

November Patient Education Call

Susan Cohen Byrne, M.A. – Dealing with Mental Health While Combating a Rare Disease

Susan Cohen Byrne

Susan is a therapist in Davis, California. She has been in her own practice for over 30 years. Susan is a patient herself. She has pemphigus vulgaris. Her journey started in 2001. She was in Barcelona, Spain at a conference with her husband and she ate something, and got deathly sick. She was so sick she didn't know where she was at times. She finally got to see a doctor and he gave her Cipro. She returned to the states about 5 days later. She didn't feel normal, and after about a month she started to feel worse. She began to get sores in her mouth that came and went. She started to see a rheumatologist. She believes he thought she was malingerer, and exaggerating her symptoms. About 3 months later, the sores still there, she went to her dentist. The dentist saw the sores, and thought it was cancer. The dentist told her to go to an ear, nose, and throat specialist. She went to the ENT, and he thought it was Herpes. He did a biopsy of the sores. The ENT called her with her results and told her that he had never seen anything about this disease before but he thinks that she has this rare disease. He told her not to look the disease up on the internet. As most do, Susan did look it up and was terrified. When she got back from vacation he confirmed that she had pemphigus vulgaris. He had never treated this disease, so now she had to pick another doctor to go to. She found a doctor out of UCSF, and she was wonderful. She prescribed Susan topical Clobetasol for her mouth, and talked a great deal about the possibility of what could happen with this disease. She became more fearful, and kept thinking, "is this going to get worse?" Her sores also began to get worse. Her doctor then put her on prednisone. Her sores began to diminish, and after about 3 years she was eventually weaned off of prednisone. Now she has sores occasionally but they self-heal in about a day or so. She now considers herself in remission.

Notes on grief from Susan: I wanted to talk about the stages of grief. The stages of grief are: shock, denial, anger, bargaining, depression, and acceptance (which I would call neutrality). I think for some people they see the stages of grief as a linear concept. My experience, and the experience that I have had with my clients, whether it is the grief of being diagnosed with a rare disease, a death, etc. People think first I need to go into shock, then to denial, and then to anger. But, really you jump all over the place. You can have all of those feelings in a day, or you can experience depression for a month and then go back to anger. There is not set linear path on how you are to experience these emotions. That is one thing that I want you to know is that it is okay to be all over the block with how you feel. The important thing is to accept what is going on with you and talk with someone that you know and love. Don't let people tell you how you should feel.

Question: What are some coping strategies to deal with the frustrations of having to deal with being unable to find a doctor who has treated no more than a handful of patients with these diseases? Also, in coping with dealing with the unknown of whether or not this disease will progress?

Answer: I think that is the scariest part of having this disease – the unknown aspect of it. What I did is that I really had to work on myself. I would recommend going to www.healthjourneys.com. They have great guided imagery tapes. There is a specific one called, “A Guided Meditation to Support a Healthy Immune System” (www.healthjourneys.com/Store/Products/Healthy-Immune-System/483). They also have in that same series ones on relaxation and sleep. These are CDs and tapes, and you can also download them to your iPod. I think it is important to ground yourself and de-stress. Not being able to find a doctor, and having to deal with people not understanding what is going on is stressful. So, it is important to take care of yourself. I also have some books to recommend, *When Things Fall Apart: Heart Advice for Difficult Times* by Pema Chodron and *When Bad Things Happen to Good People* by Harold Kushner. Also, at times your friends and partner can get tired of listening to you, especially when you are on prednisone. Although, I am a therapist I went to a therapist. I found it to be very helpful to just vent when I needed to. I think the big thing is to work with yourself in finding what is best for you. There are times where you will be frustrated, and that is okay. Every day is a new day.

Question: I can't get my doctor to prescribe me on prednisone. Why might that be?

Answer: I have never heard of a doctor who wouldn't want to give a patient prednisone unless they are allergic to steroids. There are side effects with prednisone, but that is the situation with many medications. Please call the IPPF, and they can give you tips on talking with your doctor to see if prednisone is the right option for you.

Question: I try not to make it all about me all the time, but this disease makes me feel that way. I feel like I am living every second about this disease. It affects every single aspect of my life. It has been a long journey, and a rollercoaster. I understand the concept of working on yourself, but sometimes it feels impossible.

Answer: It is so hard to see yourself beyond the disease at times. In the beginning, I felt the same way. It took everything out of me to deal with how to cope with it both physically and mentally. I think for you it is so omnipresent and constantly happening and so there is always something new to deal with. Sometimes I think it can be good to have distraction. Going other places, going to a movie, being with friends, and seeing yourself beyond this disease is important. When you are experiencing a flare or going

through a rough time with this disease talk with your partner or a therapist and let yourself vent. If you can hope that at some point you will move beyond this.

Question: Do you feel that there are predictable side effects emotionally and mentally from prednisone? I feel like I walk around more shaky in my body and psyche when I am on prednisone I notice when people find out what I have they try to associate it with the more known diseases like cancer. Being that pemphigus and pemphigoid are rare and autoimmune diseases these diseases are so complicated. I feel like I am constantly trying to filter peoples' perceptions of the disease. Do you have any advice on how to handle this?

Answer: I am not a doctor, but I can tell you my experience. You are kind of a maniac when you are on prednisone. You're not sleeping like normal, and not sleeping for your mental health is the worst thing. It completely throws you off. It causes depression. So, here you are depressed about having this disease and then depressed because you are not sleeping and very irritable. There is a book that I would like to recommend called *Coping with Prednisone* by Eugenia Zuckerman and Julie Ingelfinger. This book can be helpful in getting through the woes of prednisone. The other issue about how to handle this with other people is hard, because no one has heard of this! I felt like I had to give a brief medical lecture every time I talked to someone about this disease. In my experience people want to help, and people want to help by giving advice as opposed to just listening. This can be detrimental to the patients, because we just really want to be held in our own experience. What I wound up doing was avoiding people, and just spending time with those who would just listen to me and not offer advice. People are real quick with an autoimmune disease to say that you need to enhance your immune system. When, really, in our case we need to calm down our immune system. People are also very quick to point out, "oh, you have this because it is what you eat, how you exercise, etc." It is all in good faith, and they want to help. Ultimately, it is not very helpful, and makes you feel bad about what you "should be doing." In reality, you have been stricken with this disease.

Question: Does ones psychological state improve as you taper down off of the prednisone?

Answer: In my experience, I found actually that I was worse in my psychological state as I was tapering down the prednisone. I think the book I mentioned earlier discusses that a bit. Also, when you are being tapered down off of prednisone it depends on the dose that you are being tapered down, and how fast. Those are all factors that can affect you psychological state as well. Again, I am not a doctor, but your adrenals stop working, so when the adrenals start kicking back up as you are weaned off it's much worse. I found that experience, of tapering off of prednisone, to be almost if not more

stressful than getting the disease itself. I have found that most doctors don't speak of this process very well. I feel like we are all in the process of tapering down on our own. In the book, *Coping with Prednisone*, she has two whole pages of symptoms listed, both physical and mental health symptoms.

Statement from a Patient: It is important to see yourself beyond this disease, and it is very important to have a support system. I started a support group in Boston. The best advice I received was to pick a time, pick a date, and pick a location. Then tell the IPPF, and they will get the message out to the community for you. All you need is yourself and one other person to have a support group. I have come to terms with this disease, and the support is what helped me to get there.

Statement from a Patient: I just want to share with everyone on the call is to stay positive and get through this. Don't listen to others that don't understand the disease. You have to be the expert in you. Listen to your doctors. They aren't miracle workers, but if you listen to them, and do what they say you can get through this. It is important to find a doctor that knows how to treat this disease. This is a tough disease, but you can get through it. I went to a few of the IPPF conferences, and that was really great to meet other people who had the disease.

Comment from Susan: I think staying positive, eating healthy, and exercising is the ideal. But, truthfully, at times we get depressed. We get depressed about being sick and about being this disease. It is important to acknowledge when we do feel crappy, and when we are depressed. Hopefully there is an ebb and flow to that, but don't try to force yourself to be positive when you're not. That's when you really need your support system. That means literally a support group, or your spouse, seeing close friends, going to see a therapist, or even going on antidepressants. It can be hard to put that false face out into the world when you aren't really feeling that way.

Question: It is scary looking into the future now with this disease for me. When I was first diagnosed I tried to accept that my future was really one day at a time. I want to be able to think about the future again, and it is scary to let myself. Have you had experience with that, and how that fits in with the healing and the grieving process?

Answer: I think it is important to listen to that part of you telling you to look to the future, and go with it. For me, after that initial shock of getting diagnosed and getting on a treatment plan, then I was able to think beyond the disease. I think a part of you is there. I am a big believer in intention. Not only intending on being well, but intending on going on a trip or whatever it may be in your life, and following through with that. Anything that you are planning to do in your life I think you have to hold on to that, and really reach for it. This disease doesn't kill you. It used to. When you first look it up

online you see that it use to kill people, that's really discouraging, but it doesn't do that anymore. We do have to live with it, though, in different ways. I think that part of you that wants to move into the future...I think you should just go for it as much as you can given the circumstances. It is important to keep in mind that there is what you reach for, and then what is realistic. It is not written in stone what is going to happen with anyone in regards to these diseases. That's the horrible part of it. I think we have to hold on to our hope, and look at what can we do now.

Statement from a patient: I want to share that I was diagnosed with PF in 2011. I was 24 at the time, and I am 27 now. I am doing a whole lot better now. I wanted to call and thank you guys. I am sort of an anti-social type of person. I stay to myself a lot, and this is my first time since being diagnosed that I am hearing from others who have this disease. It really makes me feel better. It really affected my life. I lost my career and my marriage, and I was on bed rest for 8 months because my disease got so bad. It took a long time for someone to diagnose me. I feel like almost a year of my life was lost. As the previous caller said, a lot of dreams that you have kind of get shut down. I think that I have adjusted well, but still being on the prednisone and anti-depressants it didn't sit well with me. I'm calling today to say thank you for doing this, and I am so glad that I called in. I also wanted to comment that I lived in Florida for about a year. I was on the beach every day for about 5-6 months without being on prednisone, and I think something there like the salt water really helped me. I hate to think that I have to live with this for the rest of my life. As it was said earlier as well, people don't know what it takes for me to get through the day. Being on prednisone, constantly having flare ups, and always thinking, "what did I do to get this?" It gets so frustrating listening to people telling you how to help your disease when they don't know what you are going through. This is the first time that I am actually talking to people who have what I have. Everyone who has called in I feel is me speaking. I am a whole lot better though, and I thank you so much for having this call.

Comment about P/P and salt water: There are no scientific studies showing that salt water will put P/P into remission, or make the flares disappear. P/P are such patient-specific diseases that if you find something that helps your, or that makes you feel better more power to you to do that.

Comment from Susan about anti-depressants: I am not a Psychiatrist, but anti-depressants do work. It is best to work with an actual Psychiatrist as opposed to your family doctor. There are many different anti-depressants. Some may have a side effect with you, but not your friend who is taking the same anti-depressants, so they really need to be fine-tuned. I would encourage anyone who feels that they are clinically depressed, which means that you are sleeping too much, you are suicidal, and/or you

are just completely down, to see a Psychiatrist. Have them put you on something. It will work, and be patient with it.

Question: I was diagnosed 10 years ago, and was on a lot of medication for several years. Then I kind of went into remission, and stayed on a low dose of prednisone for years until I realized that it was putting me into steroid-psychosis even while being on anti-depressants. I am once again having a flare. I went back on anti-depressants, and I am having a hard time dealing with my fears of being on treatment. I am going to be going on rituximab therapy. I have three kids, and it is overwhelming to me.

Answer: I wish that I had a fix for you. It is very normal that you would be so terrified of what is next. Especially, dealing with this other level of treatment. I wish I could erase your fear from your brain. It sounds like you have made a decision to go through the treatment, and I think you need to move forward, and start bathing your mind in how you think that is going to work. If you can neutralize the thoughts of what might happen and focus on the good stuff that will happen, and how you will get better. Another suggestion that I have is, good child care. So that you know someone else who you can trust is taking good care of your children. That it's not just up to you for them to rely on when you are feeling so vulnerable. I hope that you are in a situation where that might be possible. Try to distract yourself. Sometimes I think distraction isn't such a bad thing. Go to a movie with your friends or have a girls night out. Something to take your mind off of it. There are those times when you really do need to cry and be miserable. That is what your support system is for. You can also go to a therapist where you can go and vent to them.

Question: What foods should I avoid?

Answer: I found that spicy foods, garlic, mustard, and horseradish did not sit well for me. However, it differs for everyone.

Question: Can you give a tip for all of our callers on the topic of sleeping to help them relax at night instead of robbing them of their sleep. A lot of people dwell on this disease, and it can greatly affect their sleeping patterns.

Answer: At this point for me, I can do my own meditation. What has helped me is the guided imagery tapes that I mentioned with www.healthjourneys.com. She actually has a relaxation and wellness tape, and a sleep tape. I think once you listen to that several times you don't actually have to put it on, and you can just replay it in your head. My experience is that I have trouble clearing my mind. I can say to myself, "clear your mind," but my mind doesn't clear. So, I need to make an image in my mind. My fears with this disease were so big that it would always be so ever present for me. That is

what helped me the most-were the CDs. Also, if relaxing music helps you that may help with your sleep problem.

Closing Remarks from Susan: I want to say that I feel very touched by everybody on the call today, their openness to talk about themselves. The generosity in wanting to help others on the call today has been so touching. I think this is such a rare disease and for us to be interconnected to our community is spectacular.