I chose this topic in honor of chronic illness awareness week because I strongly feel that in order to truly raise awareness of chronic illness we must start with our strongest allies in our care: our doctors and ourselves!!

Although many of them mean well, many doctors are not always trained to deal with the complex problems chronic illness can bring. As part of their training, most doctors received much more education on “acute illnesses” or illnesses that are short term and can easily be cured. Dealing with a chronic illness patient who they cannot cure and who need ongoing and complex care can often be frustrating for doctors since it questions his or her skills and abilities. As patients, we have always looked to doctors to “heal us” and we have put our medical care in their hands. All too often, I have seen chronic illness patients look to their doctors as god and as having all the answers. Rather than taking an active role in their care, patients can fall into the trap of “doctor knows best” thinking and thereby becoming a passive recipient of medical care, rather than someone actively engaged in their medical care. I truly believe that in order to achieve optimum health and gain control of a chronic illness, patients must take an active role in their care and must become empowered.

This handout and my online seminar will address just how to do this by overcoming the barriers chronically ill patients often face with their doctors, becoming as educated as possible about your particular illness, and by making doctors making more aware and sensitive to our needs by coming to our appointments prepared and through effective communication and education.

**Barriers Faced by Patients That Interfere with Active Participation in Medical Care**

1) **“Doctors Knows Best Thinking”**
   As I mentioned before, many patients believe that their doctors know what's best for them and for this reason, they don't want to “challenge them” in any way. This is partly due to intimidation since doctors are held in such high esteem and also due to lack of confidence in our own knowledge. Many of us have probably experienced a doctor who is “threatened”, for lack of a better word, by an educated patient. There are a few, however, who do welcome questions and active patient participation.
2) **Lack of Knowledge about our Illness**  
Quite frankly, many chronic illness patients are not as educated about their illness as they should be. I am amazed at how many patients I come across that can't even spell the name of their illness and don't know what medications they are on. Certainly, if we don't become knowledgeable in some way about our illness, we cannot become active participants in our care (the next section will show you how to do this!)

3) **Extreme Fatigue and Physical Symptoms that Interfere with Getting Involved with Being Our Own Full Time “Medical Case Manager”**  
Let's face it... as chronic illness patients, we have so many comprehensive needs, we must take on the role of being our own medical case manager, which can often be equivalent to a full time job (with no benefits, unfortunately!) Let's also face the fact that one of the most common symptoms of many chronic illnesses is extreme fatigue and constant unpredictable symptoms. Who can possibly work a full time job with these symptoms?? Speaking for myself, when I am suffering from crippling fatigue, I don't have the time and energy to ask my doctor questions or to get involved in my care. I just want someone to tell me what to do, what medications to take and when. This does lead to a self fulfilling prophecy of helplessness and makes me feel anything but empowered!!

4) **Lack of Knowledge about the Many Resources Out There for Chronic Illness**  
Fortunately, there are many good resources out there for general chronic illness issues and for specific chronic illnesses. Unfortunately, it is often difficult to access these resources since most “information and referral” clearinghouses or most “centers for people with disabilities” do not focus on chronic illness per se. Patients are often forced to rely on the internet for information, which can often be inaccurate or on the advice of well meaning friends on treatments and “cures” for their illness. We currently have a healthcare system that is very fragmented when it comes it services for the chronically ill. Unless we have a hospital stay or a life threatening illness where we come into contact with a social worker, most of us will not have someone managing our illness and connecting us to the right resources (This is one of the services my company provides by the way)

5) **Lack of Ability to Change and Consider Treatment Alternatives**  
Many chronic illness patients, particularly ones that have been ill for a long time, have learned to accept their illness and have probably tried many different treatments that failed, leaving them frustrated and with lack of hope. They are often reluctant to learn about newer treatments coming available for their illness since they have adapted to a life of being ill and don't want to get let down again with a treatment that fails or with a new treatment that might cause side effects and cause a temporary worsening of their symptoms (I must admit, I am one of these people!) Although it’s difficult, with a bit of coaxing and encouragement from other patients, these patients can often become more open minded to the possibility of trying a new treatment.

6) **Lack of Support from Family Members and Other Significant Others in the Patient’s Life**  
Family support is often overlooked as a significant barrier to chronic disease management, however the latest studies show that patients who have a strong support system experience fewer symptoms and have more overall control over their illness. Let's face it, when you don't have the support of those closest to you, it often can make
you question your illness and the “realness” of it. Also, not having support can often mean not having someone to accompany you to doctors appointments when you have crippling fatigue, not having someone to pick up your prescriptions, and to do other daily tasks that are often impossible when managing a debilitating chronic illness.

How to Overcome These Barriers

There are several ways one can overcome the barriers that interfere with becoming an empowered patient.

1. Become Educated About Your Illness

Getting diagnosed and living with a chronic illness can be a daunting and frightening experience and it can make a person feel a loss of control over what is happening to their body. However, being armed with as much information as possible can make you feel more in control and help you make the most informed decisions about your care. Getting educated about your illness means becoming familiar with common symptoms, diagnosis, treatment options, medications and what they do, and coping tools. Becoming educated can be a daunting task in itself due to the wealth of information available on the internet and even conflicting information from doctors.

The key to education is learning how to decipher which sources are reliable and which are inaccurate. When learning about my illness, I often went to major websites, such as the Center for Disease Control, the organization for my illness, the National Institute of Health, and other highly recognized and reliable websites. Let’s face it… anyone can put information on the internet these days. In order to be an educated consumer, we must learn how to differentiate the accurate information from the inaccurate. Usually, most websites with a .com. gov, or .org are most reliable, but that’s not always the case. Obviously the best way to learn about your illness is from your doctor, however as most of us have probably discovered, doctors don’t always have the time to provide health education as part of our visit. I am sure we also experience differing information depending on which doctor you see. That goes back to the “dr knows best” theory, which is not always correct.

Another way to learn about your illness is to attend workshops or to enlist the help of a health educator (again, a service my company provides). Illness specific workshops are often given by non profit organizations, such as the Arthritis Foundation, The Fibromyalgia Network, etc. Some of these organizations even teach patient self help courses. I have attended one of these in the past and can honestly say, it was well worth the time and energy!!

For more information on reliable sources of health education and organizations, please see my resources at the end of this handout.

2. Come Prepared to Your Doctors Appointment

In order to become an empowered patient, you MUST come prepared for your doctor’s appointments and take control of the appointment. As a person with chronic illness, having endless doctor’s appointments can seem daunting after a while. You have to
constantly repeat your symptoms to each doctor and many times, you can leave out pertinent information. Ability to provide a detailed medical history to a doctor significantly enhances his or her ability to diagnose and treat you. I cannot tell you how many times I have met patients who have no idea what tests were done on them or what medications they take or why they take them. In order to be an active participant in your medical care, it is absolutely essential that you have as much information about your condition as possible. It’s often difficult to write down all this information when you are in the middle of a flare up or relapse, so that’s why I created what I call my “medical resume” to bring each time I visit a new doctor.

Basically, my medical resume is a summary of all my important health information that I would need to share with my doctors. I have a print copy and a copy on my computer so I can easily update it. I have divided it into several different sections or headings: (Please note some of this information is from an upcoming magazine article I wrote on patient empowerment)

“Components of a Medical Resume”

Section 1: Current Medications
Here I list all of the medications I currently take, along with the reason I take them, the length of time I have been taking them, and the dosage. I cannot stress this enough: it is VERY important to know all of your medications, your dosages, and why you take them. As a chronic illness patient, as long as your cognitive skills are intact, you need to take control of your medications and know exactly what they are doing for you. This is especially important if the doctor needs to prescribe you a new medication, since he or she needs to make sure there is no interaction between it and your other medications.

Section 2: Past Medications
Here I list each medication I have been on in the past, the reason(s) for taking it, the dosage, how long I was on the medication, the reason the medication was discontinued, and any side effects I might have had from the medication. It is important to know what medications you were on in the past and how they affected you in case your doctor wants to prescribe that medication again. You also must distinguish between a sensitivity to a medication, an actual allergy, or just common side effects that might have been bothersome.

Section 3: Past and Current Diagnoses
Often, one gets many diagnoses before he or she receives the correct one. Here I list all of the prior diagnoses I received, the doctor who diagnosed me, and then all my current diagnoses. This is particularly helpful if you have multiple chronic illnesses, which is often the case—particularly with autoimmune disease. It is also therapeutic if you’d like a good laugh about all the diseases the doctors thought you had! I think we all need a Dr. House!!!

Section 4: Current Doctors
Here I list all of the doctors who are currently treating me, their specialties, hospital affiliations, contact information, and hours (mostly for my information). You can also just attach their business cards to a piece of paper. Having the names and numbers of your doctors is essential, and is particularly helpful if a doctor is going to fax test results to another doctor treating you.
Section 5: **Past doctors**
Here I list the names and contact information for as many of the doctors I can remember that I have seen in the past. I also list why I stopped seeing them (or why they stopped seeing me!!). You might ask why past doctor information is important. It is important information because those doctors might have vital records that you need. Also, what can happen (and HAS happened to me) is that you get a referral to a doctor only to realize that you saw the doctor once before and disliked him. Disliking a doctor… can that really happen???

Section 6: **Blood Tests and Other Tests**
Here I list all the blood tests and others, such as MRIs, CAT Scans, etc. that I have had over the past few years and the results. (I also keep a copy of all my blood work in a binder). It is VERY important to get copies of all your test results!! This is important for several reasons. With chronic illnesses, especially autoimmune diseases, it is not uncommon to be tested periodically to monitor your condition. Also, sometimes with certain illnesses, it takes a while for some blood tests to be positive, almost like waiting for a picture to develop. (Unfortunately, mine never looks good!!) Another reason to have your test results is because if you visit various doctors, they can often repeat the same tests—and you then risk not having them covered by insurance.

Section 6: **Current symptoms**
If you’re like me, you have a list of symptoms a mile long. (If only I could walk that long!!). It’s often difficult to remember all of them. When the doctors ask me about my symptoms, or as I refer to it, my “medical smorgasbord”, I often tell them they are better off asking me what symptoms I don’t have as opposed to the ones I do have so we can save time and energy!!! In this section, I list all the current symptoms I have, their severity, and how long they have lasted. When I get a new symptom, I simply add it to the list. I also put my most prominent or severe symptoms on the top of the list. It is often easiest to have this information on the computer as well as on paper to make it easy to update. When the symptoms are no longer present, I simply take them off the list and put them on my past symptoms list.

Section 7: **Past Symptoms**
Here I list the symptoms I have had in the past, since they often ask you that at the doctor’s office. It’s important for you to monitor your symptoms and how well your treatment is working. Also, sometimes with certain illnesses, including my own, symptoms can come and go. Having a list of your past symptoms can alleviate some of your fear if you develop other symptoms, and can help the doctor evaluate your condition.

Section 8: **Miscellaneous**
Here I list other information that is pertinent to my illness.

So, the next time you are going to see a new doctor, make sure you come prepared with your “medical resume” in order to provide a detailed and thorough medical history so the dr can better diagnose and treat your condition.

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3. Join A Support Group and Build Your Support Network
As I mentioned before, emotional and day to day support is essential to managing chronic disease. There are many support groups that exist for almost every illness out there. There are even online support groups or message boards for specific illnesses and for chronic illness in general. (My company helps with locating these resources)

Support groups or building a support network is essential because it allows you to learn more about your illness, exchange coping tips, and to gain emotional support from others who understand what you are going through. However, just like any other support service, you must choose your support group carefully since, if not facilitated correctly, support groups can often become “gripe sessions”, if you will, and chronic illness patients can often come away discouraged and depressed. Also, it’s important to keep in mind that most of the patients that attend support groups are not in remission from their illness and might be in a worse state than you are. For more information on support groups, please see the resources at the bottom of this handout.

4. Participate in patient advocacy events or other “empowering events” to bring awareness to your illness

Becoming involved in advocacy events can be a very empowering experience. I have been involved in many letter writing campaigns and several lobbying events in Washington, DC to help raise funds for and awareness for several of my chronic illnesses.

Getting the chance to give testimony about how your illness has affected you, speak directly with a legislator, or write a powerful letter trying to convince the “powers that be” to increase funding for your illness is an exhilarating experience. It has helped me overcome some of the depression and loss of control I have had over my illness and it’s a great way to become empowered!!!

I would love to eventually get together all the health organizations and illness specific organizations and have one huge advocacy campaign for chronic illness, but this week is definitely a great start to that!!!!!

5. Communicate Effectively With Your Doctor and Educate and Sensitize Your Doctor To Your Needs

Ok, here’s one of the most important ways to break down those barriers to patient empowerment and make our doctors aware!

#1: DO NOT BE INTIMIDATED BY YOUR DR!!! THEY ARE PEOPLE TOO AND REMEMBER, YOU OFTEN KNOW MORE ABOUT YOUR BODY THAN THEY DO!!

Don’t be afraid to share new treatment options with your dr. I will be honest in saying (from my personal and professional experience), some doctors just don’t like educated patients. Well, what I say to them is some patients don’t like uneducated doctors!!! If you hear of a new treatment that might be working for someone else with your illness, share it with your doctor. Bring in any articles you find about the treatment (preferably research based and not ones from Vogue magazine!!!!)
# 2 SPEAK UP FOR YOURSELF IF YOU DON’T FEEL YOU ARE GETTING THE CARE YOU NEED!!

I know this must be difficult, especially if you have a good relationship with your doctor, but it is necessary. After all, it’s YOUR body, not his or hers!! I had to tell a doctor that I didn’t think he knew enough about my illness and that I was considering seeing a specialist. Ya know what, he agreed and encouraged me. So, you never know what can happen!!

# 3 DON’T BE AFRAID TO MAKE YOUR DOCTOR AWARE IF HE WRITES YOU A PRESCRIPTION THAT MIGHT INTERACT WITH SOMETHING ELSE YOU ARE TAKING.

He should have all your current prescriptions in the chart, but sometimes Drs write prescriptions “on the fly” or over the phone and they don’t always realize the other medications your are taking.

#4 MOST IMPORTANTLY, MAKE SURE YOU TELL YOUR DOCTOR HOW YOUR ILLNESS IS IMPACTING YOU ON A DAY TO DAY BASIS.

This is so important because doctors don’t often realize the struggles we chronic illness patients go through. Tell them if you are having trouble getting up the energy to make yourself dinner or that you can’t shower more than a few days a week because you don’t have the energy. I know you think doctors don’t want to hear this kind of stuff, but the truth is THEY HAVE TO HEAR THIS KIND OF STUFF!!!!!!

A mother with a chronically ill son recently created an organization solely dedicated to educating new doctors and medical students about the day to day realities of caring for a chronically ill child. As part of the program, these new drs are now required as part of their training to spend time in the home of these chronically ill children. I’d love to see a program like that implemented for adults with chronic illness and I’d be glad to participate it in!!!!

It’s not enough to merely say to your dr, I am in pain and I am not the same as I used to be. You need to tell your dr specifically how your illness is impacting your life. He or she really needs to hear it in order to address your concerns and needs as a whole. I strongly believe that when you are treating a patient with a chronic illness, you are treating not the symptoms, but the patient as a whole. Sometimes, this means that doctors might have to enlist others to assist with your treatment plan, such as a social worker, physical therapist, etc. The main point is that he really “gets” the extent of your illness and how it impacts you in every way!!

Summary

I said in the beginning that ourselves and our doctors are our strongest allies in our medical treatment. This is because we have the ability to influence our doctors and the care they provide and our doctors have the ability to help us not only manage our illness but to push for funding for research for possible cures. If we work together and also enlist the help and support of our friends and family and the general public, we can
eventually raise awareness of chronic illness on a large scale and can ultimately improve the lives of the chronically ill!!

General Chronic Illness Resources

www.freelancehealth.com/patientservices.html
The Chronic Illness Network is the patient services program of my company, Freelance Health Solutions, which provides direct services to chronic illness clients, including information and referral and health education, among many other diverse services. My company also provides consulting and freelance services to organizations involved in chronic illness and public health projects.

www.restministries.org
A Christian based organization that provides diverse faith based services to the chronically ill, including an informative magazine- Hopekeepers, support groups, excellent articles, and more.

www.cdc.gov
The Center for Disease Control government website, which contains reliable information about various chronic illnesses, such as symptoms, diagnosis, coping, treatment, etc.

www.webmd.com
Trustworthy comprehensive patient information on many illnesses and symptoms. Also contains excellent articles.

www.NIH.gov
The National Institute of Health’s website which contains reliable information about various chronic illnesses, research studies, etc.

www.chronicbabe.com
A new website developed by a chronically ill young woman who provides inspiring, humorous, and insightful information on all aspects of chronic illness.

www.healingwell.com
Comprehensive website with information, message boards, and online support groups for many types of chronic illnesses.