

Informational Book for Patients Newly Diagnosed With Systemic Lupus Erythematosus

A Thesis submitted to the University of Arizona College of Medicine -- Phoenix in partial fulfillment of the requirements for the Degree of Doctor of Medicine

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Class of 2013

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DEDICATION:

To my parents, who taught me never to feel sorry for myself and
who cared for me, without exception, always.

To Mayan & Raya, who have always taken their role of big sister seriously,
no matter how old we get.

To my husband, Hugo, who always pushes me forward.

And to my son: my heart, my smile.

ACKNOWLEDGMENTS:

I want to thank Dr. Bill Finch and Dr. Burt Feuerstein for their role as scholarly project advisors,
and for standing behind this project and its goal to help patients rather than crunch numbers.

I would also like to thank the rheumatologists and researchers in Arizona
who generously offered their time to disperse and collect patient surveys.

Thank you Tricia Parker, former colleague, friend, editor.

To David Spero, for reading, and providing invaluable advice and for,
once again, reading and reading and reading.

And to the patients who shared their stories and their wisdom.

ABSTRACT:

Objectives/Hypothesis To provide a useful resource for patients newly diagnosed with SLE (Systemic Lupus Erythematosus).

Methods Surveys were distributed to patients currently living with SLE via three rheumatology offices. All surveys were completed anonymously. Survey responses were combined with personal patient anecdotes as well as medically focused questions and answers to create a complete educational piece under the genre of narrative medicine.

Results Patient survey responses provide a variety of information for patients and clinicians. Low response rate encouraged the addition of supplemental sections in the final product in order to create a piece with a significant amount of patient-centered information. The format therefore changed with the addition of Doctor in Training sections, highlighting answers to commonly asked patient-centered questions on SLE as well as personal anecdotes building on the narrative medicine format.

Significance The combination of patient survey responses, personal anecdotes, and question/answer sections unite to provide valuable information in a unique format to patients newly diagnosed with SLE. Specifically, the survey responses give future patients a variety of viewpoints and tips on how to handle living with lupus while the narrative medicine pieces allow patients to view themselves in the role of an expert of their disease.

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INTRODUCTION

Background

Lupus is a chronic autoimmune disease that can target any part of the body and is estimated to affect nearly two million people in the United States alone. The disease has periods of flares ranging from mild to deadly and brings with it issues that require daily awareness and monitoring. A patient actively involved and aware of her care is likely to have a healthier disease course. That said, SLE's complicated disease course makes it difficult for a single patient educate themselves about their own disease and its idiosyncrasies. It often takes patients years to learn helpful tools that help manage day to day aspect of their disease. The hope is that surveying patients currently living with lupus will uncover pearls of information for future patients to access immediately upon diagnosis. This information may take a given patient years of struggling to discover, and will hopefully allow future patients to avoid those same struggles, approach their disease with a useful arsenal of information, and avoid pitfalls of their predecessors. These pearls are compiled with personal anecdotes in the form of narrative in order to more fully express the journey from the patient's viewpoint and allow further insight into the life of a patient with SLE.

Significance

One in eight women in America will develop breast cancer. Likely due to its high prevalence, breast cancer enjoys immense funding and public awareness. Thanks to this, there are many sources – in all formats – for patients newly diagnosed with breast cancer. In contrast, according to the Lupus Foundation of America, the best estimate to date is that 1.5-2 million people in the US have lupus. The dearth of information available to patients is likely a reflection of those numbers.

Currently, there is no book written about lupus by someone who has both the personal experience to understand its day to day challenges and the medical education necessary to understand its pathophysiology.

There are a few books written by patients, a handful by medical doctors, psychologists, or therapists. There are some written as a patient-doctor team. But there is nothing written by a doctor (or soon-to-be) who is also a patient. Thus, the current literature paints the patient into the limited role of the “sick one” and leaves the explanations up to the doctor experts. A study completed as recently as December, 2011, conducted by Waldren et. al., called for the need to provide patients with pertinent information at the time of diagnosis. My study is similar to this work in that it surveyed patients with lupus; however, study participants in Waldren et al were viewed strictly as patients providing information to elucidate what patients want to know, and when they want to know it, rather than to collect experiential information from the patients.

The Lupus Foundation of America has a webpage, www.lupus.org, that provides a wealth of information for patients. However, this information is largely mechanical, (ex: How lupus affects the body. Treatments for lupus. How is lupus diagnosed.). The Lupus Foundation’s life style responses are presented as facts and figures, “80% of people with lupus experience fatigue.”

While this information holds significant value, it contrasts with this piece, which is presented in a narrative format, viewing the diagnosis as a journey and providing personal stories and practical tips to patients.

A popular resource for information among patients living with lupus is, *The Lupus Book* by Daniel J. Wallace. The book focuses on the pathophysiology of the disease, explaining how different parts of the body are affected by the disease. Dr. Wallace discusses treatment options and provides a general explanation of lupus. Again, the type and format of information in Dr. Wallace’s book differs considerably from this work.

This work’s unique perspective positions the patient in an empowering role. A fourth year medical student with SLE gives the narrative. The patient’s narrative voice allows for expression of experiences shared by many people who live with lupus, while the medical narrative voice provides the academic underpinning to explain medical aspects of the disease. This combination helps the patient see herself in a role beyond patient, able to face the disease with a new sense of ownership over all of its facets.

The first literature search, conducted in 2009 resulted in no findings of similar works. However, a recent literature search, produced the previously mentioned study, published in December, 2011 surveyed patients with SLE with the aim to ascertain what information would be helpful upon initial diagnosis. While this study shares a common theme of this work, that of uncovering a need for practical information for patients with SLE, it focused on determining what the need is, rather than providing the actual information.

Aims/Goals/Hypothesis

At this time, there is no source of practical information to help doctors or patients newly diagnosed with SLE navigate through this difficult time. That said, patients, over a period of many years, learn tips, tricks, and pearls of wisdom they find helpful and wish they would have known from day one. This project collects information and stories from patients via surveys to accurately determine what patients wish they would have known at the time of diagnosis and what they would like to tell newly diagnosed patients to help them through the transition into life as a patient with SLE. This information is paired with personal narrative illustrating various aspects of the disease process to provide a holistic account of a diagnosis of SLE.

According to a study conducted by Meszaros et. al, depression is present in up to thirty-nine percent of patients with SLE and, “The patient’s reaction to the illness may result in anxiety and depression.” Yet there is little information available to these patients on how to deal with the new issues that are suddenly a part of their lives. With that in mind, it is important to give patients support so that instead of feeling despair, they can feel informed and in control of how to move forward.

RESEARCH MATERIALS AND METHODS

The method of this project is a survey. The survey consists of open ended questions with unlimited space for patient response (Please see appendix 3 for copy of survey). The goal response was fifty surveys; however 25 surveys were collected. The main objective in this project is for it to be immediately useful to patients. In accordance with IRB requirements, no identifiable information was collected; this includes age, race, sex, etc. Thus, there is not a statistical component. Rather, the study collected experiences and advice directly from patients, then gathered, categorized, and consolidated it into useful pearls of information.

In order to survey patients, we obtained approval from the Institutional Review Board (IRB) for human subjects research. Per IRB protocol, both the student/researcher as well as the Scholarly Project advisors completed human subjects training. Additionally, all survey methods received Dean approval and were then forwarded to University of Arizona's IRB for final approval.

The researcher, acting as the role of a patient, as well as the advisor (WRF), with years of experience as a rheumatologist, chose questions based on what they determined to be core issues. These questions were grouped into naturally occurring categories: Labs/procedures, medications/treatments, lifestyle, general health, relationships/work.

In order to distribute the survey while maintaining patient privacy, we recruited rheumatologists who then distributed surveys to their respective patients. We attended a meeting of the Phoenix Rheumatology Association and presented the topic to local rheumatologists. In addition to the rheumatologists recruited at this meeting, we used the Arizona Medical Board's list of physician contact information in order to locate rheumatologists in the Phoenix Metro area who were not in attendance at the meeting. Lastly, we recruited both a lupus researcher and a rheumatologist at UMC in Tucson to distribute the surveys.

Instructions provided to participating physicians requested that physicians distribute the survey to all adult patients who meet the American Board of Rheumatology criteria for a diagnosis of SLE.

Instructions to patients gave a clear explanation on how to complete the survey to the best of their ability and to then return it to their rheumatologist in a provided, addressed, stamped envelope. The rheumatologist then removed the survey from the envelope in order to double check that no patient identifiers were inadvertently included, and returned the completed surveys to the researcher.

Over 250 surveys were produced for distribution, with the hope of receiving 50 in return. To date, twenty-five surveys have been returned. SLE is a relatively rare disease and patients who are past the initial stage of diagnosis are commonly in good control, thus, have fewer visits with their rheumatologists. Additionally, the survey has a long, free write answer format that is time consuming to complete, likely contributing to the fact that fewer than fifty surveys were completed.

RESULTS:

The result is largely a book with three components (see appendix 4). Methods used to select patient-provided information for the book are outlined in the table below.

The survey posed 27 questions. Twenty were a part of the book. I decided to use a given question and its corresponding responses based on four criteria:

- # of Responses: Number of responses to the question
- # of Themes: # of Classes of Repeated Results
- Correlated to Personal Anecdote: Whether or not author had a personal anecdote for this topic
- Sense/Nonsense: # of questions that made sense/# that did not make any sense

Of the twenty-seven questions posed in the survey, nineteen were related to topics for which I had a corresponding personal anecdote. Thus, I included those nineteen questions in this stage of the book along with the final question, "Any other advice?" Although there were twenty-five total surveys returned, respondents gave answers only for questions they felt pertained to their experiences. Thus, the number of responses to each question ranged from ten to nineteen. Of those responses, anywhere from zero to three responses per question I labeled as "nonsense", that is, the response was off point. Commonly, the nonsense responses complained about a particular experience and did not provide advice to future patients. Furthermore, themes arose for each question, and I grouped the responses for each question by them - there were two to five areas of focus for each set of responses. I was careful to ensure that a response corresponding to each theme was represented in the book, but I also minimized redundancy.

TABLE 1

| | | | | | | | | | | | | | | |
|----------------------------------|------|------|------|------|------|------|------|------|------|------|------|------|------|------|
| Question #s: | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 |
| # of Responses: | 19 | 15 | 13 | 13 | 15 | 17 | 18 | 18 | 17 | 17 | 18 | 18 | 16 | 14 |
| # of Themes: | 3 | 3 | 3 | 2 | 2 | 7 | 3 | 4 | 3 | 3 | 4 | 2 | 2 | 2 |
| Correlated to personal anecdote: | Yes | Yes | No | Yes | Yes | Yes | Yes | No | No | Yes | No | Yes | Yes | Yes |
| Sense/Nonsense: | 19/0 | 12/3 | 11/2 | 11/2 | 13/2 | 14/3 | 18/0 | 17/1 | 17/0 | 15/2 | 15/3 | 18/0 | 14/2 | 11/3 |

| | | | | | | | | | | | | | |
|----------------------------------|------|------|------|------|------|------|------|------|-----|-----|------|------|------|
| Question #s: | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 26 | 27 |
| # of Responses: | 18 | 18 | 16 | 17 | 18 | 16 | 14 | 15 | 12 | 10 | 13 | 13 | 11 |
| # of Themes: | 2 | 3 | 3 | 3 | 5 | 2 | 3 | 3 | 3 | 3 | 4 | 4 | 2 |
| Correlated to personal anecdote: | Yes | No | Yes | Yes | Yes | Yes | Yes | No | Yes | No | No | Yes | No |
| Sense/Nonsense: | 16/2 | 17/1 | 15/1 | 15/2 | 18/0 | 14/2 | 13/1 | 13/2 | 9/3 | 7/3 | 13/0 | 13/0 | 11/0 |

Table 1. Summary of survey responses. There were 27 questions. The book sampled responses from 20 of them. Criteria for inclusion included number of responses, number of themes, relationship to personal anecdote, and whether responses were sensible.

DISCUSSION

From inception, the goal of this project has been to provide a concrete and immediately useful guide for patients newly diagnosed with SLE. Although I share my own experiences and insight into the disease, I do not have firsthand knowledge of every aspect of the disease process. Thus, the patient survey responses serve to expand the knowledge base, assembling insight from numerous patients on their disease processes and how they handle its intricacies.

This work contributes to the field of rheumatology as it provides an inclusive resource for physicians to recommend to patients newly diagnosed with SLE. Additionally, physicians who have patients with SLE, namely primary care physicians and rheumatologists, can read this work and understand a true depiction of life as a patient with SLE.

The book should be offered to patients on the day of diagnosis. This provides an immediate resource for patients to peruse at their own leisure and comfort level. The Waldren et. al. study, concluded that patients receive inadequate information at the time of diagnosis leaving them fearful and confused. Additionally, the study set a charge for healthcare professionals to create an educational resource to be delivered at the time of diagnosis. This work answers that charge.

The addition of a “Doctors In Training” section, one that answers patient-centered question from an (almost) physician perspective, serves to broaden the scope of information conveyed to patients and adds to the tips provided by the patient-experts.

One drawback of the project is the lack of returned surveys. Possible explanations for the minimal response, length of the survey as well as minimal visits to ones rheumatologist after years of diagnosis, were mentioned in the Research Materials and Methods section. Additionally, the survey was only distributed in English, although a large number of patients are Hispanic and, in Arizona, may be primarily Spanish speaking.

FUTURE DIRECTIONS

The book has many options for expansion. Once diagnosed with SLE, every aspect of one's life is affected. Thus, a continuation of this work, can include additional personal anecdotes, further Doctor in Training sections, and more patient responses in the expert section. In order to foster higher response numbers, an online version of the survey can be created where patients are instructed to follow a link, complete the survey, and submit directly via the website. With additional IRB approval, the online version can be offered in Spanish as well. A web version of the survey would allow greater ease for completion for patients more comfortable with computers than paper and pen. Additionally, it eliminates the additional step of mailing the survey and ensures that patients do not lose the survey between their physician's office and their home. Lastly, a web based survey allows for nation-wide distribution. After receiving a greater number of returned surveys, the book can be expanded with the new advice gleaned from patients. Ultimately, after distribution of the book, I can create an additional survey method to evaluate its usefulness.

CONCLUSIONS

There is a genuine need to provide newly diagnosed patients with an honest account of life with SLE as well as answers to the many questions that present themselves soon after diagnosis.

Combining one woman's personal stories of living with a diagnosis of SLE in a narrative medicine format with tips from twenty-five additional people living with the disease as well as answers to medically focused questions gives a holistic view of living with the disease as well as practical guidance.

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Appendix 1 – Letter to Participating Physicians

Attached are letters to patients, surveys, as well as addressed, stamped envelopes.

Please ask your patients with SLE if they are interested in completing the survey and, if they are, please send them home with a survey and envelope.

The surveys may be completed in their entirety, but it is not necessary; whatever a patient provides is useful and welcomed.

Please remind patients that they should NOT include their name or any identifiable information on the survey as it must be completely anonymous in order for the comments to be read and used.

In order to protect anonymity, return envelopes are addressed to your office. If patients return the survey with identifiable information on the envelope, please have the survey removed from the envelope before I pick the surveys up from your office.

Thank you very much for your assistance in this project.

Appendix 2 – Letter to Patients

You are invited to participate in a study conducted by a medical student at the University Of Arizona College Of Medicine. The study involves asking patients with Systemic Lupus Erythymatosis (SLE) to write down advice they would give to other patients when they are first diagnosed with SLE. The medical student doing the study plans to compile this advice and potentially publish this advice as a guide for patients newly diagnosed with SLE. You are being asked to fill out a survey for this study because your doctor has diagnosed you as having SLE.

No information that would identify you is being collected in this survey. In fact, you are asked to be sure NOT to include your name, address or any identifiable information on your survey.

There is no direct benefit to you from participating in the study. It is hoped that the information from the survey and the guide that is prepared based on the survey may help other patients with SLE.

The risk of the study is loss of privacy but because you are being asked to leave off any identifying information, this risk is very, very small.

If there are any questions during the course of this study, you should talk to your doctor.

Participation in this study is voluntary. A decision not to fill out the survey will not affect you or your medical care. You may discontinue participation at any time.

If you choose to participate in this study, please fill in the attached survey and return it in the accompanying self-addressed, stamped envelope. Any information you provide will be extremely helpful and appreciated.

Once again, DO NOT INCLUDE YOUR NAME ADDRESS OR ANY OTHER INFORMATION THAT WOULD IDENTIFY YOU ON THE SURVEY OR THE ENVELOPE.

Thank you.

Appendix 3 – Patient Survey

As a person with lupus, you know that the diagnosis can affect many areas of your life. In the following spaces, please give tips/advice to a patient newly diagnosed with lupus concerning the listed subject areas. You do not need to fill in all of the items. Complete as many portions as you wish. In the event that you would like to provide additional tips/advice or need more space, feel free to write on the back of the pages.

Labs/Procedures:

1. Blood draws (Something you do that makes the process less uncomfortable...):

2. Urine collections (Random collections vs. 24-hour, tips to make the 24 hour collection easier...):

3. Procedures (What you've experienced: biopsies, bronchoscopy, EGD – what was it like, tips to make it easier...):

4. Time in the hospital (Why you've had to be in the hospital, What made your stay better...):
(what to anticipate)

Medications/Treatments:

5. Medication maintenance (Success in specific treatments, Conventional vs. nonconventional treatments, cost...):

6. Side effects of drugs/treatment (Short/long term side effects, Specific medications, Ways to minimize the side effects, Medications with which you've had less trouble...):

Lifestyle:

7. Sun avoidance (Sunscreens, protective clothing, activities that don't involve the sun...):

8. Stress relief (Are there any things that you have found that are especially helpful in relieving the stress that you might feel because of having SLE? Techniques, Yoga, Activities, Antidepressants, experience with counseling...):

9. Disease or medications effect on appearance (cushinoid, alopecia, acne, striae, hair loss...)

10. Traveling (Do you have advice to other patients with SLE about how to pack medications, avoid the sun? Is there anything that a person with SLE might expect to happen differently to them than to someone without SLE when they travel?):

General Health:

11. Maintaining general health (Regular check-ups, vitamins, osteoporosis...):

12. Communicating with your physician (How often you see your doctor now, how often you used to see your doctor, communicating your needs, what are your expectations...):

13. Keeping/charting your own medical records (Keeping track of your progress vs. a hands off approach...):

14. Exercise (Starting new programs, Benefits...):

15. Fatigue (Effects of fatigue on day-to-day living, How it affects specific aspects of your life...):

16. Pain (Ways to alleviate pain symptoms...):

17. Depression (Tips on how to prevent periods of depression and/or improve symptoms once they set in...):

18. Diet (What you've done to maintain your health, Weight, Well being through changes in your diet...):

19. Where you get information (Webpages, Books, Magazines, Attending lectures by physicians, Support groups, Good/Bad...):

Relationships/Work:

20. Romantic relationships (Dating, Maintaining a relationship, Sex, Communicating needs with your partner...):

21. Friendships (Communicating needs with your friends, telling your friends, changes in your relationships):

22. Family relationships (Communicating needs with your family, Change in family dynamics, Withdrawal...):

23. Pregnancy (Getting pregnant, Being pregnant, Difficulties, Ways you made your pregnancy easier...):

24. Raising children (Taking care of children while caring for yourself, Participating in activities with your children...):

25. Work/School (Keeping up with work, Telling colleagues/your boss/professors, Time off...):

26. Explaining your diagnosis to others (Different reactions you received, how you communicated your diagnosis and subsequent needs to people in your life...):

27. Any other advice:

Appendix 4 - Book

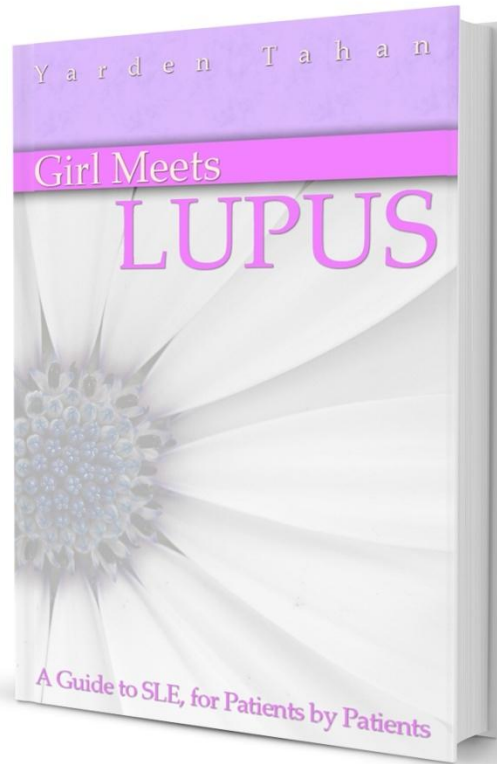


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Introduction

Growing up in the Tahan household meant quickly learning that nothing hurt that bad, nothing was that big of a deal, and, unless death was imminent, no missing school. So when, on the day I was diagnosed with lupus, my mom said, *“Maybe you want to take a year off from college,”* I knew things must be bad.

This is the point where I could have crumbled, cried, thrown my hands in the air and asked, *“Why me?!?”* I could have taken my mom up on her offer, an extra year - funded by my parents -- with no responsibilities. But I’m lucky that I spent the twenty years prior to that statement in the house of, ‘You’re fine, suck it up.’ This philosophy taught me well, and I went the other way.

Don't get me wrong. The crying happened, as did the *“Why me?!”* I once threw a phone across a room, but it was my phone in my room. After each instance where I felt like it was all too much, when I settled, when I breathed, when the shock subsided -- for the moment -- I went back to my old standby of sucking it up. That didn’t mean ignoring, and it didn’t mean pretending, it didn’t even mean getting over myself. Instead, what I learned is that regardless of what is going on -- and sometimes there is a whole heck of a lot going on -- time passes with or without me, my life moves forward whether or not I’m at the wheel, and the best thing I can do is to control what I can, accept (and occasionally curse at) what I can't, and move forward.

Lupus is what motivated me to leave teaching, a position that I happily held for seven years, and enter medical school. I admire my doctors and feel safe in their hands, but there has also always been something missing. While they are adept at taking care of the medical components of this disease, there is a dearth when it comes to dealing with its daily challenges. This is not out of malice or even simple lack of time, but more likely, lack of knowledge. The physicians caring for me have long known infinitely more than I concerning the intricacies of the immune system

and the inner workings of the kidneys; however, they are fortunate enough to not understand the daily struggles of dealing with a chronic illness and cannot appreciate the details of a life that suddenly transform in the time it takes to read a lab report.

There was a time in my life when I felt so weighted down, so encumbered by this disease. I think back to the nights I spent poring over my lab results, looking up every word and number, trying to make sense of them, and feeling so desperate and out of control. I feel as though it is a different person I am remembering, and I want to cry for her sometimes. I want to cry for the uncertainty she feels, the fear, the suffocating sense of helplessness.

So I decided to become a doctor. My intention is to learn the medicine behind disease processes and combine it with my knowledge of being a patient, so that I can better care for others. And with this intention I embarked on this project to collect information from the entire medical community, those who, through their studies, are experts in the medical aspects of lupus as well as those who, through their circumstances, are experts in living with the disease.

Consider this your Lonely Planet guidebook to lupus -- the trip on which you somehow found yourself even though you don't remember buying a ticket. I have compiled tips, advice, and pearls of wisdom from those who have long lived with their diagnosis of lupus. I call them my "Panel of Experts." They have had time to navigate this diagnosis and learn their own way of handling its peculiarities. Wisdom ranges from practical and upfront advice on how to best conquer a 24-hour urine test, to the emotional aspects of dealing with family and friends. Along the way, I shift from patient to doctor-in-training in order to include answers to some of the many medical questions that presented themselves on my voyage. Additionally, there are personal anecdotes, not just to amuse you through my own comedic mishaps, but more important, to remind you that you are not alone in this. You will have your own path and will learn your own ways no doubt, but my hope is that

some of the bumps ahead will prove that much smoother with the wisdom of others who know your struggle along for the ride.

Reading Guide

Each chapter contains a brief introduction followed by three sections: Personal Anecdote, indicated by underlined text, comments from a panel of experts, delineated by boldface text, and a doctor-in-training section, shown by italics.

A Quick Lesson: Why Does My Immune System Hate Me?

Webster's Dictionary defines Systemic Lupus Erythematosus as:

“An inflammatory connective tissue disease that is often held to be an autoimmune disease and that occurs chiefly in women, is characterized especially by fever, skin rash, and arthritis, often by acute hemolytic anemia, by small hemorrhages in the skin and mucous membranes, by inflammation of the pericardium, and in serious cases by involvement of the kidneys and central nervous system”

A fascinating read, I know.

Now although you can't tell your friends why you're the unlucky winner in the Who's-Next-To-Get-Lupus drawing (the jury's still out on exactly how it's acquired), you can give them a synopsis on what it is.

I like to frame my description as if I'm speaking with a third grader. Keeping it simple gives you a pretty good chance of being understood and may keep the follow up questions at bay. So, what is lupus? Lupus is a chronic, autoimmune disease. Chronic, meaning that although it can usually be controlled by medication and lifestyle changes, it will never go away completely, and autoimmune, meaning your immune system is attacking itself. Back to the third graders...

What you have, my fellow lupus warrior, is a super strong, super confused immune system that can't differentiate a nasty cold from its own darn kidney, so it attacks the kidney (or anything else that gets in its way) as if it's fighting a bad guy.

The reason that some organs are targeted more often than others by this half-witted immune system is beyond the scope of this guidebook, but suffice it to say, when your immune system gets triggered – either by illness, UV rays, stress, etc., anything in its reach (which, unfortunately, is all of you), is up for grabs.

Now, before you run to get your third grader a tissue, because honestly, that explanation is a little monster-under-my-bed terrifying, console him by explaining that there are many ways to control this wacked out immune system to keep the little bugger behaving, a few of which we'll discuss in this very book.

Number One - Urine Collections

Lupus introduces a lot of new demands into your life. My mother once described a chronic illness as a full-time job for which you do not get paid. One such demand is the constant barrage of fluid collections. Blood, urine, it feels like anything doctors can get their hands on, they'll collect from you. These tests can be mildly uncomfortable, but more so, they take your time and energy, two things that are usually not in abundant supply when you are first diagnosed with a life altering disease. One such test is the 24-hour urine collection. Over the years, I've grown to both despise its unwieldiness and respect the power of its results.

Why mini-fridges aren't just for dorm rooms, buckets aren't just for mops, and how a lunch cooler can make a handsome urine carrying case

I used to think that a 24-hour urine test -- the hat, the giant orange jug they give you for urine collection, the refrigeration requirements -- was the pinnacle of annoyance. I believed this until I had to take a 24-hour urine test during medical school. Suddenly, the annoyance level crept to a previously undiscovered intensity. I thought, "This is it: 24-hour urine test, literally in the middle of back-to-back med school classes, surrounded by people who have no idea I am sick. I am officially over the annoyance threshold." But, I was wrong! I speak with near certainty now that a 24-hour urine test during pregnancy is the most maddening of them all. For those who have never experienced the joy of urinating while pregnant, let me assure you, it is taxing. All of your clothes have tight, elastic waistbands. It is difficult enough to maintain balance during any menial task, much less whilst hovering, pants down, over a specified target. As though collecting every single drop of urine weren't difficult enough for any woman, when I was pregnant, the weight of an ever burgeoning uterus squished my bladder into the size of a thimble, and I seemingly went every 20 minutes, perhaps five drops at a time. I used to look down at the hat collector and think, "Really? Really, this miniscule volume of fluid is worth a trip to the fridge?" If that big, orange jug could have shown emotions, I am certain that it would have laughed at me.

My first 24-hour urine test, thirteen years ago, was not so pleasant either. It was soon after diagnosis and I was an undergrad. My eldest sister took time off from work to stay with me while I navigated through the first few weeks of this new life. She was quickly demoted from high-powered attorney to urine carrier. The rheumatologist said I needed to have the test done ASAP, and I was determined not to miss any classes because of a silly urine test (see intro regarding "suck it up" childhood). This was mistake number one. As our panel of experts will advise you, staying home

during the 24-hour urine test is the way to go. But I did not know better. My sister, my roommate's brother's insulated lunch box (he never knew), and I headed to campus with eight small, empty specimen containers – bright yellow tops and all. As this was my first collection, and a particularly clueless (or evil) lab tech handed me the supplies sans “hat” as they call it (the piece of plastic molded to fit into your toilet, hovering just above the water line, to pre-collect your urine before you transfer it into the large orange jug), who knows how much of my urine ended up in the Tucson sewage system that day? But unfortunately where this task is concerned, I am not a man, and squatting over a container with a two-and-a-half inch diameter opening is not ideal or efficient for urine collection.

Because my collection containers were so small, I made it a point to use the restroom at the slightest urge for fear that if I saved it up, my cup may runneth over. My sister stood outside the stalls of nearly every restroom on campus as I maneuvered myself behind the door, sitting, squatting, willing myself to pee in a straight line.

Alas, 24 hours passed, the collection was over, and I was back to peeing directly into the toilet. Imagine that. I turned in the specimen, and they tested it for what? I had no idea at the time. I assumed the results were good, as I heard nothing about them again. This was early on in the disease process. I was overwhelmed. I assumed that whoever was taking care of me was also taking care to know what tests I needed, why, and what all of the results indicated. There seemed to be no sense in me doubling up on someone else's job. Quite frankly, I was just happy to pee sitting down again.

Expert Comments on Urine Collections:

“The instructions are tricky. The first morning start time is actually the first urine you flush down the toilet. You start collecting your second urine of the day and continue collecting all the way up until your first urine of the second day.”

“Plan to do this on a day off unless you enjoy carrying around the urine container.”

“Plan it on a day when you can stay home or be close to home.”

“Do not drink more or less than you would on any other day; this could affect your results. It’s important to collect all urine during this period of time; not just a sample. Try to follow instructions to the letter.”

“Ask the lab technician for a “hat” to collect your urine. It fits snugly in your toilet so you urinate into it and then transfer the urine into the large jug. It beats trying to aim into a tiny cup.”

“Keep a mini-fridge (or a bucket filled with ice in a pinch) in your bathroom. It beats walking to the fridge every time you have to pee, especially if you get up in the middle of the night”

If you don’t have a bucket, another suggestion...

“Fill a trash can with ice, place 24 hour collection vessel into ice. This way it is NOT necessary to put urine in fridge to keep cold. Also this makes the entire process cleaner.”

And perhaps most to the point: *“Just Do It!”*

Doctor-In-Training:

Here's where you may be asking yourself: "What does my doctor want with all of that urine anyway?" Elevated protein in your urine is a good indicator that your kidneys are sick. The kidneys' job is to filter the blood, let the toxins out into the urine, and keep the good stuff (like protein) in the body. Sometimes with lupus, immune complexes deposit in the kidney. There, they create inflammation and the kidneys' filtration system is not effective; therefore, larger particles, such as protein, leak into the urine. By checking for this leaked protein, your physician knows if your kidneys are doing their job.

On to the test...

First, find out why you are doing this collection. 24-hour urine tests were long considered the gold standard by which to determine urine protein loss, but mounting medical research has shown the spot urine protein/creatinine ratio to be the front-runner in measuring protein output and progression of disease. Depending on where and when your physician was trained, she might already be aware of this, but if not, it is worth your weight in urine (and 24 hours of your life) to ask. Most rheumatologists and nephrologists have already joined this bandwagon, but other specialties (for example, OB) have yet to jump on board. If they need a little convincing, perhaps ask them to look over this article published in the British Medical Journal (BMJ) ("Cross sectional longitudinal study of spot morning urine protein:creatinine ratio, 24 hour urine protein excretion rate, glomerular filtration rate, and end stage renal failure in chronic renal disease in patients without diabetes" BMJ 1998;316:504). The short of it: "Compared with 24 hour urinary protein excretion rate, the spot morning ratio is an even more reliable predictor of decline in glomerular filtration rate and progression to end stage renal failure and represents a simple and inexpensive procedure in the determination of severity of renal disease and prognosis."

If she's still not convinced, hear her out as well. She might have a reason for wanting the 24-hour collection, and you can use the day as an excuse to clean up your DVR queue or to sit in a dark room pretending to be Howard Hughes.

Chapter 2: Blood Draws: Your Soon to be Most Common Awesomely Invasive Procedure

With almost any chronic illness, blood draws become an integral part of life; lupus is no exception. Your physician will check your blood for markers of disease activity as well as results that indicate specific organ function. I have long viewed lab draws with the same enthusiasm one reserves for a smack in the head. But, love 'em or hate 'em (and who really loves them?), they're here to stay.

Vampires

I don't remember my first few lab draws. I remember what was going on around that time, I remember receiving the results, but I have no recollection of the actual lab, the phlebotomist, or whether or not I experienced any discomfort. In fact, the first year and a half worth of lab draws are a blur to me. What I do remember is that after I was diagnosed with nephritis, I hated going to the lab.

Not coincidentally, this was the same time I began to have regular – very regular – blood draws. The tests were usually once a week, sometimes stretching to once a month, and during particularly rough patches, twice a week. I felt anxiety about going to the lab. I dreaded the test as soon as I received the lab requisition slip from my physician and did not completely relax until I saw the results. Thinking about it now, most of the stress of the lab draw had more to do with the potential results than anything else. Once the lab draw happened, information about whatever my blood held was, to borrow a phrase from *When Harry Met Sally*, “already out there.” And once out there, as far as lab results are concerned, it had the potential to mean more medicine, a procedure, or a trip to the hospital.

For a long time, my eldest sister came with me to all of my lab draws. She'd leave her office in the middle of the day, meet me in the lobby of the local LabCorp or Sonora Quest, and distract me during the blood draw. Even though most of my fear related to the actual results of the tests, I somehow focused my anxiety on the blood draw itself, the needle, the discomfort, the bruising. I also felt very vulnerable, out of control, and my sister's supportive presence was important.

Eventually, I stopped reminding my sister about lab appointments. I felt guilty taking her away from work and other responsibilities, and I started to feel somewhat more comfortable with phlebotomists. I found myself going to the same lab for every test, and working with the same phlebotomist. Norma and I talked while she set up her supplies. She told me about her daughter, Angelica, who was starting kindergarten at the time, and who is in high school now. As time went on, I learned about

Angelica's trouble in math class, her successes in sports, and her junior high boyfriend who was, decidedly, according to Norma, "No good." Having a friendly face greeting me at the lab was comforting, and it felt good not having to point out which vein works best and explain my needle preference at each visit; Norma already knew.

Three years ago I came for my regular blood draw, but Norma was nowhere to be found. I needed tests far less frequently and had not seen Norma for a good three months. Her colleague told me that Norma received a promotion and was now working in a Labcorp corporate office. I was happy for her and would have liked to tell her as much.

After that day, I switched lab locations. There was one closer to my house that I hadn't visited because Norma wasn't there, but since Norma wasn't at my old lab either, it seemed silly to continue to make the drive. I have a new regular phlebotomist now, Vicki. Vicki also has a daughter, although I don't know her name. Vicki's daughter and I were pregnant at the same time. She also had a boy, and I enjoy the time in the lab when I hear about Vicki's grandson and all of the new things he's learning each day.

Expert Comments on Blood Draws

“Drink plenty of water before the blood test.”

“Use a regular (meaning the same one) blood lab is best.”

“You can make appointments online through the lab company’s website so you have less of a wait.”

“Tests are good; they let us know how we are doing.”

“Ask for a butterfly needle. Drinks lots of water before.”

“Be friendly with the phlebotomist. Ask them questions.”

“Don’t watch. If you think it might hurt, grip the armrest with the hand that is not being used. Use the blue butterfly needle (it’s smaller). Mind over matter.”

“Talking with the phlebotomist helps calm the nerves. And don’t look when they insert the needle and are filling the vials. I look around the room and focus on objects or pictures.”

“Schedule in the morning if fasting. Warm vein for 10 minutes prior to draw with a heat pack or by holding your other hand over the future puncture site.”

Doctor in Training:

So what is it about drinking water that helps with blood draws? We are made mostly of water, and our blood is over 80 percent water. If you are dehydrated, your blood volume may be low, and it will be more difficult for the phlebotomist to access your vein for a good stick. Being well hydrated for a lab draw combats this.

Heat helps in the same way for vein access. When your body is cold, your veins constrict, which makes a blood draw more difficult. Arriving to your lab draw with an extra layer to keep you warm, or a heating pad applied directly to the area where they will draw blood, will make the process easier.

Needles are sized counter-intuitively, with the largest number indicating the smallest needle. One of the smallest needles, an orange butterfly, is 25-gauge. Labs do not commonly carry this size, and, if they do, it is reserved strictly for pediatrics and can cause problems with blood collections in adults. The next size up is the 23-gauge blue butterfly needle. This needle makes blood draws easier, is the least painful, and can reduce your potential to bruise. Phlebotomists do not often choose this needle unless you're a baby – and I mean that literally, a very young person, not that you're crying and whining at them. You can however request a blue butterfly, or 23-gauge needle. It is your arm, your call, and it won't cause any problem with the blood draw or collection.

Keep all of these tips in mind, but also remember, most blood draws go off without a hitch. Millions of people visit labs across the country without tanking up on water, heating their arm, or requesting special needles, and they have perfectly normal blood draws without problems. If you do run into issues, you may want to start implementing some of these tips, but you may not need any of them.

Chapter 3: Prednisone and its Nasty Friends – Medication Side Effects

I have been on a lot of medications. I've been living with lupus for over thirteen years, and even in that relatively short time, medications have fallen in and out of fashion. All drugs have side effects, those pesky things that the drug manufacturers do not plan for, but that occur in patients anyway. In my experience, prednisone causes the most dramatic effects, both positive and negative. Allow me to explain my love/hate relationship with prednisone.

Wonder What? Wonder Drug

I want you to do something for me. Close your eyes.

Wait, what am I saying? That doesn't make any sense.

First, read this, then close your eyes and do what I've asked.

Imagine a person and a beach ball. First, a person, perfectly normal looking; let's give her long brown hair. Next to her, a beach ball. Any kind, really, perhaps one with multicolored vertical stripes. Now - and you'll need to do this once your eyes are closed - imagine the person's face and the beach ball merging into one, no vertical stripes of course. Right in front of you, picture this once normal looking person with a beach ball for a face. Same eyes, same nose, same mouth, same skin, but as if it has all been stretched over this very bouncy, very beachy, very big, round ball. That, my friends, is the face of prednisone. They call it moon face, but I've never seen the moon quite so large.

The first time I received steroids was in the emergency department. It was soon after I was initially diagnosed, before I understood much of anything. I was on few medications; one of them was Vioxx, an anti-inflammatory long since taken off the market. I came home to Phoenix from college in Tucson and was feeling nothing short of terrible. My hands were swollen, my body ached, and the rash was starting. By nighttime, my fingers looked like they had been twisted into existence by an amateur balloon animal artist. I couldn't bend them. My father, after clumsily attempting to tie my hair back in a ponytail since I couldn't manipulate the band myself, decided to take me to the ED.

I sat. My hands swollen. My skin burning. My dad despairing . My middle sister came to visit with a Muscle and Fitness magazine, an attempt at distraction. I held up my hands, two red oven mitts, as explanation of why I couldn't accept the gift. I had neither muscle nor fitness. I had a body that wouldn't work, and I was becom-

ing increasingly sick of it. The ED doc saw me, peeked beneath my underwear at the spreading rash, and declared that it was a Vioxx reaction.

That it wasn't a Vioxx reaction, but clearly a lupus flare, doesn't matter now and probably didn't matter at the time. They ran a bag of Solumedrol, one gram, though my IV, and sent me home. I went to sleep that night, exhausted by the events of the past few weeks, anticipating the next day to start like all the rest: swollen joints, arms that don't rise above shoulder height, and hands rendered useless.

But that is not what happened. The next morning I awoke feeling like I had never felt before. My fingers bent, my arms lifted, and I practically sprung out of bed like a baby bunny. I vividly remember walking into my parents' kitchen and saying to my mom, "Mom, look. Look! I can move my arms." Much to my chagrin, she wasn't as impressed. She knew what I had received at the hospital and was not thrilled with its potential side effects. She told me as much, to which I responded, "I don't care what it is. I'll take that every day if it can make me feel like this." That was early on. Before mood swings. Before osteopenia. Before beach ball face.

Expert Comments on Side Effects of Medications:

Our panel of experts has been on myriad medications. Below you'll see a listing of some of those with straight-from-the-horse's-mouth comments on their less desirable side effects.

PREDNISONE

Prednisone is a glucocorticoid that is a dehydrogenated analog of cortisone and is used as an anti-inflammatory agent, as an antineoplastic (anticancer) agent, and as an immunosuppressant.

"Bone loss (meaning, osteopenia/osteoporosis)"

"Difficult to wean off of it."

"It is difficult to wean off of the prednisone."

"Weight gain, bone loss, stomach problems"

"Bad side effect of Prednisone: Thin skin, bruise easily, skin tears easily."

"Steroids make you hyper and want to eat sugar."

"See if you can take other meds that can control your disease instead of steroids (prednisone). If you do take prednisone, try not to be on them for long periods of time."

"Prednisone caused dry, bruising skin, hair loss"

"Prednisone gave me Cushing syndrome. I went from 135lbs to 180lbs in a little over three months. My facial hair was also out of control. It also gave me avascular necrosis of the hips and knees"

"Prednisone (25 year course, but I'm off it now.) Causes puffiness and osteopenia. Shots of Depo Meradrol (steroid) can help when having flares."

METHOTREXATE

“Methotrexate is an analog of folic acid also used to treat certain cancers, severe psoriasis, and rheumatoid arthritis.”

“A big spaghetti dinner on the night you take methotrexate helps minimize nausea.”

“Methotrexate made me vomit but my daughter did not have this side effect.”

PLAQUENIL (HYDROXYCHLOROQUINE)

“Plaquenil is a drug derived from Chloroquin that is administered orally to treat malaria, rheumatoid arthritis, and lupus erythematosus.”

“Not expensive. Can cause stomach and bowel problems, but most build up a tolerance to these side effects. “

“Need to get regular (yearly) eye exams because, in rare cases, the drug can cause retinal disease that can be reversed only if caught early Procrit (erythropoietin): a hormonal substance that is formed especially in the kidney and stimulates red blood cell formation”

BENLYSTA (BELIMUMAB)

“Benlysta is a monoclonal antibody used to treat SLE.”

“Now on Procrit and Benlysta infusions. No side effects from these two drugs.”

CYTOXAN (CYCLOPHOSPHAMIDE)

“Cytosan is an immunosuppressive and antineoplastic drug also used to treat lymphomas and some types of leukemia.”

“Awful side effects, but was the only medication that treated and prevented neurological aspects of SLE. Ask for MESNA and Zofran to help with the side effects. Long-term use of Cytosan (for me only six months) led to a very low white blood cell count, which is still low two years after stopping treatment.”

“Destroyed white count, required hospitalizations.”

“Has the potential to make you lose your hair, didn’t happen to me.”

“I’ve had six rounds of it, twice. The first six were terrible with a lot of vomiting and feeling very sick most of the time. The second, six years later, was easier to take. They have better anti-nausea drugs now and sometimes can give lower doses of Cytosan that work just as well.”

CELLCEPT: (MYCOPHENOLATE)

“Cellcept is an immunosuppressive agent. Works by weakening the body's immune system so it will not attack and reject a transplanted organ or itself.”

“Cellcept seems to work for me.”

“Cellcept destroyed red blood cells requiring blood transfusions.”

“Can cause stomach upset when taken on an empty stomach. You can ask your doctor if it is better for you to take it with food or without if you have that problem.”

GENERAL ADVICE ABOUT MEDICATIONS:

“Keep a journal of side effects. Diet, activities to help you and your doctor best manage any side effects that may occur.”

“Like a baby eating new foods, never start several new drugs at once because if a reaction occurs, you won’t know which med is responsible.”

“Be sure to read the inserts from your pharmacy. Be informed!”

Doctor In Training:

The truth is, steroids will make you feel great. Sometimes too great. People have been known to stay up all night, shop compulsively, even gamble, all under the influence of steroids. But that's the exception rather than the rule. It is almost certain that if you are placed on high-dose steroids for a significant length of time, you will gain weight. Your doctor will instruct you to listen to your head, rather than your stomach, to know when you should eat. It is a suggestion that flies in the face of what we've always been told and it is one that is extremely difficult to follow.

But this scenario is becoming increasingly rare. With all of the new drugs on the market, high-dose steroids are reserved for refractory cases, those that do not respond to other drugs. This means if you're getting them, you really need them. And, the lower doses that are at times still used for maintenance do not have the same level of side effects.

If you do find that you have to be on the strong stuff, know this: It works. Steroids will make you feel great, and you feel that way because they're doing a terrific job at controlling your disease. If they didn't have all of those nasty side effects, we'd all be on them, all the time.

You and your doctor will need to weigh the pros and cons of both starting and stopping steroids, just as you do with any other drug. One big difference with this though – you CANNOT abruptly stop steroids. Even if you wake up one day, stare at your beach ball reflection, and think, "Enough of this!" You cannot simply stop taking the drug or your body can go into withdrawal with grave consequences.

One purpose of slowly tapering your steroid dose is to make sure that your disease state is suppressed and will not spring back to action the moment the steroids are discontinued. As you lower the dose gradually, your doctor can monitor your labs and/or symptoms to see if you are truly ready for the decreased dose.

However, the main reason for a slow taper is glucocorticoid withdrawal. Your adrenal glands make your own steroids. But taking exogenous (from outside our body) steroids, suppresses your own adrenal steroid production. If you abruptly stop the exogenous steroids before your body has a chance to start making its own steroids, you may experience adrenal insufficiency with symptoms that include: weakness, low blood sugar, fatigue, muscle aches, joint pain, and psychosis. This can be serious, so you always have to work with your doctor to plan a safe taper off steroids.

One exception to this is if you've only been on steroids for a very short time (one to two weeks). It takes time for the body to suppress its own steroid production, so if you are on what they call a burst dose for a short duration, your doctor may give you permission to simply stop the steroids without tapering.

Chapter 4: Alternative Medicine: The Good, The Bad, The Crazy

Desperate times call for desperate measures, and it is safe to say that in the early days of diagnosis, things felt pretty desperate. Perhaps no one felt the desperation as heavily as my mom. Being a mother myself now, I understand how difficult it must have been for her to see me sick and not have any means to help me. She used to come to my house every week when I was at work, pick up my laundry, and return it washed, ironed, folded. I recall one Sunday afternoon, returning home after spending my first post-chemo weekend at my parents' house, my roommate was waiting for me in the living room. "Your mom," he said, quietly, slightly shocked as if he'd just seen a ghost. "She came over yesterday. She said you were sleeping or something at her house. She came over and cleaned the house. She cleaned the entire house." As chemo infusions came and went, my mom maintained her practice of playing Mrs. Clean in my absence, and my roommate's shock subsided. She didn't know what else to do. As far as this disease was concerned, her hands were tied. Instead, she looked to find something, anything she could do to help me. It is one such thing that I am about to share with you.

Beam me up, Scotty

During one of my weekends home from school, my mom took me to a doctor she procured after much investigating. He is an MD, graduate of the prestigious McGill University, who had since eschewed Western medicine in favor of alternative healing. He promised to cure every ailment from toe fungus to cancer using non-medicinal approaches. My mother, worried that her daughter would forever depend on steroids and other immunosuppressants and still never get better, was eager to hear what this man had to say.

Sitting behind a desk was an older gentleman, white mustache, sparse hairline, fast talker. He passed two metal rods across the table, one for each of my hands, turned a dial, and asked me to think about different foods. “Turns out,” he said, “You’re allergic to a lot of what you’re eating and this is what is causing you to be sick.” Really? That’s it? Um, fantastic? Really? So, I thought, all I need to do is cut out eggplants and tomatoes and I’m home free? Not so fast.

There were other things, the doctor explained, I needed to do in order to help cleanse my body of its toxins and get it back on the path to health. After a previous raw food fiasco, I was not a huge fan of the word cleanse, but I was willing to listen; at that point, I was willing to do most anything. He continued to talk, pulling out vials of clear liquid, each with a different hand-written label. I was to take two drops of one, three of the other, and four of the last, every day, twice a day, and I should mix them all with a full glass of water. There was also a device, he went on, a machine that aims to cleanse my pores of toxins and jump start the healing process. “Do what I say,” he said, looking my mother straight in the eye, “and I’ll have your daughter cured in less than a year.” Signed, sealed, delivered.

After asking my mom to sit in the waiting area, the doctor asked an assistant walk me to a little room where I was instructed to get undressed and to sit in a large, smooth, plastic device. The contraption was open when I arrived, a hollow tube that was split in two vertically to reveal a small, hard, white plastic bench near the mid-

dle of one half and a semi circle cut out of the top of each half. I sat on the bench as the assistant closed the container around me, leaving me defenseless, arms and legs trapped inside, with only my head peaking out the one hole formed by the two semi-circles at the top. She started the device, and heavy steam escaped all around me. The assistant made her way toward the door, but before she twisted the handle, I asked her to send my mom back to be with me.

I knew my mom was desperate. The thing is, if there is an alternative medicine type of person, she is not my mom. She is good with proven facts, follows rules, and doesn't give a lot of credence to vague promises. That said, if someone told her she could cure me if she cut off her leg, swung it over her own head three times, and did the chicken dance whilst munching tree bark, she'd be out there clucking her way to my good health. Ultimately, she believed this doctor because she wanted to believe him, wanted so much for me to be well again. I sat, encased in plastic, waiting for her, wondering if anyone had ever been forgotten in this room, trapped in the device overnight, found the next morning shriveled to the likes of a very large prune.

When my mom opened the door to the little room, the look on her face was first that of confusion, then horror, and then, after confirming that I was alive beneath the steamy haze, amusement. I started to laugh as well; what else could I do? I could feel my skin reddening from the heated steam, prickles of pain making their way up my abdomen and down my legs. Cleansing or torturing? I pushed on the tube from the inside in an attempt to free myself, but it was locked.

"I'm stuck." I said to my mom with a mixture of shock and hilarity. She stood, clumsily making her way over to me, weighed down by her own laughter. It took a few attempts with the locking apparatus to finally free me, at which point I fell off out of the entrapment, doubled over in laughter.

We called for the assistant, who walked us to the front of the office to pay our bill. On our way, we passed a room full of women with needles in their hands and IV bags perched over each one of their chairs. They looked well enough, chatting with

one another, and I asked the assistant what they were doing. “Oh,” she responded, “It’s cold season. They come in for IV saline, which helps to prevent colds.” I contemplated asking if they’d ever considered a bottle of Evian and a box of Saltines, but thought better of it. That space age contraption may have steamed all of the optimism out of me, but as I looked at my mom, vials still clutched in her hand, her last bit of hope, I knew this wasn’t the end of it.

We returned to Tucson, my vials and I. Each morning and each evening, as directed, I mixed the drops of viscous liquid into a glass of water. Two drops from one, three drops from another, and four drops from the last, stir, drink. I started to feel tired. Two drops, three drops, four drops, stir, drink. Weariness turned to exhaustion. Two drops, three drops, four drops, stir, drink. My abdomen was beginning to hurt. Two drops, three drops, four drops, stir, drink. My roommate stayed with my dog as I made my way to urgent care. I gave a med list, but was too embarrassed to report the vials; besides, I didn’t even know what to call them. Magic potion drops?

The doctor at urgent care sent me away with antibiotics and instructions to rest and follow up with my regular physician. I went back home for a week. I can’t say that any of it was their fault, but the vials stayed in Tucson. Later, I learned that the holistic doctor with the MD had his medical license revoked ten years earlier for reasons that were not listed on the board’s website. I ran through my own theories, imagining the white mustached doctor sitting across the table from a line of medical board members, trying to explain why a patient stayed locked in the steam chamber for 24 hours.

After my raw food misfortune and horror-movie steam session, I was beginning to lose my patience. I understood the negative side effects of traditional medications, and wanted to limit their use where possible, but I couldn’t go on playing chemistry experiments on my own body. I did some more research and came across another MD, this one still licensed, who practiced integrative, rather than strictly alternative, medicine. He wrote books and encouraged patients not to carelessly discontin-

ue their regularly prescribed medications but to integrate additional beneficial practices into their general health plan. As luck would have it, he was based out of Tucson. I called to make an appointment, but no one ever answered the office phone.

I heard that he was going to be speaking to a group in Tucson about the benefits of integrative medicine. I wrote him a page-long letter explaining my situation, my desperation, tucked it into my pocket, and went to the talk.

After he spoke, he came down from the podium and was swarmed by audience members, fans I suppose, asking him questions, requesting autographs in their books. I stood, silent, self-conscious, and unsure whether or not I should hand over my letter. He stopped, looked at me, and asked if I had a question. I reached into my pocket, handed over my letter, and thanked him for his talk. A week later, his office called, set up a phone appointment between the doctor and me, and organized a time for a different doctor, his partner, to come to my place in Tucson for a home visit.

My mom came to Tucson to join me for the doctor's home visit. We sat in the living room, staring out the open door into the front yard, and waited. Right on time, a large, blue van pulled up to the curb outside of my rented college house. It didn't look like the kind of car I'd grown to expect for a physician. Honestly, it looked like the kind of car that played children's music and sold snow cones out the side window. Staying in the theme of unexpected, a tall, lanky, pony-tail wielding gentlemen in jeans and a tee shirt emerged from the car and introduced himself as my doctor. It didn't seem polite to request credentials.

After looking at my home, my refrigerator, my pantry, and talking with my mother and I for hours, asking questions ranging from details of her pregnancy with me to what I was feeling up to the moment I was diagnosed, the ponytailed doctor left my home and promised that, in less than two weeks, I would have a letter filled with recommendations written by the famous doctor himself. Each day, I waited eagerly

for the mail. Once it arrived, I was pleased to see that, instead of steam capsules and mystery concoctions, this doctor espoused the benefits of a plant-based diet, regular exercise, yoga, meditation. There were no vials to sell, no costly contraption in which to bind me. And best of all, to me, his recommendations made sense.

It has been over ten years and I've been trying my best to stick to those recommendations. There are times when I falter, eat things I know are not particularly healthy for me, and, more often than not these days, forgo exercise for sleep and bad television, but I learned a lot from those two physicians and continue to explore ways to integrate alternative healthy practices as part of my overall healthcare plan.

It is important to take charge of your own health in whatever safe ways you can. Eating right, exercising, taking the time to understand your own triggers and how to avoid them, those are lessons we can all stand to follow. But it is always important to keep your wits about you. Question something if it doesn't feel right. Don't blindly agree just because it is new and different, or just because it is old and the same. Ultimately, you are the one to live with the repercussions of your choices, so choose accordingly.

Expert Comments on Medication Maintenance

“Cost will vary. All treatments are not the same for everyone. Lots of ways to have treatments, but you need to keep an open mind and positive attitude. Insurance will help with some treatments if insured. Acupuncture is usually not insured, but does help with many things. Biofeedback helps, and you can do it at home. There are good CDs you can listen to for biofeedback. Try reading positive attitude books.”

“A dental paste: triamcinolone 0.1%, very good for healing mouth/tongue sores (needs a prescription). Tell your doctor if you get the sores; it may mean that your medication needs to be adjusted.”

“Nothing works if you don’t take it as directed. Get a weekly pill container to keep you on track. Call in your refills on time so you don’t run out of your meds. Sounds simple, but is very important.”

“If using supplements, know what you are getting. The FDA doesn’t review these, so buyer beware and educate yourself. Over the counter medications can and do react with your prescription medications, be careful!”

“Exercise and eating right help.”

“I have been doing a treatment called NAET (Nambudripad's allergy elimination technique) which has helped with the GI issues and migraines, as does a positive attitude!”

“Don’t wait until you’re down to just a few pills to order refills. Ask the doctor if she has a pill that may work better if the one you are taking is not working well. Try to buy your medications through a mail order pharmacy; they are less expensive.”

“Yoga is the best medicine for me.”

Doctor In Training:

They sell it at a health food store, so it's got to be healthy, right? Not so fast. There are plenty of excellent products out there that do not need to be purchased through a pharmacy, but weeding out the good from the bad from the totally useless is tricky. As one of our experts mentioned, supplements are not under the same regulations as traditional medications, so even products that say they carry the same compound may be very different in quantity and quality.

The most important thing you can do is to keep both yourself and your doctor informed. Patients frequently neglect to tell their physicians about herbal remedies and alternative therapies, but this can only hurt the patient. Tell your doctor everything you are taking, including the blue powder your grandmother convinced you to sprinkle into your tea every morning. It will be helpful if you bring in the product as well, so your physician can get a better idea of what it contains. If you don't feel like your alternative choices are being well received, talk to your doctor about her concerns and find out what her reasoning is. There are many natural products out there that can react poorly with your other medications or the disease itself, so hear her out. Or, maybe she doesn't feel like she knows enough about what you are taking but can refer you to a practitioner well informed on integrative medicine as a supplement to your regular care. If you feel that your doctor is simply not respecting your wishes to try alternative methods and isn't offering an explanation or an alternative, consider finding a new physician before simply deciding to keep doing what you're doing in secret.

Chapter 5: Raw Food, and Other Diet Adventures

When confronted with a major life change, individuals react differently. Some calmly accept, while others fight it with all they've got. I've always said that if something is hard, you have to try harder. So, when faced with lupus, I took the latter approach – fighting -, and quickly learned that you can't fight something that is within you, at least not successfully. In the process of learning this lesson, I tried many things aimed at beating this lupus, showing it who is boss. None of them worked, but at least I provided a source of amusement to those around me for a little while, and, I hope, now to you.

Crudités Anyone?

I can admit it now, I was desperate. Six months into my diagnosis, down one boyfriend, up one dog, I should have been enjoying my senior year of college. Instead, I was obsessed. The flare from months prior scared me and I was determined not to allow it to happen again. At first, I spent my evenings in the basement of the UofA medical library searching for books with lupus in the title. Coming up short, I settled for a mention in the table of contents, and finally the index. The medical literature, although sparse, proved too cumbersome at the time. I found definitions as well as horrifying statistics, but nothing I could hold on to, take home with me, and use to make this all go away. Instead, I turned to something that felt more manageable, easier to digest. Or so I thought.

I started reading about alternative healing practices, meditation, diet, yoga, Chinese herbs, and juice fasts. I was already a vegetarian and feeling puffier than normal after six months of near inactivity, so I gravitated toward the different fasts. I started with just juice, but that lasted less than a day when I came to terms with the fact that blending macaroni and cheese was not what these people had in mind. I read book after book and called local health retreats looking for some answers before finally settling on raw food, or, as my family called it: “The Diarrhea Diet.”

I knew little about the diet, but just enough to make it dangerous. Just eat raw food, I figured, how hard could that be? I got vegetables, fruits, nuts... then I was stuck. Instead of buying raw food cookbooks, working with alternative grains and legumes, and coming up with raw versions of my favorite foods, I shoved my face full of celery sticks and cashews.

As my family’s moniker for it suggests, the raw food plan, at least as I was interpreting it, did not vibe well with my intestines. I called a local company that espoused the raw food lifestyle as part of its mission toward general health and asked about this, um, effect. “Oh, yes, that is just a cleansing reaction, perfectly normal.”

Okay, I thought, this is normal. I can still do this. Two days more of cleansing and I'd about had enough.

Since my diagnosis, my parents drove to Tucson nearly every weekend to see me, make sure I was getting out of the house, and – likely – confirm that I was still alive. My dad, after hearing about my raw food plans and subsequent cleansing reaction responded in the only way he knows how: He cooked. Upon arriving to my house, he thrust a homemade loaf of bread in my hand, “Eat this.” And thus, the raw-food diet ended.

Expert Comments on Diet:

“I drink a lot of juices.”

“More fruits and vegetables.”

“Haven’t really gotten this one under control yet. Always a work in progress.”

“I lost 75 pounds 2 years ago, then I had a staph infection in one of my knees. Three months on my back left me 40 pounds heavier. So its back to dieting. I am a compulsive diet pop drinker. I need to cut out the caffeine.”

“Don’t worry about it. I’m slim. Walking keeps me that way. My doctor is after me to take Calcium and Vitamin D.”

“Sometimes we eat bad, it’s ok but do not do it often. If you forgive yourself there’s a new day coming. Try again.”

“Cells are made of water. No cell works without it. Drink up! BTW, caffeine is negative water; you don’t need it.

Sparkpeople.com is a great support and diet resource for me.

Fruits and veggies!

Sugar will increase fatigue; you don’t need it either. High fiber is important.

Make sure you have enough protein. Some carbs are needed; your brain cannot work without carbs.”

**She included a picture of a trashcan with sugar and caffeine going inside. – want to put this in the book*

“I really watch what I eat. I have been on steroids (5-80 mg) for eight years without a break and you can gain weight easily. I try to make sure I get protein every three hours. I have trouble eating (GI issues), so the protein is important.

I try and walk every day, even if I don’t feel like it; sometimes it can pull me through the morning crappy feeling.”

“When I’m at home, I’m not really on a diet. But I do eat a lot of fruits, salads, etc. I drink a lot of water mostly. Hardly drink soda, only when it’s around.”

“Since lupus onset, have lost 30 pounds, some of which was beneficial. I am maintaining my weight well with a sensible diet.”

“No diet. I eat whatever I want.”

“Regular exercise. Eating right. Don’t diet – just make good food choices and eat sensible portions. I save ½ the meal for later when we eat out.”

“Balance – moderation.”

“I eat more fruits and vegetables than I did when I was first diagnosed.”

“I am not a good one to discuss diet. I do try and eat healthy. But my busy life doesn’t allow it. And when I am depressed, I tend to eat a lot of comfort foods. One thing is to try and eat little items throughout the day to keep energy up.”

Doctor in Training:

There are countless diets touted as the miracle cure for any number of diseases and waistlines. Maintaining weight and health is a common struggle; having a disease that decreases your energy level and at times forces you to take medications with weight-gaining side effects does not help. In their article, “Weight loss and improvements in fatigue in systemic lupus erythematosus: a controlled trial of a low glycemic index diet versus a calorie restricted diet in patients treated with corticosteroids.”, Davies et. al. discuss two alternative diet plans for patients with SLE taking low dose steroids with BMI (body mass index) above 25, meaning the patients were all considered overweight, obese, or morbidly obese. The study found that both low glycemic index (ie limiting carbohydrates) and low calorie diets were tolerable and successful in achieving weight loss for patients. Interestingly, they determined that patients experienced a statistically significant reduction in fatigue symptoms secondary to their weight loss. In general, the Davies et. al. study underscores the importance of diet and maintaining a healthy weight for patients with SLE. Additionally, the study showed that both a low glycemic index diet – focusing on limiting carbohydrates – as well as a traditional low calorie diet were both successful in achieving weight loss for patients, proving that it isn’t necessarily how you lose the weight that matters, but that you do.

If you’re overweight (BMI >25), or if you want to make improvements to your diet, talk with your doctor first. Get her opinion and consent before making any major changes, and then find the plan that best works for you.

Chapter 6: Help Please: Practical Tips on Where to Get Information

Getting information on this disease can play an important role in taking care of yourself. You're reading this book, so you've already started the process. There are many sources of information out there, both in print and in person. Personally, I've found that a flesh-and-blood example of living with chronic illness has proved indispensable in my learning how to live with this disease. I was lucky enough to meet that person even before I knew how much I'd end up needing her.

Role Model

I was first diagnosed incorrectly with rheumatoid arthritis. It was my junior year of college, and I was waist deep in political science courses. The physical manifestations of my disease process were too obvious to ignore. At any given moment, I was either swollen, rash covered, wielding useless, immobile hands, or a combination of the three. Regardless, I went to class. Occasionally, a well meaning classmate would get my attention and announce, “You have a bad rash!” as if I hadn’t noticed the dozen or so welts splashed across my body, but the professors remained quiet. All except one.

One of my classes, Environmental Politics, was taught by a smart, well-published, impressive woman. I took her American Presidents course the semester prior and was excited to have her at the helm of this new course, a subject that was clearly her passion. During one of my usual days of limping to class on swollen knees and wrestling with my hands to get them to hold a pencil, my professor asked to talk with me after class. “What’s going on?” she asked plainly, looking down at my hands, my knees, the redness across my face. I told her what I thought I knew at the time, “I have rheumatoid arthritis.” And as explanation of why I looked so grotesquely deformed in this age of modern medicine, “I’m going to see a doctor in Phoenix in a couple of weeks, but for now, I’m only on ibuprofen.” She smiled at me, sadly, knowingly. “Me, too,” she said.

On that day, the quiet, mild-mannered woman in the front of the lecture hall transformed into a superhero. This was what I’d wanted to see, a woman facing the same hardships I was facing, but still living life, successfully, and with strength. If I were almost anyone else, I would have cried at that moment.

Over the years, I have talked with many patients with rheumatic conditions, mostly lupus. I spent time volunteering for the Arthritis Foundation, and I listened in on some support group meetings. But for me, the most important source of that intangible how do I live this new life advice came from my college professor. She has nev-

er, not once, told me to do this or that or anything else. Instead, she leads by example. Even though our diagnosis turned out to be different in the end, they – and we – share numerous commonalities, not the least of which is the burden one carries when living with a chronic illness. It is not that I have never heard my professor complain or express frustration over her disease -- I have -- but far more often, I see her living her life. Yes, she has an illness. Yes, she takes strong, side-effect-laden medications. And, yes, she struggles with the same things as everyone else with a chronic illness. But that is not all of her. She teaches courses, writes books, and sits on numerous committees. She is strong, productive, and successful.

I feel very privileged to have met this woman so early on in my disease process. I often wonder how my path would have diverged had I met someone else instead. There are people who are weighted down by this illness, those who cannot see past the butterfly rash and swollen joints and who succumb to its burdens. Perhaps if I had seen that as my first example of life with a chronic illness, I would have gone the other way on that day in the rheumatologist's office when my mom suggested that I take a year off from school. Perhaps I would not have finished my education, or not have gone on to earn an advanced degree. Perhaps I would have never spent those seven years teaching high school English or sat down to write this book.

I think of how full my life has been, my entire life, and I feel so fortunate to have made the decisions I have made up to this point and to have met the people I have met who have helped guide me down this path.

Expert Comments on Where to get Information:

“I go to the Internet.”

“Books, support groups, medical plans.”

“Webpages and my doctor.”

“All of the above. Remember not all will apply to you. Take and use the best and throw away the rest. No one person is the same, so not everyone gets help in the same way. It is very important for you to figure this out. So, doing and finding out things is the only way you can find out what works for you. If it’s not working, stop. Insanity is doing the same thing over and over and expecting different outcomes. Try something new. Nothing keeps you in a bad place, but yourself.”

“I get the best info from my rheumatologist. He provides info and has excellent magazines, which help.”

“Best book is the Lupus Book (a guide for patients and their families), Daniel Wallace, MD. Also my rheumatologists.”

“Doctors, books, other lupus patients who are positive. Websites, etc. Do not attend pity parties.”

“The internet has good/bad info; don’t believe everything you read.

WebMD has good information written in layman’s terms.

Some doctors keep libraries for their patients. Don’t overlook the obvious.

“The Lupus Book” by Dr. Wallace.”

“I used to belong to a group email list for a long time. I got too sick to keep it up. I read books and receive email from The Lupus Foundation of America (LFA). I get Lupus Now magazine. I look things up on line, especially when someone wants me to take new medication.”

“Most of the time I get information from the internet or other people who have lupus. I know a couple of people who have it and share the same doctor and a lot of times it helps me understand more when I talk to doctors and other people who have it.”

“I get most information from my doctors, the internet, and magazines (e.g. AARP) and speaking with other lupus patients, all of above is good.”

“I only listen to my physician.”

“I found support groups rather depressing as many in the group complain a lot and focus on how bad they felt rather on what they could do to feel better.”

“Lupus foundation. Online.”

“The web.”

“Lupus foundation website – great! I used to subscribe to Lupus Now- can’t afford it anymore. Have purchased books on lupus and those are wonderful.”

Doctor in Training

In a study published in the British Journal of Medicine, Leydon et. al interviewed 17 patients recently diagnosed with cancer, Leydon, G.M., Boulton, M., Moynihan, C. et al. (2000a) Cancer patients' information needs and information-seeking behaviour: in depth interview study. British Medical Journal 320: 7239, 909-913., In talking with the patients, the researchers learned that a patient's desire for information on various aspects of her disease fluctuates over the course of the illness. Additionally, patients have reasons both for and against wanting further information. An interesting finding was that in the name of hope, patients expressed both their desires for and against information seeking. Some patients held such strong hope in the face of grave diagnosis, that they sought any information that could lead to a difference in their likely outcome. Others, also under the explanation of hope, purposefully avoided learning new information for fear that it would quell some of their hopefulness.

Ultimately, each person has to make the decision on how much information she wants, and when she wants it. There are numerous resources for different types of information, including books (The Lupus Book by Dr. Walden), websites (www.lupus.org), and magazines (Lupus Now).

Chapter 7: Hot & Sweaty – Exercise & Lupus

According to the 2011 Gallup poll, nearly 52 percent of Americans say they exercise three or more days a week. Sadly, nearly 30 percent say they exercise zero days in a week. Countless studies have concluded that regular exercise improves health. Having lupus offers no exception to that steadfast rule. Conversely, because lupus can cause negative inflammatory changes in your vascular system and because sun avoidance and certain medications (eg, steroids) can lead to premature bone loss, exercising can be even more beneficial to those with lupus.

Come on already, GET UP!

Before becoming sick, I didn't exercise. I was lucky enough to be born with genes that allowed me to eat what I wanted without gaining significant weight as well as those that granted me sustained energy throughout the day without having to work on it. During my freshman year in college, I watched as friends and classmates jumped from diet to diet – Eat only apples! Eat only fat free, low calorie, frozen yogurt! And, one of the most amusing to me at the time, smoke a cigarette after every meal! These same people made regular use of the university health club, the place I occasionally passed on my way to Zachary's, my favorite deep-dish pizza parlor. I, however, did not work out. I ate what I wanted, when I wanted. I didn't exercise beyond walking to and from class, and although I did gain a portion of that dreaded freshman fifteen, I was small going into college, so it wasn't a real issue.

When I got sick, everything changed. I felt somewhere between tired and terrible for about a year before I was diagnosed. As someone who grew up rarely going to the doctor's office, I was disappointed to find myself in one every other month. My voice kept going away, I felt exhausted, I had surgery on my vocal cords and didn't heal properly, I got an unexplained tooth infection, and the list goes on.

Even though I had never exercised in the traditional sense, I was a normal, healthy, teenager, and I moved around a lot. That year, everything slowed, and it showed. I started putting on a bit of weight here and there, needing to buy pants in the next size up and looking for shirts that weren't quite as snug. When I complained about feeling tired and insisting that something was wrong, my mom used the weight as an explanation of why I wasn't actually sick. "Sick people lose weight," she said, "they don't gain it."

As I mentioned before, I was diagnosed incorrectly at first. An emergency department physician at UMC told me I had rheumatoid arthritis and instructed me to take 800mg of Ibuprofen four times a day, and to go swimming. I wanted to be able to lift my arms above my shoulders again, so I complied.

The pool was my introduction to the university's rec center. It was littered with coats lining the pool on lounge chairs, each bikini smaller than the one before it. I watched as they giggled and flirted with the boys playing water volleyball on one end of the pool. I'm fairly certain they all sported figures worthy of my jealousy, but I don't recall. Instead, what I distinctly remember is looking only at their arms, even once counting to see how many times each girl would lift her arm above shoulder height as I allowed myself to indulge in self pity.

So I swam. Each day, I took my ibuprofen, put on a swimsuit and went to the rec center pool. My arms were not yet functional, and my hands were starting to get in on the action of being swollen and entirely useless as well, but I believed the ED doctor, and was convinced the swimming would help. In fact, after half an hour in the pool each morning, my body did feel looser, more functional.

The not so hidden problem, of course, was the location of the pool. I shouldn't have been swimming in that pool each day for the very same reason that all of those college girls loved lying by it; it was an outside pool, with tons of direct sunlight. I hold those morning swim sessions, which were abruptly halted when my body went into a full flare, partially responsible for kicking my disease into high gear. For better or worse, it did allow me to finally present in such a way to allow for no misinterpretations and my diagnosis, the correct one, was finally made.

After the pool fiasco, I took a step back from my short foray into exercise and concentrated on what the heck was going on with my crazy, out of whack body. Eventually, although not to the pool, I did return to the rec center. At that point I was on regular medications, something I wasn't too keen on, I was getting regular lab tests, also no fun, and I was regularly seeing doctors, strike three. On top of doing all of these things I didn't enjoy doing, I still wasn't feeling great. Without much fanfare, I decided it was time to start doing whatever I could, from my end, to feel healthy. I tried to eat better, and I started to exercise regularly. I joined my old roommate from freshman year, a girl I'd been friends with since junior high and the same girl

who had always been religious in her commitment to exercise; we did some side by side cardio on the elliptical machines. Another friend from childhood was also at the same university, and she too, like many women on that campus, was a regular at the rec center. She and I met daily to work out, poke fun at the overwhelming number of butt short wearing gym-goers, and to catch up on life.

I never weighed myself or measured my waist or arms or legs. I didn't take note of my lab results at that time or try to correlate any changes in the numbers to my new found appreciation for sweating and heavy breathing, but I felt better.

I enjoyed the sense of community that came with exercising. I appreciated being able to do something for myself to improve my health. And, perhaps most of all, after so much time feeling disappointed with my body, not in its aesthetic, but rather in its sheer inability to do the things I once took for granted, it was nice to see progress, to feel strong, to feel capable again.

Expert Comments on Exercise:

“Exercise is always a good idea for anyone, but sometimes it can be difficult.”

“Exercise helps, but start slow. Do most anything to keep yourself moving. Moving your body is the best thing for your mind, body, and spirit.”

“I walk five times a week, do water aerobics three times a week, and strength training ½ hour, two times a week.”

“I walk one mile every day (it keeps the weight down) and I have dog. Swim as much as possible, swimming is good for my skin, seems to heal it. Also, it really elevates my thinking. Get my best thoughts there. I only do the breast stroke.”

“Exercise is important. Swimming is great. Water is wonderful for aches and pains. YMCA has a great swim exercise class for arthritic patients.”

“Water, water, water! Check with your local YMCA; they have water aerobics by instructors from the Arthritis Association! This is awesome! Exercise without pain! Swim, walk! Walking is a good weight-bearing exercise – strengthens bones. Swimming is good as non-resistance exercise.

How about adding some yoga? Always check with your doctor before adding a new exercise program.”

“Any exercise is better than none.”

“I would try and exercise over other activities during the day. It is very beneficial to your health.”

“Always check with your doctor before starting a new program.”

“Even if you can only walk for five minutes, you should do it.”

“I don’t exercise, but I need to.”

“Exercise has always been important to me. I was active in sports from a young age. I try to work out and/or do a long walk with my dogs every day, but allow myself to skip if I am too tired. Regular exercise gives me more energy in my life!”

“I have started exercise programs just in my home and talking walks. Unfortunately, I work full time and have a child, so I don’t keep them up as I should. Walking, I find, is the best for me. And doing a few light (3-5 pound) weights for my arms.”

“Yoga and walking fast paced is a big help and pain reliever. I started with slow, short walks, eventually building up to 2-3 miles every other night. Wawho! My lupus, asthma, and overall health has improved significantly since I began an exercise program.”

Doctor in Training:

Researchers in Sweden compared exercise rates in people with lupus to the general population and found that those with SLE report lower rates of activity, (Eriksson K et. al. "Physical activity in patients with systemic lupus erythematosus and matched controls." J Rheumatol. 2012 Aug;41(4):290-7. Epub 2012 May 31.) Additionally, those with more organ damage, report even lower rates. The study did not indicate a causal relationship, and the chicken-and-the-egg question - does having organ damage in lupus make you exercise less, or does exercising less when you have lupus make you more susceptible to organ damage - was not answered.

What we do know is that regular cardiovascular exercise is beneficial to every organ system in your body. Coincidentally, lupus has the ability to negatively affect all of those same systems. While you can't exercise lupus away, you can positively influence your baseline health with exercise rather than compounding the negative consequences of lupus with a sedentary life style.

Talk with your doctor for recommendations on an exercise plan that works for you. Other than choosing inside activities to avoid the sun, simply having lupus should not restrict your ability to exercise.

Chapter 8: 9-5, How to Handle Work & School With Lupus

As I mentioned previously, being sick can be a full time job and, unfortunately, no one pays you for it. When you have another job on top of that, things can get tricky. Maintaining your work and school responsibilities in the face of illness can be taxing, but it can also prove rewarding and help to keep your mind on something other than your health.

Hello Boys, Meet the Men

A year and a half passed since my initial diagnosis of lupus, a very full year and a half. In that time, I broke up with a kind boyfriend, got a dog, graduated from college, and started my career as a high school English teacher. We don't know if it was the stress of the new job or simply lupus taking its course, but, once again, I flared. It was mere weeks after 9/11, and my parents were in New York for a trip my father called "His civic duty to spend money." Looking back, I don't recall if I was feeling especially tired in the days preceding, if I had any telltale signs, or if I'd even known how to read them if I did. But once it hit, there was no room for misinterpretation. I awoke with my hands swollen, unable to bend at the joint line. The look and feel were familiar to me; I had the same thing during my first flare, back when a UMC emergency doc diagnosed me with rheumatoid arthritis and sent me away with a prescription for 800mg Ibuprofen and a recommendation to go swimming every day.

But this time, rather than a student, I was a teacher. I looked at the clock. Forty-five minutes from now, thirty-one fresh-faced freshman would be standing outside room 504 waiting for their English teacher. I had two thoughts fighting for attention: 1. Get it together so you can get to work. And 2. OWWWWWWWW!!!!!!!. My joints throbbed; my skin burned. I searched through the house for some pain medication I had left over from eighteen months prior, but thought better of it when I realized I would have to drive myself to work where I would then be responsible for children.

That drive was at best uncomfortable and, looking back, most likely dangerous. My skin was stretched taut over my hands and it was difficult to get a good grip of the wheel. I pulled into my parking spot on campus, surveyed the large welts that seemed to be spreading by the minute across my arms, and set out toward my classroom. What my plan was, I do not know. How I thought I was going to get through a day managing five classes filled with 30 plus fourteen year olds is beyond me. But I

was determined, so I reached for the dry eraser marker to prepare the board for that morning's bell ringer. But I couldn't grab it. Mind over matter. Mind over matter. I grasped again, felt the cool, hard plastic against my palm, willed my fingers to wrap against it. Nothing. The swelling was too much and the marker was too slender; no amount of stubbornness could overcome it. I tried over and over and over again, even after it was clearly futile. At one point, my index finger managed a slight bend on the distal end, just enough to hook the marker and, ultimately, knock it to the floor. I bent down to pick it up, my knees screamed at me; I suddenly realized they too were swollen. I had been defeated.

No one at work knew I was sick, and I had planned to keep it that way. But there I was, becoming a statue in my own body, joints stiffened, rash spreading at a hastened pace, and I knew I couldn't let the students walk in to find me that way. I walked to the principal's secretary's office, a woman I knew well, and planned to ask her to find a substitute for the day. I don't think I realized how frightful I looked until I saw myself through her eyes. I entered the office and now it was her turn; she dropped her pen.

That was the first day of my month-long leave from teaching. It was the day my rheumatologist ordered my second 24-hour urine test, the one that would later reveal that I was spilling significant protein. The protein would then lead to the first of two kidney biopsies, the biopsy that would reveal I had Stage III, Focal Proliferative Lupus Nephritis. It is the nephritis that would once again change my world, taking my earlier diagnosis up a notch, introducing Cytoxan into my life for the first of what would be many treatments, causing my mother the kind of heartache a mother should never experience, separating the men from the boys.

Expert Comments on Work/School:

“I just deal with it.”

“Haven’t been able to keep a job. But I have had great satisfaction doing volunteer work.”

“Work full time (8:30-5:00), but I just work.”

“Try not to push to extreme. If you work outside of home, rest during break and lunch. That’s hard, but can be done.”

“I had to give up a job I loved that was really hard for me to deal with. I worked long hours and traveled a lot. Most colleges understood, but if you can’t keep up, that is a problem.”

“I was in the 9th grade when I found out I was sick. A lot of the teachers, staff, and students showed me a lot of love. They helped me out a lot. It wasn’t hard for me telling them that I was sick.”

“Sometimes I have to take time off of work to meet appointments.”

“I have been very fortunate to have had very supportive colleagues and administrators. My positive attitude and hard work FAR outweigh the minimal amount of time I miss due to my lupus. And when I had to be out for longer, they strongly supported and encouraged me.”

“I have always worked since my diagnosis. I missed work at the beginning, a few days a month. As I learned to deal with lupus and learned more about it and how far I could/should push myself. Now, I don’t miss work. My boss was made aware as I was very sick after my pregnancy and problems arose. I told her because we were very close.”

Doctor in Training

The Americans with Disabilities Act recognizes lupus as a disability and makes it against the law for an employer to discriminate against a qualified individual on the basis of their disability. Furthermore, the act sets up provisions that entitle people with disabilities to reasonable accommodations in order to perform their duties. A person who works outside and who is newly diagnosed with lupus may reasonably request an accommodation to make a lateral move to a position that is based indoors. That said, if your position is something that can only be performed outside and there is no other position for which you are qualified, you may have to find another profession. The idea of what is a reasonable accommodation differs among employers and institutions, and you will have to discuss your specific case in order to come to a conclusion.

Lupus is a tricky disease, as it affects people very differently. Some patients have multi organ involvement while others have no more than a rash and swollen joints. Both of these circumstances, and everything in between, can cause an individual great stress and can affect one's performance in work or school.

While one cannot control every aspect of their disease, sometimes infuriatingly so, you can take responsibility for the things that are within your control. It is your choice whether or not you make your boss, coworkers, professors, or classmates aware that you have lupus. If you choose not to tell, recognize that no one can offer you support or understanding if they do not know that you need it. In the same regard, everyone is, or should be, at a job or school to work or study, and it is ultimately your responsibility to know your limitations as well as your responsibilities and to come at those from an honest position of wanting to do the best you can.

If you approach your responsibilities in a sincere and conscientious fashion, you will earn the respect of those around you and will, generally, be met with warmer regards when you need that afternoon off for an appointment.

Chapter 9: Paging Dr. Help Me Please, What to do When You're Stuck in a Hospital

Hospitals and procedures are not something that everyone with lupus will experience. As with all things, it depends on your particular situation. If you do find yourself in the hospital, it can be scary and overwhelming for everyone involved. But, hospital visits can also serve to clarify an unknown in your disease process or improve your medical condition. I have had two procedures and hospital stays attributable to lupus. Both were frightening at first, but, ultimately, very informative.

Just the Truth, Hold the Sugar

Four days passed since the principal stepped in to cover my classes while his secretary telephoned my family to pick me up. It was my brother-in-law who came to the school. We called the rheumatologist, who fit me in right away. The pain in my hands was excruciating and, if you were to reach out to touch them, you would instinctively pull away from the intense heat radiating from my strained skin.

I'd like to give you vivid details of the doctor's appointment, the office, questions asked, answers given, the good stuff. I don't recall any of it. Only two things stuck with me from that visit. 1. Because it was a last-minute appointment, I was at a different office in a different part of town than previous visits. It was a large building, four floors, and I wondered if I would grow to hate that office as much as I hated the one where I was first diagnosed. 2. During the visit, my rheumatologist asked if I was experiencing a rash anywhere other than what was clearly visible to him. I remember reaching down and pulling my shirt off up over my head to reveal pancake sized welts covering my chest, abdomen, back. My brother-in-law sat behind me, silent.

I don't remember it happening, but they must have sent me away with an orange jug and a lab slip requesting 24-hour urine protein, because, as I mentioned, four days later, the results arrived. My parents were back in town and my sisters and I were all at their house for our weekly Friday night dinner. Courtesy of prednisone, my rash settled, and my hands were now flexible enough to lift the receiver when the phone rang. It was the rheumatologist's office, his Medical Assistant (MA). The results of my 24-hour urine were in; I had 2.2 grams of protein in my urine. I watched my family busy themselves scooping piles of rice, potatoes, beans, and leafy greens on their plates while the MA rattled off instructions to a half numbed patient:

"You need to go to the hospital. You need a kidney biopsy. Do you have a particular

nephrologist you want to see? Where do you want us to send the lab results? Hello? Are you there?"

A friend's father heads up the largest nephrology group in the country, which happens to be based out of my home town. A phone call later, he had me set up as a direct admit to the closest hospital, scheduled a kidney biopsy for the following morning, and gave me the name of one of his partners who would be directing my care.

I remember the interventional radiologist who performed the procedure, tall, thin, kind. I remember having to hold my breath while the needle entered my back to ensure that the kidney stayed in the area where they were expecting to find it. I remember having to, once again, collect all of my urine so they could monitor for bleeding. I was mortified at the idea of having the nurse handle the collection, so I gathered each specimen myself and transferred it into the large orange jug placed in my bathroom. I remember my best friend flying in from Washington, DC, and sleeping in the hospital room with me. At one point, she picked up the hospital phone. "Watch this," she said to me and then mumbled something under her breath into the receiver. Moments later the operator was on the overhead intercom system: "Paging Dr. Tahan. Dr. Tahan, please call the hospital operator. Dr. Tahan, please call the hospital operator." Fortuneteller.

I was in the hospital for a couple of days, and at some point during the stay, I was told I needed chemotherapy and that it would be started during this hospital visit. Chemotherapy? I was 22 years old and had plans for kids one day. Even before medical school, I knew chemotherapy could greatly impair, if not obliterate, a woman's fertility. I asked questions about freezing eggs, a new concept at the time, and one that was only available for fertilized eggs. I didn't even have a boyfriend, much less a father to my future children on speed dial. My sister offered her husband's sperm. She was serious. I politely declined.

My father cooked massive amounts of food and kept filling the room with more and more of it. My mom set up a dish with chocolates for the nurses and said that they

would come to the room to help me more if there were chocolates waiting for them. I don't know what everyone's plan was, but I had no intention of moving into that room on a permanent basis. A nephrologist came to talk to me about going ahead with the Cytoxan the next morning. I told him I wanted to wait, explore my options, figure out a way to preserve my fertility so I could have babies one day.

"You can't have babies when you're dead."

Word for word -- that I will never forget. During that hospital visit, it took six people to get an IV started in my puny veins. They put a needle the length of a ruler through my back. People were coming in to take my blood every four hours. I have no idea what any of them said. My parents must have been terrified, but I can't say for sure because I have no recollection of their words, their faces, nothing. I remember that hospital stay in bits and pieces, vague events piled on top of each other. But that sentence, "You can't have babies when you're dead." Word for word. As if he's still standing over me, saying it all over again.

Expert Comments on Time Spent in the Hospital:

“Have your family there for support.”

“If you must be in the hospital, remember you are there to get better. When the doctor comes to check on you, ask questions so you understand what the plan is. It is good to understand your disease and what options are available.”

“Try to be a good patient; this helps the medical staff provide you the best care. No one likes to be in the hospital. Take your own PJs; you’ll be more relaxed. Take plenty of magazines, books, etc. to keep yourself busy and not focus on your surroundings.”

“Friend support and visits, good books to read, milkshakes. My husband brought my dogs to visit and brought me to the lobby in a wheelchair to see them.”

“Anticipate that the nurses are very busy and you may not get the help you need instantly. Try to do as much on your own as you can. Make sure your water, reading materials, etc. are near you before the nurse leaves the room. Make a list of your questions to have ready when the doctor comes in to see you.”

“Bring your own bag packed with pajamas and toiletries. Also, bring your pillow and reading materials. Expect to get no sleep and be in a very noisy environment. Ear plugs and head phones with your favorite music help too.”

Doctor in Training

In reviewing patient responses on how individuals made their stays in the hospital more pleasant, a unifying theme evolved encouraging patients to bring with them the comforts from home. For some, that meant pajamas and a pillow. Others suggested your own reading material and music as a distraction, while others found the people with whom they are used to surrounding themselves to be the best accompaniment during hospital visits.

As a person with lupus, it is very possible that you will never find yourself hospitalized, at least not for anything related to lupus. But, in the event that you do, it is best that you plan ahead and make your wishes known to those around you. Be honest about whether or not you are someone who wants visitors at the bedside or prefers to be left alone. When left to their own devices, friends and relatives will often act according to what they want for themselves, which may or may not jive with your wishes. As with anything else, others cannot provide you the comfort you crave if you do not let them know what that is.

Keep in mind that in certain instances, there are restrictions to how many people can be with you at the bedside and during what times. It is usually acceptable for one person to stay with you at all times, but your eighteen best friends may have to wait in the hall and take turns coming in to say hello. The hospital staff is responsible for creating a calm, healing environment; therefore, they may need to regulate visitors in order to achieve that.

Chapter 10: Are You Getting All This? Whether or not to Keep Your Own Medical Records.

As we age, everyone needs to take steps to maintain their general health. This can mean different things for different people: Diet, exercise, vitamins, and annual physicals. With lupus, you may require additional steps to maintain your health. Annual physicals commonly morph into far more regular checkups and your other needs may change as well. One thing that comes up when one is regularly seeing doctors and having medical tests performed is the question of keeping one's own medical records. My view on this has evolved over the years, thanks in part to the advice I received from one of my physicians.

Bright Lights, Big City

It was after my first stint in the hospital, first biopsy behind me, the dread of Cytotoxin looming ahead, when I went to New York City. My middle sister, a journalist, found a rheumatologist at New York University (NYU) who is well regarded in the field of SLE, and I was desperate to find some answers before simply waving adieu my hopes of one day starting a family.

That was 2001, and I've since traveled to New York every year to visit the same rheumatologist. I've learned a lot over the years and feel fortunate to have him as part of my healthcare team, but it is still that first visit that resonates the most.

My oldest sister and brother-in-law accompanied me to the City and the same friend, who stayed with me in the hospital weeks earlier, took the train up from Washington, DC to join in the fun. Before the trip, I went shopping and picked what I thought was an appropriate doctor appointment outfit for fall in New York: Beige skirt, brown tights, cream top. My mom bought me a bright pink sweater with a black ribbed turtleneck to go underneath and black pants as a backup plan. She must have felt so powerless.

We took the subway downtown to the medical campus of NYU and entered the old, grey building. The front office was filled with loud, happy women, sharing stories of their weekend as they scanned insurance cards and signed in patients. Where I was used to spending close to an hour in a stale, silent waiting room before an MA came out to fetch me, this was different. No sooner had I signed in, than a tall middle-aged man looking vaguely like his NYU webpage headshot called my name and ushered me to his office.

The room was mildly schizophrenic, set up like a regular patient room on one half: Patient table, blood pressure cuff, ophthalmoscope strapped to the wall, and a professor's den on the other: A desk with two chairs, stacks of papers, and books. This was New York, pricey real estate. The two halves intertwined, and it would not

have been possible to draw a straight line dividing the tongue depressors and hospital gowns from the three dozen glass and ceramic apples littering the physician's desk.

Before any numbers were calculated or lab results reviewed, the doctor asked questions, a lot of questions. Questions about my medications, symptoms, blood work. He spoke largely in laymen's terms, but included medical jargon for what he clearly thought I should know. He asked about medication dosages, start and end dates, specific results of my kidney biopsy, and showed obvious disapproval when I didn't have all of the answers. He then said something I have never forgotten. "You need to know this. Don't rely on your doctors to keep everything straight. No one cares as much about you being sick as you do." At that point, he pulled out a flow sheet, took the year and a half worth of printed lab reports I brought with me to the appointment, and began filling in numbers. "This is a flow sheet that shows us your lab results on all of the different dates. You need one of these for yourself. More important than the actual numbers, is the trend. If we don't know the trend, we don't know much."

Although I left the appointment feeling inept and unworthy of my own disease, it is also the day I began to feel empowered. I would never know as much about lupus as my doctors back home, and would certainly never know as much as this man, but I could know the most about me, about how the disease was affecting my body, my life, and about what was being done to treat it. I made a personal promise to learn more about what was going on with my disease. I had no interest in telling the doctors what to do, but I had to be able to do my part in helping them know exactly what was going on with me at any given time. The appointment demystified the disease. Made me feel that not only was it possible for me to understand what was happening to me, but that it was my responsibility to do so.

He also told me about Depot Lupron and about the widely held belief that monthly injections of it help to preserve fertility in the face of chemotherapy. Eleven years

later, I have undergone twelve infusions of Cytosan, six in 2001/2002, and six more in 2008 with Lupron on board both times. I don't know if the Cytosan would have caused fertility problems for me or not, but as I look forward to my son's second birthday around the corner, I'm glad I was given the opportunity to try everything possible to not have to find out.

Expert Comments on Keeping your own Medical Records:

“I don’t keep a chart of my medical records, but I think it would be a good idea.”

“I don’t keep a chart of my meds.”

“Daily journal. Two page calendar: one side time of drugs. 2nd side how I feel today and what might be going on (weather, work, places), or how it affects me. You can keep record of even more, just depends on how detailed you are. Keeping track of your medical reports are very important. You need to be your own advocate. The more you do for yourself the better your health can be. Very Important! Also, always ask for copies of all tests so you can have at home and keep them filed in binders in date time. Can’t tell you how this has helped me!”

“I’m a combination of keeping my records and relying on my doctors. I trust my doctors, but I also ask lots of questions.”

“Keep a diary haphazardly. It’s by my bedside. It is a huge help. Also note at the top of the page the medicine I am taking and how much.”

“Keep track (most days) how you feel. Make notes how you feel with meds. Changes side effects.”

“You are responsible for your own health. You and your doc are a team.

When multiple docs are involved, things can fall through the cracks. Be your own advocate. Keep copies of all labs, procedure and test results in a file. Make sure your PCP and specialists communicate this info.

Hands off is for children in crystal shops!”

“I try to get all copies of labs and reports to keep in a file.”

“I keep a running update of medications and medical history on the computer, so it is available.”

“I always research new medications my doctors want me to take.”

“Do not be afraid to speak up if you don’t like something or don’t agree; it’s your body.”

“Every time I get new medication, I make new lists. I keep my medications in a box. I have a pill organizer, it is Monday-Sunday. Every week, I fill it up. When I first started to take all of these medications, my parents brought them to me at the times I needed them. But now I do it by myself. Sometimes I get tired of it.”

“I keep all medical records, especially lab reports, keep close track of blood work. I do not believe in a hands-off approach.”

“I don’t keep any of my own records.”

“I keep copies of my records but don’t stress about everything. I try to live my life to the fullest and focus on how good I am feeling rather than the bad.”

“I used to keep records by just keeping a journal. I am now aware of how my body feels and when I am tired I just keep it in mind and act accordingly.”

“I keep a copy of all hospital stay records, lab results, and other testing reports for at least one year in files organized by event and/or physician/facility. I do not read about SLE on the internet, nor do I attend online support groups. There is too much information out there that is confusing, overwhelming, and sometimes wrong.”

Doctor in Training:

There are many practical reasons both for and against keeping copies of your own medical records. Some patients choose to hold on to a copy of every piece of their charts, stating that it is important in case they change doctors or want to review something that happened in the past. Others keep just specific items – surgical or procedural reports, lab results – with the same explanation of changing doctors or having the option to view the information on their own time. There are many patients who prefer an entirely hands-off approach, preferring to leave the business of record keeping to the doctor’s office, knowing if there was a switch in physicians or a need for a certain piece of information, they could always acquire their records at that time. Wibe et. al. conducted a study on patients in Norway who elected to keep their own medical records after a hospital stay. They found a main reason the patients gave for doing this was to keep a sense of control. More specifically, patients stated that they wanted to “acquire more knowledge,” “take responsibility for the information flow,” and “examine the accuracy of the record.” In addition to finding, and then correcting mistakes, which was the case for two of the patients, study participants felt more responsible for, well informed about, and in control of their medical information when they had access to their own medical records.

A similar study conducted by Fisher et. al., “How patients use access to their full health records: a qualitative study of patients in general practice,” studied patients in a primary care setting with access to their own medical records. These patients were a mixture of what the researchers labeled, “healthy,” “long term health conditions,” “mental health,” and “pregnant.” Overall, the study concluded that access to one’s own medical records, “improves shared management, with patients using their records to improve interactions with healthcare providers, make decisions about their health and improve the quality of the care they receive.”

Neither two nor ten studies can determine if it is best for you to keep copies of your own medical records. You need to think about the type of person you are, what you like to know and not know, and if the information will prove useful and empowering

to you, or overwhelming and frightening. At the end of the day, the records belong to you, legally, so you can ask for them, and stop asking for them, whenever you decide.

Sample of blank Personal Lab Summary with Corresponding Medication Dosages

| | | | | | | | | | |
|--------------------|--|--|--|--|--|--|--|--|--|
| Date | | | | | | | | | |
| Hb/Hct | | | | | | | | | |
| WBC | | | | | | | | | |
| Platelets | | | | | | | | | |
| ESR | | | | | | | | | |
| C React Protein | | | | | | | | | |
| BUN | | | | | | | | | |
| Creatinine | | | | | | | | | |
| Serum Albumin | | | | | | | | | |
| Cholesterol | | | | | | | | | |
| Urinalysis:Protein | | | | | | | | | |
| Blood | | | | | | | | | |
| Glucose | | | | | | | | | |
| Casts/HPF | | | | | | | | | |
| RBC/HPF | | | | | | | | | |
| WBC/HPF | | | | | | | | | |
| S.G. | | | | | | | | | |
| 24h U Protein exc | | | | | | | | | |
| 24h U Creat exc | | | | | | | | | |
| 24h U Creat Clear | | | | | | | | | |
| C3 | | | | | | | | | |
| C4 | | | | | | | | | |
| CH50 | | | | | | | | | |
| DNA Antibodies | | | | | | | | | |
| Weight | | | | | | | | | |
| BP | | | | | | | | | |
| Drug Doses: | | | | | | | | | |
| Prednisone | | | | | | | | | |
| Azathioprine | | | | | | | | | |
| Plaquenil | | | | | | | | | |
| Cytoxan | | | | | | | | | |
| NSAID | | | | | | | | | |
| Other: | | | | | | | | | |
| Other Results: | | | | | | | | | |

Chapter 10: Wait, What Did She Say? Advice for Communicating With Your Physician

Of all of the relationships that may change when you get lupus, none may prove as dramatic as the new one you are about to establish with your rheumatologist. Like me, many people newly diagnosed with lupus are relatively young and healthy and have not had to see a physician for more than an annual physical for most of their life. At first, your visits with a rheumatologist will be far more frequent than once a year, but with time and improved control over your disease, those visits will become less and less frequent.

The New Men in my Life

I was in the process of applying for a position with the Peace Corps when I was diagnosed with lupus. When I spoke with the coordinator about my medications (it was a requirement to disclose all medical conditions and medications), I was informed that, at this time, I would not be a good candidate. I understood why he said as much and realized it was silly of me to think otherwise. I'd just been diagnosed with a significant disease, probably not the best time to head out to a remote area with little access to health care. So, from the beginning, I was prepared to lose certain things because of lupus. I was not, however, prepared to gain so many new relationships.

In fewer than two years I had a relationship with a phlebotomist, a few medical assistants, an oncology nurse, a rheumatologist, an interventional radiologist, and a nephrologist. Let me assure you, the term "relationship" is not an exaggeration. Depending on the state of my disease, there were months when I spent far more time with the health professionals in my life than any of my friends and many of my family members. And because, over a certain time period, lupus was the most significant part of my life, these were the people who really knew and understood this very important part of me.

In the beginning, I had a very knowledgeable and capable rheumatologist. He wasn't overly friendly. In fact, it might be a stretch to call him friendly at all. He was matter-of-fact and he didn't spend time on pleasantries. During one of the earlier appointments, it came out that my parents bought me a Weimaraner puppy as a get well/please-don't-be-sad-forever gift.

"I have Weimaraners," he shared.

I was startled; the man could talk about normal things.

I took that as my opening, "Oh, Gefen, that's my dog's name, she's great. Aren't they just the cutest dogs?"

“They’re my wife’s dogs. I can’t stand them.”

All-righty then.

I wasn’t necessarily bothered by the physician’s stoic nature, but I wasn’t drawn to it either. This was all very new to me. I was scared, I was confused, and I probably could have used a little more empathy at that time. That I wasn’t getting it in the doctor’s office was okay, I had other options. What I couldn’t deal with was the staff.

On a good day, they were curt and dismissive. On a regular day, they were rude. The doctor regularly ran late, and patients piled in the waiting room, not so patiently. I routinely requested a copy of my lab results after each appointment, and this request was clearly not appreciated. There were a lot of sighs and eye-rolls and, at times, it was all that I could do to keep myself from saying, “Why do you care? Is it that taxing to make a photocopy? WHAT IS YOUR PROBLEM?” Looking back, I’m not sure why I didn’t.

Instead, I found a different doctor. Sounds easy, but in this town, rheumatologists are not easy to come by, and finding one who was up to date on current practices proved even more challenging. After going out and seeing my options, I wondered if I wasn’t a bit too hasty in leaving the first office. Yes, the people in the front were far from Disneyland greeters, and the wait proved excruciating at times, but the doctor was capable, current, and cared about his patients’ health.

Years later, when a friend was diagnosed with ankylosing spondylitis and needed a rheumatologist to manage her care, I gave her his number. I warned her about the wait times and the front office staff, but also told her that, ten years into things, I’d probably deal with some of that in exchange for a good doctor who knows what’s what.

Expert Comments on Communicating with Your Physician:

“I see my doctor every 6 months. The first doctor who diagnosed me was in a different state and he gave me very little information.”

“I used to see my doctor three times a month when I first got sick. Now I go every 2-3 months because I am much better.”

“I used to see my doctor every month, now I go once every three months.”

“Very, very important between the two of you (doctor & patient), you will determine how good your health can be. Don’t be afraid to ask questions. The doctor depends on you to help let him know how you have been and what you feel. This is one of the most important relationships you will have.”

“I have an excellent relationship with both my rheumatologist and my internist. I see my rheumatologist every three months. He monitors my blood work every six weeks and notifies me immediately if there are any changes.”

“My doctor is great. We are both trying to get me to lower prednisone and up Methotrexate so that I don’t have such thin skin, which is caused by the prednisone.”

“I see my doctor every three months and have blood work a week before I see the doctor. Ask questions. Knowing, understanding is very important.”

“Keep a note pad to jot down questions for your next visit. If you don’t, you’ll forget and have a missed opportunity.”

“You and your doc are a team. You must communicate well to win the game. You have the doc’s attention for a few minutes; make the best of that time. Ultimately, it is you that has to put the plan in action and maintain day to day so make sure you’ve given your input and understand the plan.”

“I see my rheumatologist every 2-3 months; more often if problems arise. I also see my PCP every 2-3 months.”

“Make a list of what you need to talk about before going to the doctor, that way you don’t forget what you need to discuss.”

“As far as how often I go, that depends on if I am having a flare, or how sick I am, so that varies. I definitely go to the doctor a lot more now than before.”

“My doctor and I communicate pretty well. I feel comfortable with my doctor; she understands and listens to me.”

“I communicate with all physicians regularly and see each one as scheduled by them. I ask questions and believe in being my own advocate. I expect to go into remission with maintenance medication.”

“I call my doctor whenever I have a question and he is generally fast to respond. I go every 3-6 months.”

“Now, I see my doctor every 3-4 months. I used to see him monthly. Write down questions before going. Type up list of meds and take an updated copy each time you go.”

“I see my doctor about every three months. It depends on how often I have flares. In the last eight years, I haven’t had them as bad as I did in the past (no major organs). I think it is due to the new drugs they have now. I have a hard time telling the doctors how bad I really hurt. I seem to minimize the pain. I don’t tell them how often the pain wakes me up and how I can’t lay or sit sometimes.”

“I used to see my rheumatologist once a week when first diagnosed. As we progressed and I learned more about lupus, we have gone to once every three months. Since I was diagnosed 12 years ago, I know that I get labs done, see my doctor for review, and discuss any changes. I don’t see my primary care doctor unless it has to do with my overall general health.”

“Some of the best advice I received and give to others is to find physicians who I am comfortable with and respect. Although I am not seen as often as before (used to be every month), I know my care is coordinated, shared between all of my doctors, and

is more than sufficient. Good coordinated care by a great team of physicians equals fewer flares and better health.”

Doctor in Training:

The frequency with which a patient with SLE sees her physician depends entirely on the state of her disease. In the beginning, your rheumatologist will likely want to monitor you every couple of months until it is clear on which path you are headed. If you are in stable condition, clinical remission, you may be seen once, twice a year. Think of it as an annual checkup that everyone should get. If you're on the other path, inflamed joints, rash, protein in your urine, you'll likely need to go more often until an appropriate treatment plan has been implemented and disease response to said treatment has been documented by an improvement in symptoms and test results.

You will help both your physician and yourself if you write your questions in advance and bring them to your appointment with you. Ask your physician if she prefers to address your questions at the beginning of the appointment or the end. By doing this, you and your physician will be on the same page and can organize your appointment in the most helpful and efficient manner.

Chapter 12: I Never Knew it Was Possible to be This Tired - Fatigue

Of all of the things I was before I was diagnosed with lupus, tired was not one of them. I was well known for my energy and activity level, tapping my feet, zipping from here to there, and regularly pulling all-nighters without difficulty. Over the years, lupus has given me a lot – knowledge, self-awareness, insight. It has also taken a lot away, and my energy was probably the first thing to go. (Don't feel sorry for me – it is back.☺)

Barren Exhaustion

I remember the conversation well. I was on the phone with a close childhood friend, catching up. She was busy with two little kids and I was just starting my career as a teacher, filling my weekends with chemo infusions. “I am so tired,” she lamented, “you have no idea what tired is until you have kids.”

I understood what she meant, and likely understand it more now as my own toddler runs circles between my legs during every waking hour, but it still sounded a bit funny at the time.

It was true, I had no children of my own to care for, and the 150 or so I taught each day went home after the bell to run circles around their own parents. That said, I was pretty sure the past year and a half, raising lupus, had provided me a thorough understanding of fatigue.

There was the general fatigue I felt all day, every day, leading up to the flare. It greeted me each morning and stuck by me throughout the day constantly nagging and questioning, “You sure you want to get up and go to work this morning? Are you seriously planning to stay up to grade papers again?”

I was also familiar with knock-you-on-your-butt-glue-your-eyes-shut fatigue. There was more than one afternoon when I found myself on my living room couch, having just sat down to rest for a moment, physically unable to open my eyes. Coming from a house where naps equaled lazy, this level of exhaustion was one of the toughest of all of the new pills I had to swallow.

The weekends after Cytoxan infusions were the most severe. If I was awake, I was vomiting, so most of the weekend, I slept. I learned to get a lot done during waking hours and to plan accordingly. Overall, I think the unrelenting fatigue helped me gain invaluable time-management skills and, now, with Cytoxan behind me and my disease stable, the fatigue, along with the rash, the arthritis, and the weekly lab draws, is gone.

I know, just like everything else, the fatigue may return at some point. I also know that it is a sign of something else, something more. When lupus is active, you have signs and symptoms, fatigue is just one of those. When you get the disease under control, those signs and symptoms remit right along with it. I view fatigue the same as I do a malar rash and swollen joints, a herald calling me to pay attention and seek outside counsel on my health.

Expert Comments on Fatigue:

“I am usually very tired by mid-afternoon.”

“I drink a lot of juices and find that it helps a lot.”

“Fatigue is very upsetting because you can’t get things done, even the simplest things.”

“You will have good days and challenging days. Try not to focus on bad days for this keeps you in a bad place. Be kind to yourself. Pacing yourself will help. If you have a great day, remember not to overdo or you will find next day not as great. I can’t tell you enough about pacing yourself.”

“Fatigue is definitely an issue. I work full time. On Saturday and Sunday, I try to get extra rest. Sleep in Saturday, do errands, then take a nap. Sunday, church and nap. I should go to bed earlier. When I go on vacation and get extra sleep, I feel much better.”

“Try to take a power nap. If not, relax, read, or rest and have quiet time.”

“Fatigue – what an awful concept! Learn to manage your fatigue. Some days, you just need to throw in the towel and rest. It is okay to have bad days.”

“This gets back to learning your limitations and managing them to the best you can be. Don’t compare your energy level (or lack thereof) to others. Work for your best.”

*“Sleep 8-10 hours for someone with lupus is **KEY!** I cannot emphasize this enough.”*

“You really have to prioritize your days activities and realize you won’t get them all done. Some days you may get nothing done.”

“Fatigue is the worst aspect of dealing with lupus. I cannot perform most of the daily tasks as they were done previously. Very little housework, walking dog, driving, shopping, etc. My spouse takes care of these tasks for now.”

“By the end of the day I am drained.”

“I try to get at least seven hours of sleep each night. I have become a super-napper, being able to take a Weds pm (midweek) 45 minute to 1 hour nap so I can become refreshed to make it thru the rest of the week. Again, exercise gives me more energy overall.”

“I’m too tired to answer all this ☺”

“I feel like I am always tired. Sometimes it keeps me from attending certain events. And when I don’t get certain things done because of it, I get stressed.”

Doctor in Training:

According to an article published in International Journal of Clinical Rheumatology, (Ahn GE and Ramsey-Goldman R. Int J Clin Rheumatology. "Fatigue in systemic lupus erythematosus." 2012 Apr 1;7(2):217-227.) 53-80 percent of patients with SLE list fatigue as one of their core symptoms. In assessing the severity of fatigue, it was determined that fatigue as described by patients with SLE is greater than that of the general population, and similar to the level of fatigue experienced by others with chronic illness, such as Multiple Sclerosis (MS) or Lyme Disease. Additionally, the origin of fatigue is described as multifactorial, contributed to by, "physical activity, obesity, sleep quality, depression, anxiety, mood, cognitive dysfunction, vitamin D deficiency/insufficiency, comorbidities such as fibromyalgia, or related to the SLE disease itself or the treatments used to manage SLE."

While the list may look overwhelming, it is comforting to see so many correctable items on it. Taking them in order:

Physical activity: Who wants to exercise when you're already tired, in pain, and not even able to enjoy the sunshine? You should want to! Although it may sound contradictory, working out will actually give you more energy. Exercise has innumerable benefits ranging from the physical to the emotional, and it can help combat fatigue.

Obesity: Here is another thing that is largely under your control. Combining exercise and healthy eating will slim your waistline and boost your energy.

Sleep: Obviously, if you're not getting enough sleep, you're going to be tired. That is true for everyone, not just those with SLE. Plan on setting a regular sleep schedule that does not fluctuate widely from day to day. Wake up at the same time and go to sleep at the same time, in general, each day. Keep the TV, phone, and computer out of your bedroom and get to the business of sleeping! If you tend to feel groggy when you get up, even after a full 8-10 hours of sleep, consider incorporating exercise in your morning routine. If you're up before sun hours, take a walk around the block,

or stay indoors and do some jump rope and light weights in the privacy of your own home.

Depression/anxiety/mood: This one offers a greater hurdle. Our Panel of Experts will offer their own tips on combating depression, but one rule that tends to hold value over time: Request outside help. Whether it is talking to friends and family or seeing a trained professional, discussing your problems and seeking solutions is a good step toward feeling better.

Cognitive Dysfunction: Treatment for cognitive dysfunction varies widely, mirroring the diverse range of its causes. Most people with SLE do not suffer from cognitive dysfunction, but if you feel as though you are, “in a fog,” as many people describe it, talk with your doctor. Determining the cause and appropriate treatment will likely prove more challenging than jumping on a treadmill, but it can be done.

Vitamin D deficiency/insufficiency: This one is as easy as a needle stick. Patients with SLE largely avoid the sun, and are therefore more likely to suffer from vitamin D deficiency. If you haven’t been tested in the past year or so, ask your doctor to add the test to your next lab slip. If you’re low, your doctor can easily prescribe replacement D.

Comorbidities: Again, this one is as varied as its causes. Many patients with SLE have no comorbidities; many do. Continue managing your comorbidities with the assistance of your physician, just as you do your SLE.

Treatments: This is probably the trickiest item on the list. You’re taking this drug to make you better, but now it is causing you to lose sleep (or gain weight, or become irritable, or...). Steroids are well known for causing sleep disturbances, but other drugs can do the same. Talk with your physician to determine if changing the dosing time will help, or if you can consider lowering the dose.

Chapter 13: Gee, and I Thought Dating was Fun Before... - Romantic Relationships

Dating is challenging by anyone's standards. That is why there are websites, companies, and millions of grandmothers devoted to introducing you to your perfect match. Having SLE can add a unique anxiety to the process as you fret over if to tell, when to tell, what to say. Even if you're in a long-term relationship, the changes brought on by having lupus can create issues in your relationship. Learning to communicate your needs and listen to the needs of others will help you to navigate the journey with this new baggage on board.

Where Foot Meets Mouth

I was in the midst of a dry spell in the dating department and so was particularly intrigued when a close friend told me about a coworker at her law firm: Cute, witty, vegetarian – sold.

We met and flirted at a few group functions, and so even before he asked me to dinner, I was somewhat smitten, having planned our happy life together in my head. Dinner was nice. He was funny and interesting and I was happy to be on a date that didn't involve a tweed jacket, a comb-over, and 45 minutes of "Would you rather..." questions. I have my eldest sister to thank for setting me up with that last one.

All was going well, he was sweet, I was charming, and date number two was already in discussion.

During the drive home, he gave the perfunctory complaints about work every young lawyer rattles off as his battle cry. The hours are crazy. The senior partners are evil. And there is no way anyone should ever be expected to get that much work accomplished in one day. "On a lighter note," his face lit up, "I just completed all of this paperwork for the new firm. I got disability and life insurance and am pretty sure I'm worth more dead than alive."

"Hee Hee, Giggle, Giggle." Alright, so it wasn't that funny, but this was a first date and laughing at jokes, even bad ones, sits right next to, 'Don't discuss religion or politics' as one of the rules of good first date etiquette.

"What would really be great," he continued with the enthusiasm of a high school student plotting his senior ditch day, "is if I could get some disease, collect disability, and not have to work ever again."

"Yeah, I guess," I responded, unconvinced "except for that whole having a disease part of it."

“Well, you know, I wouldn’t get a real disease. I could tell them I have one of those made up disease that no one can really ever verify but you still get to sit home on your lazy butt all day. Something like...”

Wait for it, wait for it, you know it’s coming.

“Lupus.”

Silence. Awkward shift in seat. Silence. Awkward smile. Silence. Starting to get internally defensive. Come on now, Yarden, try to stick with the silence. Nope.

“Well,” I started, “They actually can verify if someone has lupus. There are specific blood tests for it. It is, in fact, a real disease.”

Now it was his turn to be awkward, only he wasn’t. “Oh great, you probably have a great aunt with lupus and you’re president of her support group or something.” His tone was a mix of sarcasm and accusation.

Was that another attempt at a joke? I wasn’t biting.

“Nope. I don’t even have any great aunts, I was just saying...”

We struggled into a different topic, but I could see the wheels spinning in his head. I only hoped he was trying to figure a way out of this conversation and back into my good graces, rather than out of any conversation with me, permanently.

I didn’t say anything about that portion of the date to my friend. I told her I had fun, told her it was nice, but didn’t go into details. Perhaps I didn’t want to wreck the golden image I had of him with the truth of his own words. More likely, I was a little bit ashamed, irrationally so, but all the same, ashamed of this complicating puzzle piece I would forever inadvertently bring into any and all relationships.

I didn’t tell her, but he did. And then, she told him. Told him why I shifted in my seat, went silent, and shifted again before becoming, as he correctly interpreted, a bit defensive. We went out again after that, but it was awkward, already strained

far too early in its course. Instead of feeling irritated or, as I should have, indifferent to his reaction, I took it as some sort of challenge to keep him around, to not allow the thing I could not control, control me.

We went out again, this time, to a movie. Nothing was brought up about what he had learned, only that he apologized for putting his foot in his mouth, this time eyeing me inquisitively as he did so. The next day, he emailed to tell me he had a cold. I emailed back, offering to bring him mock chicken soup. He responded, "I don't need anything. I was just telling you because I know you need to be careful with that." It had the potential to come from a sweet place, but I could feel that it hadn't. I wrote back to tell him that I'm fine, not all that fragile, and to let me know if he wanted the soup.

We exchanged emails and phone calls for a while. He was busy at work, I was busy with school and work, and as the banter progressed, the awkwardness began to fade and the flirting escalated. He picked me up once again for dinner. Again, it was fun, interesting, we both ordered tofu, which, at the time, was enough for me to forgive all previous sins.

Then, nothing. Nothing with the added bonus of no explanation of said nothing. Every woman's favorite.

A week later, he invited my friend on a group trip to Mexico; she asked why he hadn't invited me. He told her, as an answer to her particular question and by way of explaining why he had stopped calling me entirely, that I would never be able to go to Mexico with him and sit outside on the beach. Good attorney, doing his due diligence.

I was, again unfairly so, ashamed. This was nothing I could discuss my way out of, nothing that could be fixed or worked with. I wasn't so thrilled with the situation myself, but I didn't have the option of avoiding it. In some way, I respected him for knowing his limits up front.

He was the first, but unfortunately, not the last to take his bow when faced with the occasionally difficult reality of this disease. In the end, much like anything else, you learn from it and end up in a better place because of it. Only four years into a marriage, I already know that life presents bigger challenges to a relationship than sunny vacations. If you're going to jump ship, better do it sooner rather than later. Looking back, I should have thanked him for packing up his bags before they got too weighted down with real emotions and too many unkept promises. I should have thanked him for making room for my husband, a man who has never shied away from this disease or from what it brings to the table. A man who, instead, accompanies me to important appointments, holds my hand, and finds a way for us to take those vacations, sun be damned.

Expert Comments on Romantic Relationships:

“What helps is being truthful to my partner and having an understanding partner.”

“Sometimes, when I first got sick, my relationship with my husband was hard. We didn’t really know what to expect with the marriage but we survived the battle of 12 years with SLE vs. 30 years of marriage, and the marriage won. We have a good relationship.”

“Having a partner who is kind and caring is the most wonderful thing. If not partner, then friend who understands you will have ups and downs and will respect that.”

“Longtime married – 46 years, 15 years with lupus. Husband is very understanding and helpful. It took him a while to understand the fatigue part of the illness, but he got there.”

“If in a romantic relationship, let your partner know how you feel and what you need. Remember your partner, it works both ways.”

“First, learn your limitations – then communicate those to your special people (on a consistent basis). Your limitations will ebb and flow on good and bad days so be flexible to adjust. Maybe that bike ride needs to wait until tomorrow.”

“Talk about how lupus is affecting you. Find a local or internet support group to help you vent. Misery and pain loves company, but other people may not want to hear about it all of the time.”

“My husband of three years has been very supportive (the last one and a half years has been very hard on me and I can’t seem to get better). It is nice having someone to support me that way. I had been going through this alone for so long. God blessed me with a wonderful man. We talk openly about everything, which is the most important thing you can do.”

“When I’m in a relationship, most of them understand and care for me. I’m single right now because I need to get myself better and worry about myself. But when I was in a relationship, my partner helped me when I needed help, etc.”

“My spouse and I closely interact with my physicians and each other by monitoring all treatments and results together.”

“I look at it this way. They are going to like me for how I am not how I look.”

“I am very fortunate to have a very supportive and loving husband. We met after I was already diagnosed, so he has lived thru a lot with me. He is very proud of my positive attitude and will to live a full life and not let my lupus limit me.”

“I have been married since I was diagnosed. I don’t feel he understands completely what I go through daily. Because I am always tired, our sex life is minimal. Also, because of fatigue, I feel sometimes my daughter doesn’t get all the attention she needs. I have a desk job, so I usually don’t miss much work and my coworkers are very understanding. I always have been very truthful and help them to know when I feel bad.”

Doctor In Training

There are many aspects of a relationship that may change when one of the partners is diagnosed with a chronic illness. One of the more personal, and less often discussed changes that may take place relates to sexuality. A nursing study of 81 women with chronic illness sought to determine strategies for nurses to discuss and facilitate solutions for issues relating to sexuality for women with chronic illness. (Kralik D, Koch T, and Telford K. "Constructions of Sexuality for Midlife Women Living with Chronic Illness. *J. Adv Nurs.* 2001 July, 35(2): 180-7)

The study found that numerous factors play into a woman's perceived sexuality, body image, communication, caring for others, etc. Not surprisingly, these things are commonly affected by a chronic illness. In the case of SLE, both the disease itself as well as the drugs used to treat it can cause unwelcomed changes to one's skin, physique, and hairline. Making matters more challenging, initially, the sudden and unwelcome intrusion of a chronic disease in your life leaves little time to discuss issues that were at one time considered cornerstones of your relationship. Simply knowing that these changes are normal, even expected, and commonly temporary can help to alleviate some of the anxiety.

The goal is to continue to value and respect your relationship. Discuss the changes you are experiencing, both emotionally and physically. If jumping into the conversation with your partner feels scary or overwhelming, try writing your feelings down or discussing them in a support group before bringing them home for a real and constructive conversation. Individual, or couples counseling is another option.

Chapter 14: Here Comes the Sun, Little Darling – Sun Avoidance & Traveling

The word vacation should elicit sighs of relief and screams of joy, unfortunately, when trying to plan a trip whilst keeping in mind the limitations in place due to your lupus, the sighs may be those of annoyance and the screams may be those of frustration.

Pardon me Jeeves, do you have my parasol?

“You look like P. Diddy.” My husband (then boyfriend) said as he ushered me through the streets of his hometown, Guatemala City, holding a thick, silver umbrella above my head, the sun shining bright in a clear blue sky. It was my first trip to meet his family, and, although I was looking forward to it, I was also worried. Guatemala is closer to the equator, year-round sun, and a high UV Index. Before the trip, my husband, never one to plan ahead, was scouring webpages, searching for sun protective gear, reading the latest medical literature on sunscreen, and ordering various items from an Australian website touted as the *crème de la crème* of sun protection. We weren’t yet planning a wedding, but I was sold.

It wasn’t the first time I knew I loved him though. That happened early in the relationship when, after a particularly difficult day of MCAT studying, I complained about my eyes hurting from all the small print. We were headed to pick up a rental video. We had established a sort of custom where, on Friday nights, we rented a foreign film and watched it at his place. The films were usually in Spanish, his native tongue -- ones he had seen and loved or some of the newer releases. That night, he chose a film in Hebrew, my first language. I was surprised, as he’d been looking forward to seeing numerous other films, and we knew nothing about this one. “You’ve been reading all day,” he said to me. “With this one, you can just listen.”

So there we were in Guatemala, some eight months later, seeing the sights. It was *Semana Santa*, Holy Week, and Guatemala was filled with the hustle and bustle of locals preparing for the holiday. Children filled the city streets, creating carpets from colored sawdust while women set up shop along the sidewalks selling *dobladas*, *chiles rellenos*, *tostadas*, and grilled meat alongside holiday treats of plantains in mole sauce and *empanadas* filled with sweet milk.

I had never been to Guatemala, or really – not counting a Club Med trip to Sonora Bay, Mexico, as a child – anywhere in Latin America. I wanted to see it all. So, each morning, I dug into the bag of goodies my husband ordered for me, and spackled on

SPF 65, thick, gritty, screaming of serious protection, on all reachable surfaces. I perched the special, wide brim, sun protective brown hat over my head, grabbed my solar block umbrella, and set out to the city streets.

We got the occasional stare or two. My skin, pale in nature, had become nearly translucent from the years out of the sun, and, umbrella or not, I would have stuck out walking around this city with my husband and his brother, both naturally bronzed and clearly locals. The fact that they took turns holding the umbrella over my head as I snapped photo after photo – hundreds at least – only served to increase the absurdity of it all. Who was this girl strolling through town with two men who appear to be, what, butlers? And thus, I became P. Diddy and my husband? Fonsworth Bentley, I presume.

Expert Comments on Sun Avoidance:

“Use sunscreen every day and still stay out of the sun”

“Wear sunglasses and hats and long sleeves. I don’t even walk the dogs after 6:00 AM until it is sundown. During times when there is sun, I stay in the house and only leave to get into a car and then into another building.”

“Stay covered with light clothing and hats.”

“The sun will cause a flare. Protective clothing and hats help. You can get some at Bass Pro Shops and others can be ordered in catalogs. Wear sunscreen like Vanicream SPF60 (can be found at Walmart behind counter, ask the pharmacist). This is the best in my opinion.”

“You can go in pool in the evening after the sun goes down. Walk in the mall. Always keep an umbrella in car, so you can walk outside and go to parks.”

“I don’t leave home without sunblock SPF 50. I don’t swim outdoors. I also drive to the Pavillion to walk my dog under the leaves.”

“I don’t have much of a problem with sun. I wear long sleeves.”

“It is impossible to avoid sun completely, especially if you live in a sunny area. Arizona is hard. I use sunscreen and wear long sleeves and hats, especially when I drive.”

“There are several brands of clothing made for people with lupus to protect you from the sun. But in my opinion – listen to your doc and stay out of the sun! It will flare your lupus. If you must be out – wear sunscreen and protective clothing and a hat.”

“I swim after dark. I walk after dark. 10 minutes of sun will lay me up in bed for days (or longer). Try to plan your activities outdoors for the evening when sun is less intense.”

“There are a lot more choices out there now for protective clothing. REI and Columbia make the best shirts; they have a lot of ventilation. Both have a wide range of styles and colors and you can get them on sale, or go to the Columbia outlet for really good prices on shirts and pants. Columbia has the most stylish pants. Columbia makes great pants for walking, but they are expensive. Ulta MD has the best sunscreen.”

“I use sunscreen, protective clothing, hats, and avoid sun as much as possible.”

“All activities involve the sun in Arizona. I always use long sleeves, sunscreen, big, big straw hats when I’m out. Occasionally, I wear short sleeves.”

“Sunscreen and avoiding the 10-4 sun exposure. Long sleeved shirts. Hat and pretty parasols. Swim in the pool with the sunshades overhead.”

“Coolibar (www.coolibar.com) sunscreen protective clothing. Have been buying them online for three years. Especially love their hats and shirts. They always have a sale in Sept-Oct.”

“My dermatologist recommends Neutrogena sunscreen. You can buy it during the summer months at Costco for a great price and they usually include a lip conditioner.”

“I try to go out early in the morning or early evening. I limit my activities. It is hard enough to get through my housework. I stay mostly indoors.”

“I try to stay out of the sun; however, when I can’t, I always wear sunscreen. Lubri-derm has daily lotion with SPF in it, and it smells nice. I also have Coolibar shirts and jacket that has SPF in the material.”

“When outside, I wear clothing made by Coolibar. It contains SPF in the clothing. The lupus foundation of Southern Arizona in Tucson sells this clothing. I always wear sunglasses and a wide brimmed hat outside. Indoor yoga is a good activity. Since I love gardening, my husband brings the pots, soil, and plants to me in the

garage so that I don't have to be in the direct sunlight. Also, I go for long walks after the sun sets."

Expert Comments on Traveling:

“I always try to move around when flying rather than sitting in one spot.”

“Wear sun block, hats, sunglasses, long sleeves, and get plenty of rest.”

“Stress is very hard on SLE, but I find the more control on how you do things, the better. Sometimes going someplace that gives you that feel good feeling helps, not hurts. Make sure all your meds are listed and how often you take them. The more you do to keep records for yourself the more you can say what works for you or doesn't. Trial and error is a good learning tool. Write things down in a journal of how you feel on trips. Everyone is different, so you might be tired at first, but pace yourself and don't try to do too much until you decide you can. Always be kind to yourself and hopefully the people around you will understand.”

“Always, always carry your meds with you. I carry them in a daily medication tray. I also tape them shut.”

“Medication in purse. If you bruise easily, be careful with suitcases so you don't get injured. Wear long sleeves, running suit, or jacket. Protect arms from injury. Try not to carry anything more than a purse over your arm.”

“Getting ready to travel is stressful even for healthy people. Don't worry. Expect that you may get sick on a trip, upset stomach, headache, or feel very tired. Rest as you go. Plane, car, etc. Take time out; it's part of your life. It is what it is. Remember, everyone is dealing with something.”

“Travel will affect you; plan for it! Take naps if possible. Take a pillow with you.”

“Pack meds in weekly containers (day of week, etc.). Take extra meds in case you get delayed.”

“As much as you're tempted – Stay out of the sun!”

“Pack in advance to reduce stress of travel.”

“You can request a wheelchair and to board early because of lupus if it makes it easier on you then having to wait in lines. I always pack my meds in a ziplock even though I have them in a pill pack. The pillpack can open and spill; this way they are contained. As for the sun, wear hats. There is a lot of sun protective clothing. Stay In the shade and try not to go out in the middle of the day.”

“Just try to be in a comfortable place when you do travel.”

“Always take a long sleeve shirt or two. You never know what you are up against. Don’t forget medication. Get a pill box and pack that first.”

“I got an extra large pill box that can hold a week’s worth of meds and I had my pharmacist label it with my meds (no bottles). Take a hat and sunscreen. Carry your meds in your carry on!!!”

“I travel to the beach in Mexico and meet a large group as we have a time share. Some I know very well, some not so well. But – you have to realize it doesn’t matter what others think; do what is best for you!”

“Beach – Yes you can! Coolibar makes sun protective cover-ups, swim legs, hats, umbrellas. I am completely covered J. Might get a few funny looks at first, but I got used to them very quickly.”

“I often get sore and tired when traveling. Try to get rest before your adventure starts. If you can, take a pillow and eye mask, if you need to, take a nap. Also, the pillow helps for comfort. Also, make rest stops and get up and walk around. Always pack sunscreen; it’s my ritual. With meds, keep them in your purse or check on bag if flying.”

“Always carry your meds on your person when traveling. I transport them all in the bottles from the pharmacy with the complete labels affixed. I do bring weekly/daily organizers with me to dispense medication into. I dispense meds into the pill organizer when I arrive at destination, making it easier and quicker to take all medications. Bring a typed copy/list of all meds, how they are taken/prescribed, a list of all

allergies and responses to them, all diagnoses and surgeries, and physician (name, phone number, specialty) and emergency contact information.”

Doctor In Training

When traveling, it is important to take extra precautions with the sun. While you may be accustomed to the level of exposure you get at home and have devised ways to avoid it altogether, travel brings with it entirely different circumstances. Certain areas in the world have greater sun exposure with a higher UV index, which means that, for you, exposure carries more danger in less time.

The EPA has a great website where you can check the UV index for where you live, or where you're going. <http://www.epa.gov/sunwise/uvindex.html>

Buying special SPF protective gear is great, but it is not a passport to transform into a sun goddess during your voyages. The extra protection is for the times when you find yourself accidentally in the sun or when you need to take a sunny route to get from point A to point B. Still, be mindful of the time you are spending outdoors, and try to plan outside events during non-peak hours.

Chapter 15: BFF – Friendships & Lupus

It's not just your romantic relationships that are affected by your new diagnosis. Anyone in your life who is close to you, spends time with you, and cares about you, will be affected. It is up to you to decide how open you want to be about your disease and expect a lot of questions. If you don't yet know how to answer them, say as much, and keep the people who are important to you informed so they can continue to be a part of this aspect of your life.

Night Runs and Wedding Bells

My friends were all very supportive through my initial diagnosis, first with lupus, then nephritis. I had visitors to the hospital during chemo infusions, phone calls, and the modifications I had to make to my life (staying out of the sun and being more vigilant about my health in general), were taken well. It took me a while to share a lot of the details, but eventually, as I became more comfortable with them, I branched out and told the people who were closest to me.

Some friendships grew stronger in the process. A few years after diagnosis, and after completing the first of my six rounds of Cytoxan, I decided I wanted to run a half marathon. A close friend and previous college roommate agreed to train with me. She kindly complied with my training schedule, running very early in the morning or late in the evening in order to avoid the sun.

Another friend, the same who came to stay with me in the hospital, signed me up for Lupus Now magazine and became equally informed on the diseases as well as my personal version of it, always asking questions and keeping abreast of any changes.

I never used my diagnosis as a crutch or an excuse and, in return, when I explained a limitation, it was taken seriously and respected accordingly.

It has been thirteen years now, ten and a half since the nephritis. At this point, I have friends who know and friends who don't. The ones who have been with me the entire time know everything, although it rarely comes up these days. I get an occasional request for an update: "How are you feeling?" "How is it going?" "Anything new?" But luckily, there has not been much to report as of late and I say as much, allowing the conversation to shift to more interesting topics.

There are other friends who know me, but don't know this piece of me. When I first started medical school, there was a scare with increased urinary protein and some poor lab results, but with a few minor medication and life adjustments the numbers

corrected themselves without much effort and it seemed unnecessary to involve this new group of people into what was beginning to feel, in some respect, like a part of my past.

There were some awkward moments as I shied away from the sun with little explanation or escaped to New York City for my annual appointments each spring, but the issue was never pressed and I left it at that. It wasn't that these new people were not worthy of the knowledge or that I did not see hope for lasting friendships, the kind where you share all of life's intimate details, but these were medical students after all. An entire herd of people setting forth to diagnose and cure, being trained to look at disease as a question needing answers, and I already had enough investigators on my case.

It is with some sadness that I blame lupus for the loss of one friendship; the weight of it is too much for some to bear. I will always give her credit for her earlier displays of support. Accompanying me to chemo infusions, calling to check in on a regular basis. But this disease knows no boundaries and for her, it crossed a line.

Her wedding was approaching, a day she had likely been planning even before she and I met, at eight years old. I was to be a bridesmaid, an honored position. The trouble started early on with a bachelorette weekend in Palm Springs. Phoenix is no picnic, sun wise, but Palm Springs with its acres of golf courses and endless swimming pools offered its own set of challenges. There are some who will never fully understand all of your new restrictions. They will recommend sunscreen so that you can join them on a poolside chaise lounge and offer wispy branches as protection from hours of rays. The weekend was marred from the beginning by its location and the problems continued with the lack of understanding over my need for rest and a proper night's sleep.

The escalation came on the wedding weekend itself. I had expressed earlier concern over the events surrounding the ceremony. I was expected to wear a strapless dress, to spend the afternoon participating in group photographs outside, and to cap it off

with a walk down the aisle in the California sun. It was something I knew I would not be able to do, but – in error – agreed to wait until I saw the location on the wedding weekend before making a final decision.

A conversation with my mother the day before the event left me promising not to go forward with the earlier plan, and I agreed not to arrive to the outdoor wedding until the sun had started its descent. My mom had seen me through over six months of Cytosan, returning to her home after each treatment, listless with semi-permanent IV lines taped across my arm, spending weekend after weekend vomiting in her bathrooms. She was the one who spent her Sunday nights returning me to the hospital when the vomiting became intractable so that they could give me the good stuff, the IV Zofran, and get me all patched up and ready to work again the next day. To put myself at risk of having to do it all over again, to force everyone else to do it all with me, was selfish.

I called the bride-to-be the day before the wedding. I didn't expect it to be a surprise, I told her this was a real possibility a month earlier, but she did not take the news well and, instead, it was the final culmination to the end of our then faltering friendship. We tried to talk it out weeks later, screaming over one another as if volume equaled justification, but it was futile. To her, I was the monster who deliberately ruined her wedding day by not taking part in it. To me, putting me in such a position and not understanding why I had to get myself out of it was unforgiveable. The incident ended in a pseudo peaceful truce, agreeing to disagree. It was clear to me that she would never see beyond her own needs, and it was with that realization that I came to peace with the fact that now, more than ever, she was not the kind of friend I could have in my life.

In the end, it was not Palm Springs or broken bridesmaid duties that ended the decades long friendship, it was just another limitation of lupus. You get to a place where you realize your time, some days filled with doctor appointments, lab visits, 24-hour periods dedicated solely to urine collection, is limited, and you no longer

have the luxury, energy, or interest to spend it defending the choices that are no longer your own to make.

How I would have liked to be a part of that wedding, to spend the day with all of my friends, posing for pictures, laughing, making memories. I'll never understand why she would think that I would willingly give that up, but that question has found itself at the bottom of a very long list as the years click away. In turn, other friendships were strengthened by the experience as friends rallied around me, offered their support and understanding, and, ultimately, a weight of burdensome expectations was lifted from my shoulders.

It was with that experience that I realized that lupus, like many significant struggles, offers a magnifying glass to crevices in your life that you perhaps did not want to see so clearly. It is with that same glass that I see my other friends, the ones who have stuck by me, running in the dark, and who shine that much brighter in their magnified state.

Expert Comments on Friendships:

“Most friends don’t know what it is; be truthful and explain.”

“Not all family will understand and this one was hard for me, but I had to come to peace and pray that they will never have to go through something like this. Fear for some people makes them turn away because they don’t know how to act, so they avoid instead.”

“My friends and their relationships with them are my lifesaver. I also am very close to my children.”

“They are important. Find someone with same interests, by joining a class, learning a new hobby, etc.”

“Friends are good and bad. Most of my friends have been helpful and very understanding. Most go out of their way to help me. However, I have lost friends because they could not handle watching my body deteriorate and see what I’m going through. Others can’t handle being friends with someone who can’t do things or has to cancel things because of health. Some people do treat you differently.”

“Most of my friends understand and care for me. I never lost a friendship because they didn’t care or didn’t understand. Most of them help me out a lot. It’s not hard for me to tell people I’m sick. I’d rather have them know just in case something happened to me or, so if they see me take 25 pills, they understand why.”

“I have close friends with whom I communicate freely. They recognize that I have limitations in activities we used to do. They offer spiritual support through church and prayers. They are very important to my well being.”

“I am very open about my lupus. My friends are very supportive and impressed by my positive attitude.”

“My friends are wonderful! They always watch out for me. We talk about my day to day experiences. I couldn’t get through it without them. We laugh all the time and I feel laughter is the BEST medicine!”

Doctor In Training

Caring for someone with a chronic illness introduces a unique set of challenges. The brunt of those challenges usually falls on family and medical personnel; however, people who share close friendships with someone living with a chronic illness may also feel some of the burden. With lupus in particular, lifestyle changes – such as sun avoidance, necessity of adequate rest, additional physician visits – can force changes to previously laid plans.

Researchers in Singapore interviewed family members of those with chronic illnesses and found a correlation between the ability to discuss, “the perceived burden” of caring for someone with a chronic illness with the level of burden itself, suggesting that encouraging friends and family members who – in whatever respect – feel they are in a care-giving role to discuss their feelings, may help to alleviate some of the trepidation. (Vaingankar JA et. al. “How much can I take?” Predictors of Perceived Burden for Relatives of People with Chronic Illness.” *Ann Acad Med Singapore*. May, 2012, 41(5): 212-20)

Chapter 16: Girl, You've Got That Glow – Pregnancy & Lupus

Family planning is one of the most personal decisions an individual and/or couple can make; it is also usually one of the most joyous. Although having lupus can complicate the process, it does not have to affect the ultimate outcome.

Ten Little Fingers. Ten Little Toes.

We were married almost a year when we decided to try for a baby. The plan was to give birth at the end of my first year of medical school in order to take advantage of the summer off to spend with the baby. Most of my friends were already mothers, some of them two, three, even five times over. One after another, they got pregnant in the blink of an eye, most without officially trying.

The first month we started trying, I got my period, which felt like a failure of epic proportions. How could this be? I started charting my basal body temperature each morning, waking at the same time each day, not making a move until I had my temperature recorded. Month two came and went. My history of twelve Cytoxan infusions moved from the back of my mind, where it had been residing relatively quietly for years, to take front and center. Had the Lupron not worked? Was I incapable of getting pregnant? Should I have taken my brother-in-law up on the offer of sperm some ten years earlier? For me, even a twisted Jerry Springeresque family would be better than none at all. Another month passed.

We decided to seek outside counsel. My husband's friends used a well-known fertility doctor in town with two adorable results; we made an appointment. Everything you read will tell you, at my age, you wait a year of unsuccessful active trying before seeing a fertility specialist. I have never been known for my patience. Furthermore, I had a bona fide reason to question my fertility and didn't see the sense of suffering through twelve monthly disappointments before doing something about it. I was also, as I always am, on a timeline. I already missed my hope of having a baby in time for summer; I could not risk dragging the process into third and fourth year rotations.

His office was sleek and new. Pictures of soft, smiling babies plastered the walls and shone from the cover of glossy pamphlets. This felt cruel. The doctor went over the plan for couples, like ourselves, who have no children. He explained the tests they would perform on my husband. He was to come to the office and give a deposit.

They then test the sperm for quantity, motility, and morphology. The doctor then turned to me. Since I was getting a regular menstrual cycle, he was not interested in lab work and instead wanted to head straight for the money – my uterus. There was a list of tests that were to be performed, one after another, even before learning the results of the previous ones. The tests involved intravaginal probes, dye injected into my fallopian tubes, and possibly, biopsies. -- all the fun you can imagine packed into one toe-curling afternoon.

We left the office with a stack of papers and a number to call to set up the appointments. I called the following day and learned that each exam was only performed on a given day of the month at a given time. I was in school -- school, with an unforgiving schedule and no time off set aside for uterine exploration. We decided my husband's tests were a little more straightforward, and that even though probability suggested otherwise, we should at least rule out a problem on his end before delving into the chasm of female infertility. Another month passed.

It was winter break and we spent it in Europe seeing the sights. I ate endless mounds of dark chocolate from Parisian Christmas fairs, and my husband sipped warm spiced wine on the cobblestone streets of Brugge.

Two weeks after we returned to the States, and a few days early, I started bleeding, again. It was the same day my friend, married a little over a month, called to tell me she was pregnant. It was a wedding night accident, a surprise. They hadn't even been trying. I was happy for her. I was devastated for myself. We had friends in town, and I tried to keep on my game face.

The next day, still distraught and realizing I hadn't bled more than a little bit, I decided to take a pregnancy test. It was silly to take the test. My actual period wasn't due for another two days, and I had already bled some the day before. But if there was a possibility, even a sliver of one, it was worth it to find out. Maybe, somehow, possibly, I had no reason to be sad, and every reason to be happy. My husband was

off at the park with our friends and their children. I stayed back to study, avoid the sun, and, I suppose, to take this test. Two minutes later: Two Pink Lines.

They were faint. So faint, I wondered, as I stared at them in disbelief, if I was imagining them. I moved from room to room to check in different lighting. Bedroom: Still there. Hallway: Still there. Kitchen: Yup, still there too. I called my sister, she had taken her fair share of pregnancy tests: “What if there are two lines, but one is really, really, really faint???”

“A line is a line.” She told me. I sunk to the floor, tears of joy.

When my husband returned, he was with our friends. Their kids told me all about the park: The train, the rides, the ducks! I couldn’t just blurt out the news; they – like everyone else - didn’t even know we were trying, so I waited. Finally, once they left, I sat my husband down on the brown tweed sofa in our family room and told him the news. He cried, too.

We wanted to keep this to ourselves until I was into my second trimester, but I couldn’t keep it a secret from everyone. That evening, we went to my parent’s house to share the news. My dad, never one for open displays of affection, broke his unspoken rule as he hugged me, smiling from ear to ear. My mom did not share in his reaction. She stood, silent, her face formed into something between a frown and an intense stare. She was thinking of what was best for her own baby, me. “What about school?” she questioned. “Are you even supposed to be getting pregnant right now? What about your medications? You could get sick again.” My husband and I did our best to reassure her that this was a well-planned event, we had the doctor’s approval, and all precautions had been taken. I also had to promise that I would not drop out of school when I had the baby. “If you quit school,” she warned, “I will never forgive this baby.”

My pregnancy was challenging only because I, by matter of custom, was considered high risk. That my son and I were perfectly happy, healthy, and developing as if

we'd read the book, mattered not to my OB. I was high risk, and I had to follow the rules of the label. That meant 24-hour urine tests, twice weekly checkups, non-stress tests, biophysical profiles. By the middle of my pregnancy, I had to have an ultrasound every week. All of this might have been exciting if I had nothing else to do and didn't hate doctor's offices so much. But, I did, and I do, so the whole thing was nothing short of a pain in my ever expanding, well, bottom.

Week after week, I'd squeeze in two appointments between lectures and exams, confirming at each one what I already knew: The baby, my baby, was perfect.

Thirty seven weeks after we learned of his impending arrival, my water broke. I won't terrify you with the gory details of natural childbirth, but suffice to say, it was uncomfortable. Of that, I cared not, because at 5:09 AM on September ninth, in the face of lupus and Cytoxan and the countless other medications I had been -- and was still -- on, my absolutely perfect little boy arrived, 7 pounds, 6 ounces, pink and screaming with ten perfect little fingers and ten perfect little toes.

Expert Comments on Pregnancy:

“I had my children before I was diagnosed.”

“Always check with the doctor. It can be difficult, but possible.”

“Pregnancy #1 was tough, #2 was a disaster!”

“It is important to PLAN your pregnancy. Discuss with your doctor. He/she may want you to see a neonatologist before becoming pregnant. This “high risk pregnancy expert” can help you plan for a successful pregnancy and birth of a healthy baby. Also, some important blood test prior to pregnancy are in order. Test for lupus anticoagulant and smith antibodies (just to name a few). These may have been performed by your rheumatologist prior to your lupus diagnosis.”

“Told I shouldn’t get pregnant.”

“I tried getting pregnant. I was three months along when I lost the baby. The whole time I was bleeding. My doctor told me I can have kids, but she just wants to make sure she has everything under control first.”

“Not applicable, due to the fact that I am 80 years old.”

“I was not able to become pregnant due to always being on strong meds. I went thru a period of sadness at this but then grew to accept my situation. I am an early childhood teacher so I have been a “mom,” for many, many children.”

“I did not have lupus until I got pregnant. I decided to not have any more children.”

Doctor in Training:

Pregnancy in the face of lupus is possible. The most important thing is to plan ahead. Studies show that if a patient is in clinical remission for six months prior to conceiving, she greatly increases her chance of having a healthy, normal pregnancy. Even if you are feeling great, you will still need to be followed by an OB who specializes in high-risk pregnancy and who has the resources to give you and your baby appropriate checkups and testing throughout. Additionally, before even considering getting pregnant, you need to discuss any and all medications with your doctors. Find out which ones are labeled as safe during pregnancy, which ones are not labeled safe but are widely accepted anyway, and which ones are an absolute contraindication. If you need to stop some medications, it is best to switch over to whatever alternative drug is chosen and to give yourself time to ensure that the new medication is working to treat you appropriately. Once you've been on a pregnancy-safe drug regimen for six months and have remained clinically inactive, doctors usually give you the go-ahead to start trying.

In the face of past Cytoxan, your fertility may be compromised. The likelihood depends largely on how many rounds of chemo you received, at what dosages, what age you were at the time you received Cytoxan, and how old you are now. You can talk to your doctor about your specific likelihood, and, as mentioned, there are tests that can be performed to confirm whether or not you are still ovulating.

If you've never received Cytoxan, having lupus does NOT affect your fertility. You start out just like everyone else, basing your likelihood of a quick route to pregnancy on you and your partner's age.

Chapter 17: Crying Game – Depression & Lupus

Living with lupus can be both difficult and emotional. If you've ever found yourself frustrated or crying over aspects of your disease, you are not alone. The goal is not to avoid those feelings all together: although that may sound attractive, it is not always practical. Instead, it is important to recognize how you feel and to work through it. For some, that means talking with a friend and for others it means getting professional help to deal with your emotions. Whatever works for you, it is useful to have a plan in mind. As you're about to read from my example, the sadness can, at times, overwhelm you.

Tissue Please

Counting today, but not counting the two weeks after I gave birth to my son, during which time I was a total lunatic, I have cried out of sadness, frustration, anger, a total of three times during medical school. With so many new expectations, high stakes tests, surgeons literally yelling at me, you'd think there would be copious reasons for crying, and there are, but none of those got to me. Every reason I've cried over these past three plus years has had something to do with lupus.

Before school began, my husband and I decided that we wanted to get pregnant. We took all of the necessary steps, meeting with doctors, changing medications, and following labs. It was a couple of months into school when the protein in my urine increased, and there was talk of switching me back to my old meds, the ones that I was not allowed to use when pregnant. I sat in my car, parked in the school parking lot, talking on the phone with my doctor in New York. Reverting to the old medications meant no pregnancy. We discussed the possibility of egg harvesting so that my sister could carry a pregnancy for me. Thankfully, we also discussed the option to give the new meds another month – a month where I was more cautious about the sun, rest, stress, and to then check my labs again. The second option worked, but in that moment, when I hung up the phone and sat in the semi-privacy of my car, I cried. I was scared and overwhelmed and mourning the ideas I long held about how one goes about starting a family. My plans never included so many people in on the decisions.

My second tearful event didn't happen in my car, but it revolved around it. I was pregnant, and my last urine test showed increased protein. The OB, who spent what felt like my entire pregnancy waiting for me to flare, showed a colossal degree of concern. "The solution," he said, looking more at my husband than at me, "We admit her to the hospital for strict bed rest and so we can monitor her blood pressure, urine, and labs."

My husband, usually a quiet man, answered incredulously, “Admit her to the hospital! For some urinary protein?”

I had an alternative solution. Seeing how everything, with the minor exception of increased urinary protein, was fine, I would take extra good care of myself, stay out of the sun, lower the stress level, and would repeat labs every week. It worked before I was pregnant, it should work now. Saying that, in addition to, “There is not a chance I am going to the hospital,” solidified the plan.

Our classes were held in more than one building, and a major street often separated morning from afternoon sessions. I paid for an annual parking pass, but parking was only available near one of the buildings, so my day involved a fair amount of outside walking. Parking and walking to the building across the street once wasn’t the end of the world, but with switching classes, going to the student lounge for lunch, and returning to the car in the afternoon, it ended up being a lot of time in the sun. I wore sunscreen and covered up as much as is possible in the Phoenix heat, but I had just promised the OB that I would stay out of the sun completely. Because it was so important, I broke one of my cardinal rules and set out to ask for some assistance.

I went to the dean of student affairs, explained my issue with the sun, and asked what could be done so that I could park in one of the open lots at the other building and drive between buildings rather than walk. She was nice, explained that the other building was owned by a different entity, and essentially said that her hands were tied. As a bonus, she topped off the conversation by saying that with impending construction, the lot where I currently park will be gone soon, and we’ll all have to park much farther away.

I’d like to think that it was the pregnancy hormones that allowed me to tear up so readily. Whatever the case, there I was, standing in the associate dean’s office, crying. The truth is, I hate asking for help, and, even more, I hated that I needed help

with something as silly as parking. It was just another thing that was a little different, a little more difficult, and on that particular day, a little more dramatic.

My third – and hopefully last – day of med school crying was, coincidentally, today. I was in my school's brand new building, meeting with two people to discuss this very project. There were differences of opinion regarding writing styles, what to include – and not include – in the work, and, most striking to me, the role of a patient. This project, from inception, viewed the patient as an expert. I know, 13 years after diagnosis, I feel I've earned some expertise in what it means to be a person with lupus, and I refer to patients in this project as experts repeatedly. I listened as one of the men working with me on the project rattled off his list of objections, "And this one still really gets to me," he said, having offered the same complaint one week prior, "Calling the patients experts. Patients are not experts." I can't say I broke down from that comment alone, but it is fair to say that it offered a huge push over the edge. There I was, nearing the end of medical school, having done years of work on this project, and I had someone who I thought was on my side belittling the importance of the patient, of me. It is everything you fear your doctor is thinking. They teach you a lot in medical school -- compassion, respect for others, modesty are not on the syllabus.

And so there I was, sitting in an office, crying, without even the excuse of pregnancy to defend myself. Right or wrong, I was raised not to cry, and so I was mortified as I sat, exposed. In my head, along with the constant track of my own voice yelling, "STOP CRYING!" over and over again, I had a million and one things I wish I would have said in response. Instead, I wiped away tears and willed myself to calm down.

Graduation is still nine months away, so I suppose there may be another source of crying in my future, but I find it interesting that after all that medical school has thrown at me, this disease is still the only thing that is emotional enough to induce crying. I am lucky enough to have not suffered depression from lupus. I have felt sad, angry, frustrated, but not to a pathologic level and not so much that I needed

outside assistance. If it ever got to that point, I would get help, just as I go to my rheumatologist for management of the physical aspect of this disease, I would see a professional for the mental aspect if it became a problem. For now, I pet my dog, think about hugging my son when he wakes up from his nap, and concentrate on filling my medical school graduation requirements. Not everyone will see me, or any patient, as an expert, but I'm confident in what we all know.

Expert Comments on Depression:

“Having someone to talk to helps.”

“Keep active and socialize. Be around friends and family.”

“Read positive books, walk, talk with a special friend who understands. Treat yourself to something special (shopping, food, movie, etc.). Don’t retreat into dark spaces and stay there; this just feeds depression.”

“Lots of exercise when my joints aren’t too bad. Eat lots of protein, fruits, and vegetables.”

“If I feel depressed or angry, it is usually caused by some illness – virus, etc. As soon as I get better or go up on prednisone, I feel good again. Not depressed about lupus. Usually don’t bring it up in conversation.”

“It is part of the disease. Accept you will struggle with that each day. Get out, go to mall where there are a lot of people. Remember there’s a world out there. Life goes on. Try to be part of it. Look for happy moments, small moments, green trees, babies, etc. Have a piece of chocolate, eat slowly. Do what makes you feel better.”

“Okay – you’re depressed. That’s okay. No one would expect you to celebrate lupus! We all agree – it sucks! Discuss with your doctor the best ways to treat depression. You may need anti-depressants. This does not mean that you are weak or have failed. It means that the chemicals in your brain need some convincing. Trust your doc.”

“Journaling. This helps you feel that you have control over things you feel you have no control over. Trust me. Journal by bed. Write in it before bed your honest unbridged feelings! Then your mind can rest that you’ve addressed the issues. Give it a try; what do you have to lose? BTW, this is just for you; if you know it’s not to share, you can be brutally honest. You’ll be surprised what you feel and write.”

“I try to be really in tune with my body. Be conscious of any emotional changes (ie: depression and irritability). When I realize it, I take a step back and analyze what is going on and figure out what the trigger is. I also pray a lot more and try to spend more time reading my bible and talking to my husband about it. Remember, it is okay to be upset occasionally about what is happening. Lupus can change your life.”

“When I’m depressed my body hurts, I don’t really eat and I sleep a lot. To make myself better, I write down how I feel.”

“I take anti-depression medication. I also talk with my spouse, friends, and my dog!”

“Prayer, meditation. Time for me. Fun with family and friends. My dogs.”

“I have several periods of depression due to lupus. I will go so long hurting and aching then all of a sudden, I get tired of it and get depressed. After a while I kick myself in the butt and start telling myself this disease is not going to get the best of me. I seem to push myself more than I should, so I try to catch myself before I start hurting or the pain becomes excruciating and stop to rest.”

“Depression comes and goes. The best thing I have found is talk with family or friends. I have one friend with lupus and talking with her, because she truly understands, helps a lot. And when the symptoms are starting, getting out and doing something you enjoy helps.”

Doctor in Training

Determining the cause of depression in a patient with SLE is not always straightforward. In response to, “Why would a patient with SLE be depressed?” Those of us who have lived with the disease may unanimously shout, “Take your pick!”

Auerbach and Beckerman from Yeshiva University in New York wanted more specifics. In an attempt to determine the psychosocial needs of patients with SLE, the researchers determined that a majority of depression caused by SLE was related to changes in appearance and physical abilities. (Auerbach C, Beckerman NL. “What social workers in health care should know about lupus: a structural equation model.” *Health Soc Work* 2011 Nov;36(4):269-78.) This information helps the medical community know where to focus its collective energy. But, until all of the ugly aspects of this disease, and hopefully one day the disease itself, can be cured, you’ll have to take the bull by the horns and deal with this issue straight on.

As with all causes of depression, discussing your feelings, anxieties, and concerns, is helpful in alleviating them. There are psychiatrists and psychologists who specialize in working with patients with chronic disease, but that is likely not necessary, as any trained professional can assess your emotional state and help you to arrive at plan toward mental health. In a pinch, a close friend or family member can help facilitate the discussion as well.

If there is a specific aspect of lupus that is causing you heightened stress or depression, discuss this with your physician. There are treatments for hair loss, striae (also known as stretch marks), acne, and a slew of other disease related issues that are often listed as a source of depression in patients with SLE. Also take relief in the fact that, just like all aspects of this disease, the changes in appearance and limitations on physical activities, will also wane in time. Nothing is constant, and as you work toward the main goal of getting your disease under control, the rest will follow suit.

Chapter 18: Love Thy Neighbor & Other Lessons for Stupid White Cells - Explaining Your Diagnosis to Others

We've all learned that some topics do not lend themselves well to polite conversation, money, politics, and now, lupus? You'll find that some of the people you encounter are far more comfortable discussing the disease than others and that, over time, you'll realize that far fewer people need to be told anything at all unless you are so inclined.

Laughing Gas

I had one, rare day off during third year rotations and in it I scheduled what should be my semiannual tooth cleaning that, since medical school, had quickly shifted to a, maybe, once a year event. Upon entering the office, a woman behind the front desk handed me a clipboard and asked that I complete an updated patient information sheet. I checked the pertinent boxes: Do you have a medical condition for which you regularly take medications? Check. Have you ever had chemotherapy? Check. Are you wondering why your dentist is asking you these questions? Check, Check, Check.

After x-rays and a swish and spit with some mouthwash, the dentist appeared. We chatted a bit, exchanged the obligatory, “How’s your family? What are the kids doing these days?” and set out to the important business of shining my pearly whites.

He perused my annual update paperwork, his eyes running the length of the form in under a second before making an abrupt stop at what I figured was the medical section. He and I had been over this before, he knew – at least he knew at some point– that I had lupus and that I was taking medication for it. But I’m not his only patient, and the instant recall portion of one’s memory has only so much room, so there were questions to be asked and questions to be answered, yet again. This did not surprise me, what did however, was the phrasing of his questions.

“I’m looking at your medication list here; remind me again of what you have.”

“Lupus. I have lupus, but I’m fine.” It was routine for me to add that last bit after I told someone my diagnosis.

“Lupus, huh. Do you have any hope with that?”

Just like that, “Do you have any hope with that?”

I laughed. Really, there seemed to be no response more appropriate to a question reeking of such blatant inappropriateness. Did he just say that?

He continued to stare at me, waiting for an answer to what he deemed a perfectly acceptable question.

“Hope? What do you mean? Hope for it to go away? Hope that I’ll have a normal life?”

“Sure,” he responded, choosing not to elaborate further.

“Well, it is chronic, so I don’t have hope for it go away, but I’m fine. I’ve had it for a while now and, really, I’m doing just fine.” And then, maybe because he didn’t look so convinced, or maybe because I needed something to further solidify it for myself, I added, “Some theorize that it improves with menopause, so it could, at least partly, go away after that.”

“Menopause, huh?” Not impressed. “Well, you’ve got a while before you hit that.”

“Yes, I sure hope so.”

Expert Comments on Explaining your Diagnosis to Others:

“I have a hard time explaining it.”

“People are shocked and say, “Oh my God!””

“I usually don’t bring it up.

“Have had lupus for 40 years. 1st time diagnosed, very ill, deathly, in hospital, in and out for one year. When I became ill in 1974, not much was known about lupus. I was given prednisone as much as 100 mg. every day. I was cushingoid, weighed 87 pounds (normal weight 109 pounds) was diabetic on insulin. By all means I should not be alive today, but I was a fighter.”

“Best advice I can give here... Lupus is a part of you – yes. But it isn’t what defines you. If you introduce yourself, “Hi, I’m Jane, I have lupus.” You might as well say, “Hi, I’m lupus!” Don’t let it define you. Don’t take on the “sick role.” I’ve worked professionally for a lot of years with people who have NO IDEA I have lupus because it isn’t who I am. I guess my point, you don’t need to tell everyone you meet or know. I only tell those people who need to know for some reason. I also don’t want to be pitied or judged by my lupus. I don’t want people to think, “Oh, she cannot do that because she has lupus.” Let your decisions to do or not do something be decided by you. Now, I’m not saying not to educate those around you; this is a whole different issue. Just choose whom you thoroughly discuss lupus with.”

“I do not openly tell people I meet because I don’t want to get a lot of questions.”

“Sometimes, when I tell people I’m sick, they always ask me can they get it too; I tell them no all the time. Then they start asking all kinds of questions. I get tired of it sometimes because they think I’m a disease and can’t touch me or something. It hurts sometimes, but I get over it because I know I’m not a disease. I’m just sick.”

“Some people react as though I am terminal due to lupus. I explain the facts as well as I can. Others are familiar with lupus patients who are in remission, as I am presently.”

“Most people cannot believe what I have lived thru. I am careful to not try to scare people but to educate them. I normally only talk about it if people ask me.”

“I will have to explain it to my new boss soon, I am nervous because he may think I can't do my work. But in the past, as I tell people – friends, clients, coworkers, I find they have compassion for me and say they had no idea. I usually tell just a little about it and if people ask more questions, I will tell as much as they want.”

Doctor In Training

Explaining your disease to other people can be one of the most challenging aspects of lupus. As your disease fluctuates between periods of flare and remission, it may be confusing for others to understand why you are feeling great one day, and stuck in bed the next. Additionally, often people with lupus do not look sick, further exacerbating the lack of understanding about the disease.

In a Lupus Foundation webchat, licensed psychiatrist, Dr. Robert Phillips, discussed some of the challenges in discussing the diagnosis of SLE. (Chat Transcript for Dr. Robert Phillips October 10, 2007 ,

http://www.lupus.org/webmodules/webarticlesnet/templates/new_communitywebchats.aspx?articleid=1288&zoneid=93) In particular, Dr. Phillips focused on recognizing and understanding the general public's ignorance of the disease. Unlike some other diseases that receive a lot of press and recognition, lupus is still largely unknown and commonly misunderstood. Keep in mind that comments and questions usually stem from an honest lack of understanding and curiosity.

As usual, follow your instincts and share as much as is comfortable to you. If someone's comments sound harsh or offensive, keep in mind that they likely do not have the knowledge base that you have about the disease. Explain what you can and want to explain, and move on. You have enough to do; trying to convince someone about the validity of your disease should be very low on your to-do list.

Additional Expert Advice:

“Just learn to be open, be yourself, and true to yourself. Learn as much as you can to find out how to help yourself. If you know this, then you can tell others what your needs are. Wish the very best for all.”

“Remember – you have a disease, it does not have you.”

“Prayer, faith, and strong will etc. is why I am here today. Best of luck to you.”

“I’m a type A person. When I was diagnosed with lupus 21 years ago, I decided that this disease would not get the best of me or control my life. So I fought it!”

“You must learn to Live With It and make accommodations to be at one with yourself and the disease within you on a daily basis.”

“My best advice, learn what ticks off your lupus and avoid it! Learn to recognize the “Day After Signs” ... ie ... I did ____ and the day after, I flared!”

“Eat right, exercise regularly (walk, swim – stuff that is easy on the joints!) and get plenty of rest. You will need 8-10 hours of sleep at night to function well. If you short yourself – you will flare!”

“You must learn your limits then educate those around you. I’ll tell my husband, “I can shop 15 minutes more, then I’m done.” If you find it hard to know your limitations, how hard must it be for others to know them? And limitations change and vary; listen to your body. When it says, “Stop!” – you need to listen.”

“Preferable, you’ll stop before you’ve pushed yourself too far! This takes time and practice to learn. Be gentle with yourself and forgive yourself when setbacks happen.”

“Stay focused on God, pray daily. Keep a positive outlook on life. Always look for the good in everything and look for a way to use what is happening to you to help others.”

“Try to help others, it will help you not to focus on your problems. There is always someone in a worse situation than you.”

“Get plenty of rest, eat as well as you can, and try to exercise as much as you can.”

“It is not easy to find other lupus patients who are the same age (80) as I am, and who were diagnosed at such a late age. It would be interesting to communicate with an older patient to compare treatments, results, etc.”

“Just try to keep a positive outlook. Realize that new discoveries are more frequent these days and someday soon they may come up with a cure or medicine that will help the symptoms of lupus. Learn your limits and when you are tired don't feel guilty about lying down or resting. Even if it is a couple hours after you have awakened. Stay out of the sun as much as possible. Stay away from people who don't understand how you feel. They add a lot of stress to your life unknowingly.”

“I have become a huge fundraiser for the lupus foundation. I found being a part of the fundraiser helps me realize I am not the only one. There are many people who suffer daily and keep going. And sometimes I think it can't get worse and I realize how blessed I am, reading other people stories or meeting other people. I enjoy raising the money, but also spreading awareness.”

Finale

I look forward to adding more anecdotes, patient expert comments, and doctor-in-training informational sections.