Understanding and Managing Lupus Psychosis

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Lupus and the Brain: Understanding Lupus Psychosis

Psychosis is a mental disorder characterized by a disconnection with reality, where thoughts and emotions are impaired. It can be mild or severe and present itself in many different ways.

This abnormal thinking and feeling can lead to delusions (false beliefs), hallucinations (false perceptions), and disorganized speaking and behavior. So what does psychosis have to do with lupus? Well, a lot more than you may realize.

I have personally experienced moments of psychosis during my battle with lupus. Initially, I was embarrassed — afraid that it was a sign of weakness and instability — or worse, that I was just plain messed up! However, I have learned that I'm not alone and there is no reason to feel embarrassed or ashamed.

It *is* real and perhaps some of you have or will experience some type of psychosis in relation to lupus. It can be difficult to discuss and scary to reveal, but it is imperative to seek help if you start to notice yourself losing touch with reality.

'Your Brain Starts Playing Tricks on You'

Allow me to give you an example of what this might look like. It's a perfectly normal day and your phone rings. You look at it and see that it is your dad calling you. Under normal circumstances, you would probably answer the phone, happy to hear from a loved one. But in a state of psychosis, your brain starts playing tricks on you.

Why is he calling me? What does he want? Did I do something wrong?

As the phone continues to ring, you feel your heart rate speed up and your mind plays out absurd scenarios in your head; you become convinced that something catastrophic will occur if you answer the phone. The ring finally stops, but then you hear the voice mail notification and you are overwhelmed by anxiety.

Do I listen to the message? What is he going to say? Will I have to call him back?

You decide to ignore it and try to forget that you have a message waiting, but it continues to haunt you, torture you, mock you and tease you. Finally, almost in tears, you hold your breath and with shaking hands and you press "play." I know, it sounds ridiculous, right? But for a person dealing with psychosis, this situation is very real.

During states of psychosis, I have been known to exhibit erratic behavior, send text messages that do not make sense, post status updates to Facebook that are out of character for me, have strange conversations with loved ones, become consumed by weird thoughts and paranoia, experience blackouts, suffer from confusion, headaches, and speech difficulties, hyper-focus on insignificant or unimportant things, struggle with massive mood swings, and neglect the necessities and responsibilities in my life.

Next page: Brandy shares her personal experiences with lupus psychosis

Experiencing Lupus Psychosis

In addition to the paranoia example above, some of my personal experiences with psychosis include:

1. **Confusion**: One summer evening, shortly after sunset, my adult son found me outside in my pajamas. I was face-down, lying in the front lawn, sleeping. I had no idea why I had gone outside or how long I'd been there. It was probably one of the most frightening situations either of us has dealt with.
2. **Blackout**: My husband had taken me to a "new" Denny's for breakfast (it was in a location I was unfamiliar with). However, upon mentioning that I didn't know a Denny's existed there, he told me we had just been there the week before. I looked around and tried to recollect something, but it never came to me.
3. **Delusional**: At one point, I was certain my sister was "out to get me." I was so convinced that I misconstrued her messages and conversations of concern, encouragement, love and assistance into something "sinister." I verbally attacked her and was willing to completely sever ties with her and abandon any relationship we had. Fortunately, she was patient with me and didn't allow that to happen!
4. **Disorganization**: My car uses a smart key and I always keep it in the zippered pocket of my purse. Somehow, I "misplaced" it, which was odd because there was no reason to ever remove it from its location. Because my car was at home, my key HAD to be as well. However, I never found it. It was a costly mistake!
5. **Neglect**: I take many medications because of lupus. At one time, my medication list was longer than my mother's who is a senior. During one particularly "psychotic" month, upon reaching refill time, some of my pills would already be gone (for days) while others had far too many left. Apparently, I would take medication, forget I took it and take it again or fail to take it altogether, which may have been what caused the "psychotic" month to begin with.

Finding Lupus Psychosis Support

My list could go on and on with some examples being far more severe, but I'm sure you get the idea. Luckily, I have a strong support system and people in my life who love and care for me. I greatly appreciate the fact that they don't hold my psychotic episodes against me.

I'm always apologetic and show extreme determination to never go there again; but so far, it seems there is always a next time. Granted, it may be days, weeks, months or even years before I am plagued by another episode and it's difficult to determine the triggers.

However, bit by bit — episode by episode — I'm learning more and trying to be proactive. I have discovered that there actually is a significant relationship between lupus and psychosis. Depending on how lupus manifests itself, certain people are more prone to experiencing psychosis than others are.

Although I may not be able to stop an episode in its tracks or prevent them from happening entirely, there are things I can do (with the help of others) to get through them safely and as quickly as possible. It is my hope that with care and diligence, I will eventually be able to eliminate psychosis from my ever-growing list of complications.

The Connection Between Lupus and Psychosis

Psychosis can certainly be an independent psychiatric disorder in those with lupus as well as the general population. However, research shows that two-thirds of lupus patients experience "neuropsychiatric manifestations" related to systemic lupus erythematosus (SLE) including non-independent psychosis (although a small percent).

Next page: helpful tips for effectively dealing with psychotic episodes

The Connection Between Lupus and Psychosis

The most common neuropsychiatric manifestation is cognitive deficit. However, in addition to psychosis and cognitive deficit, headaches, lupus seizures, peripheral neuropathy and cerebrovascular events may occur. These manifestations may be due to medications or brain involvement, known as lupus cerebritis.

Lupus patients who experience psychosis are generally treated with antipsychotic medications, such as olanzapine, in addition to cortisone-related medications, such as prednisone, and immune suppression medications, such as cyclophosphamide). It may be important to note that steroid medications (prednisone) can actually *cause* psychosis as a toxic side effect, although it's not common.

Dealing with Psychotic Episodes

1. **Keep a journal**: If you experience a psychotic episode, write about it. Include what you were doing, what you ate, drank, medications you took and interactions you had. Over time, you may begin to notice certain patterns and identify specific triggers. Perhaps a certain medication or situation sparked an event. By gaining this knowledge, you can make the necessary changes to keep an event from repeating.
2. **Have a buddy**: Because I believe my unintentional misuse of medication strongly contributed to certain psychotic events, I relinquish control of my meds to my husband from time to time or when things aren't going right. Sure, I keep a calendar and a pill organizer, but if I'm struggling with confusion or memory loss in the midst of a really bad flare, these devices may not help. I have also discontinued (through tapering and with the assistance of my doctor) specific medications that I was able to identify as "psychotic culprits."
3. **Make a video or write a letter to yourself**: I know it may sound corny and it's a bit like the movie *50 First Dates*, but it really can help you reconnect with reality! Experiencing psychosis is scary. It's important to ground yourself and remember who you are, what you are doing, and that you are safe, cared-for, and loved by others.
4. **Follow your doctor's advice**: If you are struggling, talk to your doctor. I assure you, they've heard it before and can be a great source of information and support. Often times, medications can be changed or adjusted to keep your lupus under control and alleviate negative side effects, including psychosis.
5. **Be smart**: I know this is vague, but it is probably one of the best pieces of advice I can offer. If you are prone to psychotic episodes, make sure you have a support person nearby who can talk you down, reassure you, or keep you from making a bad choice (such as getting in a car to drive alone).

Fortunately, full-on psychosis is rare with lupus. Although it can occur, it's important to remember and understand that your friends and family care about you and they will worry if an episode should take place.

Often times, the things people do or say in a state of psychosis scream out, "please, help me!" When those you love and care about answer that call, trust them, rely on them, and accept the comfort, advice, encouragement, love, and support they offer.

You might feel vulnerable and judged, or want to roll up into a ball and disassociate yourself with the outside world, but in all honesty, that isn't going to help one bit. By openly sharing your experiences, you are more likely to help yourself because you are facing the problem head on with strength and determination.