what you were doing. It is exhausting, time-consuming, and requires recovery time, whether it is a short visit or an extended visit.

Compartment #6:

Make sure you take care of your health. Much has to do with your attitude and desire to stay busy and involved. At some point, I will shut my business down because Patty will need me at home 100% of the time. Having an internet mission with Caregivers-Wear-Plaid offers me the opportunity to transition and have interests that keep me involved and contributing.

Gee whiz, I started out talking about why you should not feel guilty when you do things for yourself away from your wife, and somehow that led into retirement. If you are in your middle years of life, this is a time to start thinking about it and making sure you will be financially secure in your retirement years. It's the non-financial opportunities that lay before you. Put a lot of thought into it. Most of what I've learned in life has been applied in my today's world. Again, just saying.

Finally, and I am sure that I mentioned this in a previous chapter, sit down with your wife and discuss your concerns about feeling guilty when you are doing

things that her disease does not allow her and you to do. You need to know that she is OK with whatever it is that you are doing, but more importantly, you need to give yourself approval.

CHAPTER 28

Dealing with Holidays and Special Events

For many people, holidays, such as Christmas and special events, birthdays, and so on, are difficult to deal with. In fact, Patty becomes easily depressed during the holidays. As I mentioned in my dedication to this book Patty just wanted to stay home and be quiet for her 75th Birthday. So what do you do to help your wife and yourself through these times? In our case, it is difficult to escape because the Holidays are a ramping up of a season. Patty used to enjoy buying presents for our kids and grandkids, and we made that a year-round project. It is my year-round project because Patty does not get out as much as she used to, and she seems to have far fewer Energy Passes daily. On the other side of the coin, deliveries from Amazon and Zulily do come through the door periodically. It makes it a lot easier for her to shop and participate in the annual process of gift-giving.

Patty has several boxes full of this year's presents and fill-ins. Many families will make this effort a little easier by agreeing to pick a name out of a hat and buying that one gift for them so that when the family gets together, everyone gets something. Saves on the wallet and usually makes that one gift much nicer than having many. Of course, grandkids are a different subject, and we continue to overload them, but that is a Grandparent's prerogative.

We certainly made Patty's 75th Birthday a life event with our family and our lupus family of friends. So here are some tips to make your holidays and other special events more enjoyable:

1. Plan Ahead

I will use Patty's 75th Birthday as an example. When I knew that we would be going to the Lupus Mardi Gras Gala, it dawned on me that this would be a good way to get our son and his wife to come to Charlotte and join us as a surprise. They arrived the night before the Gala to celebrate Patty's Birthday, and they walked through the door with dinner from Del Fresco's, an expensive restaurant in town. Patty had no idea they were coming. I also invited our daughters to the Gala, and our oldest was able to make it, so when we got to the Gala the next evening and Patty saw Kelly arrive at our table . . . again, she was surprised. Of course, when everyone sang Happy Birthday to Patty that night (250 plus people in tuxedos and gowns), with cameras flashing as her birthday cake was brought to her . . . imagine how surprised she was. To pull this off, it took a lot of planning with family, friends, and the Lupus Foundation of America North Carolina Chapter. Patty is never surprised. She is usually the one surprising others. So we surprised her, and she talked about how great that evening was for a long time. I'm sure she continues to share the story. So, plan ahead as much as you can. The opportunity to pull this off came out of the blue, and it just takes a little bit of leadership and creativity on your part to make things special.

2. Don't be a victim of the Season or the Event

What I mean by this is that every little thing you do for your wife is appreciated whether you realize it or not. I extend this thought that if your wife is not appreciative, she may need to be reminded from time to time in a gentle and kind way. This is a team effort, and you can't have someone sitting on the bench griping or unwilling to get into the game. So her maintaining a positive attitude is just as important as you keep one too. Conversely, if she is engaged in the process, stand aside and let her do things for herself. If she needs help, she will ask for it.

We have friends who see us as their mentors as they travel their life of lupus together. They both have servant's hearts, and we have come to value their friendship, knowing that we are there for each other. It's little things, but lupus friends come through the door with dinners periodically, gifts of time to sit and talk or send Patty flowers, and so on.

I encourage caregivers to become involved with a support group. Just about every major autoimmune disease has some type of support mechanism, and you may find groups on FaceBook or other Forums to communicate with if there are no active chapters in your living area. These relations help everyone get through these times. It provides a purpose, and that is something everyone needs in their life, whether they realize it or not. Every year we have a Holiday Luncheon at a restaurant. Everyone brings one present, and as they are opened one at a time, the next person can elect to open an unwrapped present or take one from another who has already received a gift. It's a lot of fun and helps everyone get into the Holiday spirit.

Another idea is to take the Holiday off. One year Patty needed a neck operation to fuse three vertebrae and remove some bone spurs. We opted for Christmas Eve for the operation. The hospital should be quiet. We had a reason to stay quiet and a focus on recuperation which began on Christmas Day when Patty was released from the hospital. One year we simply did not do anything. Our kids were scattered here and there with their spouse's families, and we took the opportunity to tell them to go have fun and enjoy . . . that we would talk to them on Christmas Day. It's O.K. to take a year off if you or your wife is not feeling well.

If your wife is well enough to travel, that vacation special being offered is certainly an option. Volunteering at a soup kitchen or other opportunity on Christmas Day or any other holiday for that matter is a good way to stay involved

and feel good about yourself by helping others in need. It is a good way of giving back and keeping one's mind active versus allowing depression to creep in. If you know someone who is alone, both of you can visit a friend or acquaintance and spend 30 minutes or more just to hold their hand . . . for them to know that someone cares. It is amazing how these little actions can lift your spirits, your wife's spirits, and those you take the time to give the simple gift of caring.

Most importantly is to keep your focus on the one(s) you love and care about, and not you. When you give of yourself to others without any desire of return in kind, you will receive far more than one could ever imagine in many different ways. By doing so, you will be less likely to become depressed, and those you touch will be a lot happier too.

3. Exposure to light

Sitting in a dark room all day is not the best therapy for anyone. It has its drawbacks, to say the least. But being exposed to daylight is important, and in some individuals, the adverse effect of not enough light can result in what is known as "Seasonal Affective Disorder" or SAD. For those living with lupus, being out in the sun too long can result in flairs, but that should not limit your wife to taking a walk with you for 30 minutes or so if she has an Energy Pass to do so. If she does not, there are light boxes that can be used to get the effect, but she and you should talk to her doctor first in case she has other medical issues that may adversely affect her with this treatment.

4. Traveling

Almost every year, except a few when Patty's health would not allow us to travel, we would make the trip to Florida to visit relatives. An annual reunion with

her side of the family. For years we would make the ten-hour drive straight through, not staying over halfway down to buffer the trip. As mentioned previously, you would think just sitting in a car, not having to pay attention to the road, listening to the news or music on the radio, and so on, would not be exhausting, but any action for someone living with lupus can be just that. On our last trip down, I suggested to Patty that we leave a day early and stop along the way. Break the trip up. That way, we could arrive at our destination the next day around noon and have lunch under the beach cabana, and then check in at 3:00 pm. We arrived at noon, and our room was all ready for us. How nice was that! We then enjoyed lunch, the breeze, each other's company, and the views for the rest of the day. It was like having another full day of vacation.

On our return trip, we left at 5:30 am in the morning and arrived back home at 3:30 pm in the afternoon. Patty traveled well, sleeping a good part of the trip as usual. We find driving less frantic than flying because we have control of our time. Knowing that traveling is not something that requires exertion is never-the-less an ordeal and tiring to someone living with an autoimmune disease such as lupus.

5. Stay involved with each other

What I mean by this is to find things to do together. Take a walk every day together at her pace, if she can. What games do you enjoy playing together, and if you do not, find one that you can try together and enjoy? You may find yourself cooking for your wife and yourself. Today, I do all of the cooking, which is not my forte, but I am getting better at it. I have learned a lot about cooking from Patty, and I know she appreciates my efforts and the food. When she has the energy her cooking is simply terrific. The idea is to do as many things as you can do together, recognizing that she only has so many Energy Passes available during the day. So there are times when you will want to go do something, and she just can't do it. That's a little hard to get used to at first, but what is important is her.

6. Handling depression

Depression is very common during the winter months and can easily become a problem during the Holidays. With an autoimmune disease, especially one that is disabling, it is easy for your wife to become depressed. There is nothing wrong with your wife calling her PCP and asking for help. If it helps her get through the Holiday Season, that's what she is looking to do. Depression is such an important topic that I have devoted an entire chapter (coming up next) to it.

7. Binge and drink a lot

O.K., it is not recommended as one should not overeat during the Holidays. You know, keep that waist trim, etc., but don't let that stop you from enjoying. Too much alcohol can become a problem, so if you are a drinker, enjoy it but try not to overdo it. And, by all means, if you are out celebrating, use a car service or a designated driver. For her, water is the best. As your doctor will say, moderation is the key to all things.

8. Handling stress and worry

There are many ways to handle stress. Eating well, dancing and shaking to release endorphins, deep breathing, visualizing passive scenes from nature, screaming at the top of your lungs (it's very relieving), and of course, getting a good night's sleep. The process of stress, which is a mental reaction to something, can and will lead to anxiety (cause distress) which is one definition of "worry," to which a dictionary meaning is "a state of anxiety and uncertainty over actual or potential problems." It's real but also a game your mind will play with you. How often does one go to an event, such as a dinner party, a wedding, or a funeral, with

a sense of anxiety to only discover that they enjoyed the event, the people, and what they feared most or even least never happened?

When stress is not relieved, it can lead to anxiety and thereby "worry." You need not "worry" about your wife. She will have an uncanny way of handling situations in a very sensible way. In other words, do not be overprotective but watchful. Let her enjoy the little things and cherish the big ones. Patty had a lot of stress going to the Annual Lupus Foundation Mardi Gras Gala. She was going for me, not for her, because she knew it would be an exhausting evening for her. It turned out to be a cherished memory with no stress once our son arrived with his wife. From there forward, as much as she was tired, we all had a lot of fun.

I end this chapter with one simple statement. It's your attitude towards the Holidays or an event that will be the Holiday's or event's attitude towards you. Be positive and positive things will happen.

CHAPTER 29

Depression

The inability to kill the sadness within.

"If you don't stay active in life, life will not stay active in you!" I quote myself.

This chapter is about depression and what you can do to identify it not only in your loved one but also in yourself. Too often, as a caregiver, we forget about ourselves and our health until we realize that we have a problem too. I have found, as we get older, that *If you don't stay active in life, life will not stay active in you!*

Exactly what do I mean by that? It's exactly what you think it means because activity in all of us is a little different, but in some ways very much the same. For example, we talked about the importance of exercise and staying in the best possible shape you can. If watching TV or looking at media is a good part of your day, you'll come to realize over time that your life is being sucked away from you both mentally and physically. If your day is spent getting to and from work and you sit behind a desk all day, there is a little health benefit to you both physically and possibly mentally too. Staying busy doing positive things in your life is certainly an important habit to get into. It does not take long for boredom to take an active lifestyle out of your life. It is a rut that you do not want to get into regardless of your age or circumstances. The only difference between a rut and a grave is the depth of the hole, so stay active in your life so that life stays active in you!

A client and I were having lunch in a 50's style restaurant when I saw this sign hanging on the wall. Don't think I can't. Think I can, I can, I can!

What does depression . . . to be depressed, mean?

In essence, it means changes in one's mood, behaviors, thoughts, or feelings. For example, in the last three years, as Patty's lupus and other medical issues have progressed, I find myself getting weepy, i.e. on the verge of tears. That is a sign of depression.

How can you tell you are depressed?

Depression, at least in my experience, can sneak up on you for many other reasons, including that you are a caregiver for someone living with a systemic autoimmune disease. Here are some of the behaviors you may experience that indicate you are depressed.

1. You have lost interest in activities you once enjoyed doing or are discovering that the pleasure you enjoyed from those activities is no longer there.

1. You're finding it difficult to concentrate on tasks because negative thoughts keep dropping into your mind, such as worry, feeling worthless, or guilty that you can't get away with doing things that your wife cannot. i.e., for the longest time, I felt guilty about playing golf with my buddies. We have one day of the week that we play golf together, which for me does not always work out because I have my own business, and clients come first. If Patty schedules a cherished doctor's appointment on my golf day, well, she comes first. If I did not have the business and Patty was not sick, I sincerely doubt that I would play golf any more than one time a week. But I do enjoy playing as well as the friendships. As I said, for the longest time, I felt guilty that I could get away for a round of golf while Patty was at home, unable to do much. Rather than letting this fester into a problem, we discussed it, and she assured me that it was not a problem. If I cannot play golf with my buddies once a week, I may find some free time to go play 9 holes and make some new acquaintances. There is always a way to work around things. Having said that, while I was writing this, a doctor's office called the house to set up an appointment for Patty. I found myself praying that it would not be tomorrow when I played golf with my buddies. I didn't say to her, "Not tomorrow dear . . . I am playing golf," and I have never asked her not to make a doctor's appointment on my day to play golf. Patty comes first, and by keeping that in perspective, I know we have bigger fish to fry. Yes, there are days I will keep my schedule open from my business to attend a charity golf tournament, such as the Lupus Foundation of America's Annual Golf Charity Event. It's a good way to give back and have some fun at the same time too. It's all about choices and balance.

Recently, while editing Caregivers Wear Plaid, Patty really began showing signs of depression. She had fallen and fractured her wrist. In a soft cast for the better part of the week, the surgeon suggested that Patty's wrist may or may not be broken. Sometimes fractures over a period of time better expose themselves to x-ray. He did not feel an MRI was necessary at this time. "Put on a wrist brace, and I'll see you in three weeks, and we will make a determination," he said. Tuesday night, I suggested that I play golf the next day. Our T-Time was at 9:00.

When Patty did not wake up until 8:45, I knew there was a problem. She was depressed. I said nothing, made her breakfast, proceeded to work on Caregivers Wear Plaid, and kept an eye on her. Sometimes it is just best to leave things alone and let her work through the emotions she is dealing with, not feeling well, and the zero Energy Passes. She did not mention golf, nor did I. What was important was that I valued her more than playing a round of golf. I wanted to keep an eye on her. The next day, she was feeling a lot better. In the grand scheme of things missing one round of golf is not the end of the world. But it also shows that you are living within your wife's limitations.

3. Feeling sad or empty is another sign of depression. I think a lot of this has to do, from a healthy caregiver's point of view, with whether the glass in your life is half full or half empty. The question comes to mind:

"Do you work to live, or do you live to work?

If you "live to work," then your focus is not on your family to the degree it should be. If you "work to live," chances are there is a better balance in your life with your family, friends, and work. There is no constant with that statement. We are all different. But what occupies your time? Here is what I mean: I have noticed that when the weather is bad, and I do not have a client to see, I sit and watch a lot of T.V. with Patty. I become tired and have less energy, which are both signs of depression. Exercise is important as we get older, i.e., if we don't use it, we will lose it. I at least walk two to three miles at least three times a week, and I still do yard work. As I get older, I realize that I need to do more to stay in shape and at least keep my body moving. Again, if you are not active in life, life will not be active in you! So what floats your boat? What is it you can be doing to keep yourself active during these downtimes or in retirement? "An idle mind is a devil's workshop," so goes the Chinese proverb. This discussion will be for another book, which has not been written yet. An important thought you need to keep in mind.

1. I have never had trouble sleeping and being overtired, but that is definitely a sign of depression. In the early 70's I took a course in mind control. It was a five-day course, and all attending probably slept more during the course than not. One of the things I learned during that course is that our mind never goes to sleep. In essence, it slows down and does so in a rhythm that cycles down to the REM (Rapid Eye Movement) state of mind. I am sure you have heard of REM. It is at the bottom of the 90-minute cycle our mind normally goes thru during the sleep cycle to slow the brain down and rejuvenate the body. REM resides in our subconscious mind versus conscious, but that is a different topic for a different time. The average person probably gets five 90-minute cycles in a night, which is 7 1/2 hours of sleep. If you wake up in the middle of a cycle, the normal sleep rhythm of the mind is interrupted, and you will probably not feel rested . . . like you had a bad night's sleep. The fix is a simple one, but not one that patients or professionals in this arena always accept. The mind is very receptive to conscious thoughts. Every night when I go to sleep, I close my eyes and simply say to myself, "It is time to go to sleep, and when I awake, I will be totally refreshed, and in tune with life and when I awake I will make it a great day!" Patty will tell you that I am asleep within moments. If I know that I will not be able to get all five cycles in, I will calculate how many I can and tell my brain to wake up at the end of a cycle and drop additional cycles off. If you don't think this works, how many times have you gone to sleep at night and reminded yourself to get up earlier than normal for an event, i.e., going on a trip, having to be at work early, and so on? Because you do not trust yourself, you set your alarm clock. How many times do you awake within moments before the alarm goes off? Again, I am not a doctor nor a sleep expert. I just know what works for me. One final thought. If you have a problem that needs solving, just ask your brain to solve it while you are asleep. Worry not about it because more often than not, when you awake, the answer you are looking for is there. It may not be immediate, but it will come to you in the shower, taking a walk, or even driving to work. It truly is amazing how capable our brains are.

2. Thoughts of death or suicide. This obviously is not something one should quibble about. Get to your doctor and talk about all your depression symptoms. There are antidepressants that your doctor can prescribe. My Primary Care Doctor actually wants me to close down my business, not only because of my age but my health (which, fortunately, is great). He wants to make sure I remain as healthy as possible while I am a primary caregiver. His comment was, "normal people retire a lot earlier than you!" I said, "Doc, I enjoy what I am doing, and I have great flexibility. But I do realize there will come a time when I physically cannot keep up with the demands of the job." As I say to my clients, "When it is time for the old fool to be forced into retirement, just let me know!" It always gets a laugh, but there is a lot of truth to the statement. I do not consider working as working, but rather being involved with other people. It keeps me active, and after all, how many people really travel all that much when they retire. Very few that I know of, but there are some. Unfortunately, Patty traveling a lot is not something she is capable of doing due to her overall health and knowing that we need to be close to home for her doctors. So having my own business is not such a bad idea to keep me active and involved. Writing this book and what it brings going forward will be less demanding as I segue into the next adventure in my life, which will keep me involved with other people. As I say, If you don't stay active in life, life will not stay active in you! Always keep active if the good Lord is willing to give you the time, inclination, and health to do so.

If you do have thoughts of suicide, don't hesitate to call the National Suicide Prevention Lifeline (1-800-273-TALK [8255]). They are available seven days a week 24 hours a day. It is Free and confidential. The organization is so good that they will refer you to appropriate counseling in your area. So, don't ever think you are out there alone.

Since writing the above paragraph, COVID-19 has come and is now very much gone. My business has evolved from going to see the client in person to see them on Zoom. This actually came at a very good time because Patty's health had

declined, and I realized that being away from home was not a good idea. I was about to shut the business down or have someone come in and stay with her while I was at work. Since the pandemic has abated, my clients, for the most part, have opted to stay online with our meetings as it saves them time and money. In every adversity lays the seeds for success or opportunity. We are fortunate from that standpoint. And, if I did not have the business, I do have my writing. What do you have? What is it that you want to do that will keep you busy and your mind occupied with positive thoughts?

3. Last but not least is a change in your weight. Are you gaining because you find yourself eating or drinking more (boredom, lack of interest, etc.)? Or are you losing weight due to other medical reasons other than food and alcohol intake? Again, go see your Primary Care Doctor!

https://www.qualityhealth.com/tag/depression+original-articles

Obesity and Lupus

No matter how one looks at weight, being overweight is a risk factor for one's health, whether they have lupus or not. It can lead to depression, fatigue, joint pain and an increase in your wife's lupus activity, and other medical issues. Unfortunately, if your wife is on prednisone, there is a love-hate relationship and a good chance that she is going to put on the pounds. To her, the emotions associated with her weight increase are a lot different than what you would experience. "Will you still love her if she puts this additional weight on?" she will think. "How will her friends and family (self-identity) think of her if her weight increases significantly." If they do not understand lupus, how are they going to understand her gaining weight? What's going on!!!!!!!!!! Taking steroids is normally the culprit to weight gain with an autoimmune disease, but then snacking and overeating can put the pounds on too.

Bruising and Lupus

If you notice that your wife is bruising easily, it's a good chance that it is due to her lupus. For her, it is very frustrating because she cannot remember bumping into something or any other impacts that would cause bruising. Bruises just seem to appear unexplainably, so what is going on?

Lupus attacks healthy blood platelets, and the first thing her doctor will check is her blood platelets to ensure that cancer is not the issue. The other avenue your doctor will explore is the medicines your wife is taking. For example, aspirin can disrupt blood platelets which can result in the appearance of bruising. It certainly is not a vanity winner and can add to her depression.

Medicines, such as prednisone, which, when used over time, can thin the skin, and can lead to bruising. NSAIDs, non-steroidal anti-inflammatory drugs, such as aspirin, and ibuprofen (Motrin & Advil), are medicines anyone with lupus wants to stay away from. They can also cause all kinds of problems, such as nausea, vomiting, diarrhea, constipation, rash, dizziness, headache, drowsiness, and even loss of appetite.

Bruising can also occur from Mosquito bites and leave permanent bruises that are light in coloration to what appears to be abuse. You may hear the diagnosis of Purpura, and unfortunately, if that is the case, nothing can be done. An example of Purpura is when you have blood drawn, and the small blood vessels leak blood into the skin, causing what appears to be a bruise. One does not necessarily need to have an underlying disease, such as lupus, for this to occur. First, realize that bruising to any woman affects their image and vanity. Thus, the shorts during the summertime will probably not be worn, and she will look for other ways to cover up the bruising, such as using a spray tan.

What can you do?

Love your wife for all that she is and all that she has meant to you and your family. Loving your wife has a lot more to do about who is living inside and not her appearance on the outside. Let her know that you love her as often as you can. That means daily. Patty and I share that blessing at least twice a day, if not more. Your wife will learn to cope with her bruising and autoimmune disease in the acceptance process. Some guys don't care how their wife looks, but for a woman, especially aging is a concern if they feel that their partner is not committed to them. Self-doubt, fear that their partner will not stick around, inability to work and fend for themselves, living with a systemic autoimmune disease . . . There are a lot of negative thoughts that can go through anyone's mind that can lead to depression. As your wife's caregiver, it is your job to not add to the stress but rather help her be the best that she can be in the comfort of being secure. It's learning and your willingness to *live within her limitations* because you love her, and it's the right thing to do!

CHAPTER 30

Handling Stress

Some people stress out before there is anything to stress out about! Stress is the fuel to opportunity . . . to become more today than you were yesterday!

The word "stress" seems to come up in all discussions around autoimmune diseases and how dangerous negative thoughts are to your health and to your wife's health too. The only thing that separates us from most two and four-legged animals in the world is our ability to think, connect thoughts and make rational decisions. When one's stress hormones are activated, the long-term result can lead to high blood pressure, depression, and a lowering of the immune system's ability to fight for you versus against you, as it does with lupus and other systemic autoimmune diseases. It can also lead to a heart attack, anxiety, and more. No one is ever stress-free. It affects people differently, both mentally, physically, and emotionally. For most people, stress is not a problem in their life, but when living with someone who has a systemic autoimmune disease, you can be assured they are stressed, and it is hard to believe that the caregiver is not too.

Stress can show itself in muscle tension, chronic pain as associated with lupus and other autoimmune diseases . . . the tensing of the body.

Stress can weaken the immune system, which is kind of like a love-hate situation. Your wife is living with a disease that, by definition, says she has a compromised immune system, and the stress she is experiencing only adds to it.

Stressful events can often lead to headaches. The stress at work, the stress at home, a poor diet, and little or no exercise can all build up to a headache. Stress! Depression by its mere definition is a stressor. Fatigue is another sign of stress, along with a poor appetite, weight loss, etc.

So let's add it up. How many stressors does your wife have living with lupus?

- Fatigue
- Joint pain (chronic, muscle tension)
- A compromised immune system
- Stress at work, because she is fatigued and not getting the accommodations she needs to remain working.
- Headaches
- Depression
- Insomnia
- You

If you think you are stressed, imagine what your wife or child is going through.

There is a lot being learned about stress and how food can be a positive or negative impact on your stress levels. Caffeine, alcohol, and refined sugars somehow communicate negative signals to the brain, and thereby your brain feels more stressed. So, there is a lot that can be going on inside your body as well as outside that is contributing to your stress.

In a moment, I will give you some tips on how you can combat the stress you have in your life and that of living with your wife. To be honest, when I started writing Caregivers Wear Plaid, I realized that it is really important for you to understand how negative thoughts can really affect and control your life. Gossip, bad feelings about others, and things not going your way are all things that you should have control over. We all gossip, but when it is negative, it conveys stress inside and outside of you. When you express bad things about others, it conveys anger, which is just another word for stress. And when you are stressed because things are not working out for you, that is when the opportunity for success is in your hand. Really? We learn by our failures just as much, if not more so, than from our successes.

Being a caregiver is, more often than not, learned over time with all kinds of frustration, stress, guilt, etc. That is why I know this book is important, even if it does not help you through this time in your life. It's a choice though, isn't it, to accept and change what was once so common to a new normal in your life . . . that of being a caregiver to your wife. No person changes their old ways to seek the knew until they personally find a reason to do so. The key is to identify and release your stress. You can go back to Chapter 12 - The Five Stages of Acceptance, to help you through this.

Yes, there are times my buttons are pushed. It takes a lot to release, but I do it quickly because I understand how dangerous those emotions can be. And yet, it is important to release. I have noticed conversely that some people become stressed over an incident, such as an argument with their loved one, and it can take days (normally three) to get over. If the stress is from someone at work, it can become a training opportunity. At home, if it is a child, it's an awareness opportunity or tuff love, and if it is your wife, it is understanding the opportunity on how you can personally improve. And then there are those times . . . well . . . there are just those times!

I am sure that you are dealing with all kinds of stress. There is a lot of stress at home and at work, and if you have been having trouble managing it, I hope the following will help. Before I do that, however, you know there is no panacea to reducing one's stress. It requires, more often than not, a mind change. For example, exercise is touted as a way to reduce stress, and it is. But, if you are not one that exercises on a regular basis, getting into your mindset and changing your mindset over time is the only way it will work. In other words, taking one walk ain't going to help you too much. It's consistency over time that does. So here are some tips:

Tips to relieve stress

Again, your job as a caregiver is to reduce stress as much as you can, and I recognize that is not easy. Your wife's illness is stressful enough for her and you, too, as you live within her limitations. However, don't add to what is already difficult circumstances. The way in which you talk to your wife can create tons of stress, and a lot of that has to do with your delivery. Try not to be condescending. I know that you do not mean to, but what you are, the way you express yourself speaks so loudly she can hardly hear a word you are saying. Remember, she is dealing with a lot more than you could ever imagine, even though she does not look sick.

Tip # 1: Exercise, Loosen up, and shake the stress away. The benefits of walking 20 minutes three times a week are so beneficial to your health and your stress levels. It gives you a chance to think, solve, and understand. There is not a doctor who will not ask whether or not you exercise. They understand the importance of keeping everything moving, the juices flowing and the muscles contracting. It is not always easy for someone living with lupus because their joints ache, they are fatigued, and they are depressed. Walk with your wife if she has the energy to do so. It will help her immeasurably and you too. If your wife is sedentary, talk to her about getting a floor bicycle. They are inexpensive and can

help with stamina and muscle tone. If your wife gets into exercising, going to a gym is always good, but make sure it is well maintained and kept clean. The alternative is using an exercise bike at home or getting out for a walk.

Tip #2: Get a good night's sleep. We sleep in 90-minute cycles, as mentioned before. One of the best lessons I ever learned was to learn how to sleep, quiet my mind, and enjoy the subconscious side of my life.

Tip #3: Just imagine. I have a peaceful picture in my mind that I can go to any time I want; that just relaxes my brain and puts me at peace. There are few things in our life that are finite (death of a wife, a child, a parent, a friend, loss of a job), and yet life goes on. To grieve is normal, but other things that stress us out have an answer, and one needs not worry about it. If you have moments of stress or anxiety, visualizing a passive scene from nature, someplace that brings quiet, comfortable thoughts, along with some deep breathing, can easily bring relief. Like most things, it takes practice. If you want to learn more about how to do this, read Jose Silva's book "The Silva Mind Control Method." It is available on Amazon. I am sure that you will be able to find other more recent books on the topic. I took a five-day course based on "Silva Mind Control Method" back in 1970. I wouldn't want to imagine what my life would be like today if I hadn't taken that course. We slept through most of it. Today, the principles of "Silva Mind Control Method" are the foundations of many similar programs and therapies, whether they realize it or not. Reiki is one of those.

Tip #4: Breathing. We are always told to breathe from our gut, and frankly, I don't think I have ever gotten to the point of being able to do that unconsciously. But, taking a deep breath through your nose and exhaling it slowly through your mouth is known to reduce stress and anxiety and calm your nervous system. "Controlled breathing has been shown to reduce stress, increase alertness and boost your immune system," says Belisa Vranich, a psychologist and author of the

book "Breathe." Do this in concert with imaging, and you will be surprised at how more relaxed, anxious, and stress-free you will become.

Tip #5: Get one of those stress-free squeeze balls. You can find them almost anywhere. They will not only help your muscles but help keep the juices flowing and reduce stress.

Tip #6: Procrastination can cause stress, but it can also be beneficial. I have done some of my best work when I have been under pressure to perform. Too, if your wife asks you to do something, you can reduce a significant amount of stress for her and you if you do what she requests ASAP. Either that or take notes. You do not want to hear, "Didn't I ask you to do this last week!" I can feel the stress now!

Tip #7: Go have a good cry, or better still, find a remote place where nobody is around and scream. Simply let it out. It may seem a little radical, but it is cleansing and surprisingly refreshing.

Tip #8: Talk your stress out. I have a friend whose wife has lupus, and it is very stressful for him. Having someone you trust to whom you can vent your feelings too is a great way to reduce stress. Stress is negative energy that the body generates in the fight-or-flight response. The opportunity to release that stress with someone else who understands is very cathartic. This interaction will often produce oxytocin, a hormone that will calm you down. Oxytocin, that stress reliever hormone is released, especially in women, when with friends and children. Patty always feels less stressed when our grandchildren come to visit. The other side of that equation is that she is wiped out after they leave. But, they do not know that. They only see Patty, who is interested in and enjoying them. It's the same when family comes to visit. She looks the best that she can; she enjoys their company,

but she also knows there is a price that she is willing to pay for that social interaction.

Tip #9: Light a candle. It sets a stress-free environment that both you and your wife can enjoy. Who knows, it might lead to something else!

Tip #10: Learn to laugh a lot. A good laugh, a belly laugh, where you just can't stop yourself from laughing, can release a lot of stress. Some of the advertisements on television are so creatively stupid that I can't help but laugh. Laugh at your own stupidity. Your wife will appreciate that. Or just start laughing. It becomes infectious and will do you a lot of good.

Tip #11:

1. Write down what you are stressed about. If your stress is over whether you should do something or not, take a piece of paper and draw a line down the center of the page.

2. On the top left, write "Reasons to Do," and on the top of the column to the right, "Reason Not to Do."

3. Start thinking about reasons to do and not do and write them down in the appropriate column.

Which-ever column has more points helps you make the decisions you need to make and thus reduces the stress level too.

Tip #12: Have some chewing gum. Obviously, if your teeth are not in good shape, this may be an idea that causes you more problems than the benefit derived. But, chewing gum has been associated with lowering stress. It will also promote blood flow to the brain. A study performed at Cardiff University https://doi.org/10.1016/j.appet.2012.02.052 indicated that "chewing

gum reduced stress (both at work and outside work), reduced fatigue, reduced anxiety and depression, and led to a more positive mood." Obviously, if you are in a business meeting, chewing gum is probably not a good idea. Otherwise, pop in your favorite kind.

Tip #13: Socialize. This is one area when living within your wife's limitations that you find your friends and even family may not be around as often as you wish. You're not invited as often to dinner parties or other events because your wife is not feeling well and, over time, has been mistaken as "she no longer wants to be friends." It's tuff. You may find that your social life is withdrawing from you. It is one reason why support groups are so important for socializing and building new friendships with like people.

Tip #14: If you are a satisfier, someone who has difficulty saying "No," learn to say "No" versus taking on more than you can handle. You can't be all things to all people, and yet we often have a compulsion to say, "Yes," because we want to be successful and not let people down. This can bring on additional stress that is not necessary. As I like to say, you are Chairperson of the Board, President, Vice-President, and Secretary of the greatest corporation that ever existed. That's you! So how are you running your company? That's You! Saying, 'No' will allow you to concentrate on what is more important to running your company and those you serve. If you are looking to be served versus serving others, then you have your priorities mixed up. However, not to be confusing, over-serving can be a negative too.

Tip #15: Listen to the music you enjoy. Music can be a relaxer, a motivator.

Tip #16: Pets? Dogs are known to be a wonderful stress releaser. Of course, when they poop or pee in the house, it can cause anger and stress. Or, if they don't stop barking at your next-door neighbor for hours on end . . . but most dogs are

always there to give you love and attention, even cuddle with you. Their companionship is known to reduce heart attacks and lower blood pressure, among other things.

Dogs can also improve your social life. They need to be walked, and often you will run into other dog owners and strike up a conversation (socialize). There is a lot of research indicating that having a dog is very beneficial to one's health, especially if you and your wife are in your later years. But we know that dogs can also be a tripping hazard that can break bones and require greater restraint (physical ability) to walk. Also, note that if your wife is limited in her movements, having a dog at home when you are not can make it very difficult to let Fido in and out to do his business.

We also personally know of two dogs (Maltese's) that can and do alert their owners when a heart attack is imminent. No kidding. Some dogs, better than others, have the ability. Individuals living with lupus are at greater risk for heart disease because of their mix-tissued disease association. Those extra minutes of alertness to the problem have made a significant difference in emergency care. Yes, dogs can become your best friend, but don't let your wife know that. She needs you too! Dogs are wonderful, and cats can be too. A fish tank allows the mind to wander into another world, and a bird may very well carry on a conversation with you. Whatever your preference, the idea is to enjoy and reduce your stress levels.

Tip #17: Improve your work-life balance. As I have mentioned before, if you 'live to work', that can bring a lot of stress into your home life. If you' work to live' by not bringing work home, you have a better opportunity to balance your work-life experience. Easier said than done, but all these stress release tips, when applied, can certainly help you along the road to achieving a stress-free, anxiety-free life. Of course, there are always those situations where a stressful reaction cannot be suppressed. But, those should be rare if you keep things in

perspective. Don't become a victim of your own emotions. You can change your thoughts and thereby change your life.

Tip #18: Take a shower

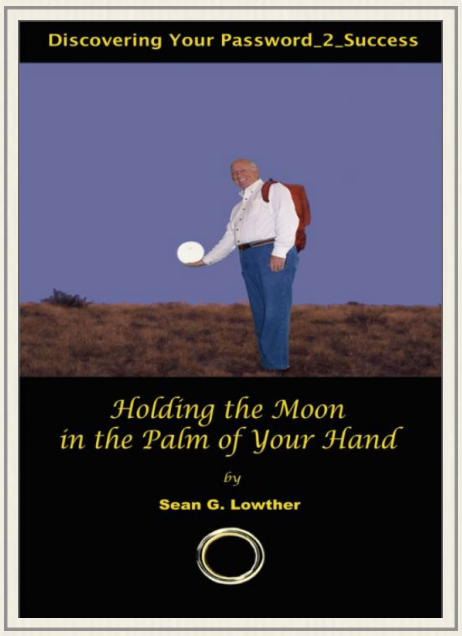
Tip #19: Seek out professional help.

This is just the start of ideas on how to reduce stress in your life. I am not into podcasts, per se, but today there are tons of podcasts online which allow me to get other perspectives other than reading books on the subject. Recognize that most means to reduce stress are probably not in how you live your normal life today. It will require you to create that new normal, and that comes from embracing principles such as eating right, exercising, and channeling positive thoughts. Repetition is the aid to change. Unfortunately, no person changes their old ways to seek the new until they personally find a reason to do so. This is your time!.

I learned at a relatively young age how to not worry and build anxiety that can lead to severe health issues. Part of that lesson was learned in Viet Nam, learned through life and the insight of many others to whom I will always be grateful.

Personal Development has always been important in my life and I am happy to say that I continue to learn and benefit from greater understanding every day

Holding the Moon in the Palm of Your Hand (HTM) is 54 motivational poems on how to become more today than you were yesterday through personal awareness. HTM asks the reader to change by exploring ideas that can bring about positive results in life through greater awareness. Each poem delves into a specific principle, word, or idea that unravels the human ***Password_2_Success*** through greater understanding and awareness.



Other books written or co-written by Sean can be ordered through https://caregivers-wear-plaid.org/ website.

CHAPTER 31

Lupus, Sex and Pregnancy

Yes, yes, yes! Every guy wants sex, and your wife does too. There is no reason why the two of you cannot have a healthy sex life together unless her lupus or other systemic autoimmune disease is very active. Trust me, she will let you know. Know that if your wife is on medication for depression, such as Prozac, or Zoloft, her sexual desire could be decreased, and she could have difficulty reaching orgasm.

You may need to be a little more organized versus spontaneous to your desires and hers. In every adversity lays the seeds to success, so no matter the problem, always look for a solution. The first thing your wife needs to know is that you want her and that you want to have sex with her, but you realize that it may be difficult for her. So open up the discussion so that both of you can communicate your needs, concerns, and desires. Some of her concerns can be that she has oral or genital sores from her lupus, that she is just fatigued, or her joints are too painful to have sex. If your wife is putting on weight due to prednisone or other medications, it is not her fault. Let's face it; it's just more to love! Do not let that get in your way so that it does not get in her way. Accept her and love her as she is because right now, it is all that she's got.

Sit down and discuss your desires for sex and how to make it enjoyable for both of you. That means initially, her concerns and physical issues need to be addressed, i.e., if vaginal dryness is an issue, there are lubricants that can be used. If she is depressed, her doctor can prescribe medications.

Depending on your wife's progression of the disease, it may make sense to either be spontaneous, i.e., she is feeling good and wants to have sex now, or, and I know this sounds a little cold, but make an appointment to have sex. At least you know it is agreeable to both of you. Now everyone is different in their lovemaking, but setting the tone, such as candles, taking a shower together, a glass of wine, putting on some soft romantic music, anything to relax both of you will work. Be creative and ask her what she would like to do . . . and don't rush things.

Once in bed, you will discover what works. Even if intercourse is not on the agenda, there are other sensual ways to please each other. That, of course, is what you are both comfortable with . . . and that is the one thing you need to remember in your lovemaking. It is not about you and your needs, but rather hers. Trust me, she will take good care of your needs better than you could have ever imagined. So enjoy each other and the experience. After all, it is an important expression of the love you have for each other. As I expressed earlier in this book, your attitude towards life will be life's attitude towards you. Conversely, your attitude towards having sex with your wife will be your wife's attitude towards having sex with you as long as it is positive and caring. Living with an autoimmune disease is a new experience for both of you. Communicate your concerns, show her that you love her, no matter what, and be patient in your lovemaking. You will find that you will become closer to one another than ever imagined, less inhibited if that is an issue, and enjoy this normal, natural part of life together.

Additionally, if you show your wife that you love her every day through conversation, a kiss, holding hands, or simply doing things together that you both enjoy, the issue of having sex is an activity reinforced by the love you show for each other each and every day. However, there is always a "however," and that is the potential of pregnancy.

Pregnancy and lupus

If you and your wife have decided to have and are working toward having a baby, then you and she need to see a rheumatologist and her OBGYN prior to conception. Oops, and lupus is not the best thing to happen, but not the worst either. It makes sense to plan under the circumstances and have that discussion with your doctors to have a level of assurance.

Both doctors, your rheumatologist, and OBGYN, can talk to you about the risks, which are dependent on how active your wife's lupus disease is at the time. Remember, your rheumatologist has had much for medical education than your primary doctor and OBGYN. So make sure that you have this conversation with a rheumatologist. Patty and I know many lupus couples where there have been no complications with childbirth, i.e., normal delivery and no apparent related health issues. However, women with lupus do have a slightly higher degree of risk. Since you have 50% participation in creating a baby initially, being an educated parent can reduce anxiety and stress on whether or not your wife should get pregnant at this time; the risks you both should be aware of if she does get pregnant.

Contraception

If you are not planning on children at this time or in the future, you need to make decisions about contraception or a vasectomy. There are about 20 different birth control options on the market, including the pill. They all have their own degree of safety. Do not rely on condoms alone.

Condoms are about 85% effective. What this means is that you should not rely on anyone's form of contraception. IUDs (Intrauterine Devices) are a contraceptive device your wife can have placed in her uterus as a means of

contraception. It usually lasts up to 12 years, according to some sources, and can be removed if you and your wife decide to have a child. Consult with her OBGYN. Having said this, it always seems to be the woman's responsibility for contraception, and that should not be the case, especially if she is dealing with an autoimmune disease. i.e., your wife is probably taking enough medicine, and adding the "pill" may seem like just being one more pill, but I am always concerned about medicine interaction. So talk to your PCP or rheumatologist. It may be time for you to step up and be the one more proactive in contraception if your wife and you do not want children at this time

Again, having an intimate relationship with your wife is possible depending upon your wife's level of health and personal preferences. Always talk to your physicians openly if you have any additional concerns. Having said all that, "Have fun!"

CHAPTER 32

Wrapping It All Up

When I started writing Caregivers Wear Plaid, three-plus years in the writing, I never intended for it to be this long. There is more to talk about than anyone could imagine, including me. Where do you stop? I know Caregivers Wear Plaid is packed with a lot of good information you could benefit from. That is up to you as no person changes their old ways to seek the new until they personally find a reason to do so. Your loved one is that reason. It is no longer about you if that has been the case in the past.

When COVID hit in 2020, I finished the first iteration of Caregivers-Wear-Plaid and put it up online for FREE. With Patty's health declining and requiring more of my time while still maintaining my business, there was no time to adequately support all that we wanted to do on the Website. Great intentions and poor follow-through. You know what happens when things are out of mind. Nothing gets done. But, I know this is important work, and I know it is important to allow the bookselling system to support the distribution. It is now for sale to defray some of the costs, and we hope you will recommend it to others in need. You never know!

Let your doctors know

WE ASK that you let all your doctors know about our book, as they are acutely aware that the caregiver is a patient too. Our research shows very little on the

subject pertaining to a husband as a part-time to a full-time caregiver for their loved one.

Above all

Now that you have finished our book take the time to go back and read the chapters that most interested you. Being a good caregiver does not happen in a day or even overnight. The rest of Caregivers-Wear-Plaid will serve as a good resource as the need arises. It requires love, compassion, and a focus on her needs. That will come in time as your role is ever-evolving, as her disease is.

The most important thing to facilitate all this is you and your loved one communicating with one another; how you each feel, honestly expressing your needs as sh too to you, and respect for one another because you are in this together.

Patty and I genuinely wish you and yours the best.

God Bless!

Patty and Sean currently reside in The Village of Lake Park, North Carolina. We have four children and five grandchildren and love the comfort of living by the lake.

Here we are, above, in Fourth Grade, and to the right at a Lupus function several years ago.

If you wish to reach out to us you can do so at:
slowther@stealthawareness.com

Other books written by Sean:

Holding the Moon in the Palm of Your Hand - 2011 - eBook only
https://www.amazon.com/dp/B00846OV0W?tag=sa-b2c-new-20&linkCode=osi&th=1&psc=1&o=740311&p2=%5EY6%5Echr999%5ETTAB03%5E&n=7867ff6a&ln=en

Authors Notes

No book is written by one alone. It has been a wonderful opportunity for Patty and me to work on Caregivers Wear Plaid together. Her insights on lupus are extraordinary. Having been a caregiver to her all these years has at least given me some insight into what your life looks like.

We want to thank Dan Klutz, a neighbor, and friend, for taking our picture as it appears on the cover. If Patty looks a little fuzzy, it is because she is! Ha! Her photo was taken with an iPhone while we were on vacation. I merged the two, her picture and Dan's photograph of me, into the background.

A special thanks to Jill Magda RHP, our pharmacist. She has simply been terrific over the years and reviewed the chapter - Your Pharmacist Loves You. And to Susan Corbett, PharmD, RPh, and a lupus warrior, as I garnered from her a lot of the information and understanding of the pharmacist's world and processes as shared in Chapter 26, Your Pharmacist Loves You.

We also want to thank the many friends and lupus acquaintances who took the time to read, give comments, and edit back to us. It is invaluable and greatly appreciated.

I'd also like to thank Grammarly for bailing me out on editing Caregivers Wear Plaid. After several friends with English degrees anxiously wanted to edit our book, they all failed to even start or exhibit little progress. It is one reason why

most people do not accomplish their dreams in life because they do not commit to achieving their vision of the future. That is for another book. In the meantime, Grammarly not only checked for grammar but plagiarism too.

I also want to thank Patty. She has had my back ever since we first met in 4th grade. Though our travels through life have taken us down many different paths, our being together again over the last 20 years has brought me greater understanding and humility about the life she has endured with lupus. She rises above the disease and inspires many to live their lives to the fullest regardless of their circumstances. Her insights and knowledge while writing Caregivers Wear Plaid have been invaluable to the process. And thus, we share in the creation of our book, which we hope opens a new chapter in our life by helping countless others through the magic of the internet and the content we create.

Finally, when you download Caregivers Wear Plaid or purchase a printed copy through your favorite bookseller, you can stay in touch with us through Youtube, where I will share additional information. So please subscribe at Caregivers Wear Plaid or visit our website at www.caregivers-wear-plaid.org.

Thank you for who you are and your commitment to your love one's health and quality of life. Whether you realize it or not, you are a very special person to do so!

Patty and Sean live in the sleepy little *Village of Lake Park*, North Carolina. Their involvement with the Lupus Foundation of America North Carolina Chapter goes back over 20 years . . . both serving as board chairs. Patty from 2007 - 2009 and Sean from 2013 to 2015.

Their involvement goes beyond volunteering to mentoring those who are in need through better understanding their disease, circumstances and providing encouragement for the now and their future as patient / caregiver.

Other books written or cowritten by Sean are:

Holding the Moon in the Palm of Your Hand - Author

Low Tech Hacking: Street Smarts for Security Professionals
- Co-Author

Techno Security's Guide to Securing SCADA: A Comprehensive Handbook On Protecting The Critical Infrastructure
- Co-Author

A Manager's Guide to Safeguarding Sensitive Information Properly - Author

An Employee's Guide to Safeguarding Sensitive Information Properly: 12 Keys Every Employee Should Know - Author

Praise For

Caregivers Wear Plaid

What Others Are Saying

"I really enjoyed ***Caregivers Wear Plaid!*** It certainly made me feel so loved as to what you caregivers do! It mostly gave me time to reflect on how at times, we are very demanding on you. I have tried to be more careful and NOT be so pushy. I loved it from a Thriver's point of view."

– Carol, a lupus thriver

"Caregivers Wear Plaid is great and an eye opener. I am sure somebody famous said, and if not, I will say it, "It is not how much you think you know but how little you really knew." How little I knew, and the patience necessary to be a good caregiver. I am learning every day."

– Derek, husband to a lupus thriver

"I think ***Caregivers Wear Plaid*** is really going to help so many people! It's wonderful!"

– Jenny Prince, CEO & President, Lupus Foundation of America's North Carolina Chapter