Coping With Lupus Fog

by BARBARA LEECH

How Lupus Affects Memory and Tips for Reminders

If it were not for post-it notes, I think I would be completely lost. Lupus seems to have tapped into my memory banks for a sizeable withdrawal of daily information.

My life is filled with deadlines for work, parental commitments and doctor's appointments, but no matter how much I try and commit them to memory they become muddled or totally forgotten.

The fact is, lupus brain fog can make an important event on my calendar completely vanish from my memory. I don't mean believing it is scheduled in the future rather than today, but vanished like it never existed.

Much to my embarrassment, I have forgotten birthdays, doctor's appointments and even a family member's funeral. I have been asked, "How could you forget this!?" and I don't have a great answer.

Lupus robs you of dignity as well as the person you once were. I find myself trying to explain lupus when even I don't fully understand its effect on me.

Fighting Through the Lupus Fog

I've found myself in a moment of uncertainty about how a seat belt unlatches or how to turn on my car's windshield wipers, and it's more than a bit frightening. I know I am not alone in these panicked moments when it seems like I have suffered some major memory loss.

I knew I had to do something when one day I forgot exactly what time I was supposed to pick up my children from school, something I had done five days a week for several months. I got the exact time confused with when I normally arrived back home with them and therefore left 15 minutes late.

So there I was, walking in as the last parent for pick up, something I never would normally do to them, something that is completely not me.

Doctors do not seem overly concerned with the memory issues lupus can cause. This leaves us fending for ourselves as we try and navigate our life and responsibilities as parents, employees and as a partner with lupus. Having a system to help you is imperative to keeping your life on track.

I have learned through others with lupus, as well as my doctor, that the wolf can create memory issues and brain fog which at times makes us lupies so forgetful that we can feel uncertain of how to do routine tasks.

It is debilitating and jarring to realize you forget more than just doctor's appointments and family birthdays, but also how to do mundane things you have done a million times. The other day, I could not figure out which knob turned on the front burner of my stove. I am an avid cook. It was unthinkable to me that I could forget this.

I have also had moments where I couldn't remember the road I was driving on. I feel suddenly lost and confused as to where I am, and wonder if I have perhaps missed a turn because I did not recognize it.

The good news is, it is not all the time and sometimes the moment of confusion passes and my memory comes flooding in like a warm breeze. But when memory escapes me, I am scared even though I know lupus is the cause.

Next page: tips for remembering despite lupus fog.

Tips for Remembering

I have come up with some strategies to manage my calendar and see my way through the fog. Without these strategies, I am not sure I would still be employed or have family and friends still speaking to me.

- **Post-it notes to the rescue!** I use more sticky notes than any other human I know, except maybe my young son who either really likes to stick them on things or has watched me for too long and is mimicking my survival tactic. Each night I go to the calendar and create post-its for what I absolutely cannot forget to do or attend for the next 48 hours and I stick them where I will see them easily when I need them. I do this for every appointment, phone call, errand, or celebration.
- **I have pickup times and locations for my children posted on my refrigerator like I might do for a babysitter.**
- **My monthly planner has every obligation or event written in it as soon as I know about it.** If I wait to scribble it in, I stand a 50/50 chance it will not make it on my calendar.
- **I set alarms on my phone or even the kitchen timer.** I use them to remember conference calls I need to log into for work or when I need to leave in order to be on time somewhere.
- **I ask for reminders.** I have forgotten more doctor's appointments than I care to admit. I ask that they call me the day before to remind me, then I write a post-it and stick it on the coffee pot so I see it first thing and then I set an alarm so I remember to leave on time.
- **I keep all medical information, list of medications, specialists' names and dates of when certain events/hospitalizations have occurred in my wallet.** More than once I have been asked my history or a specialist name and my mind completely goes blank. I basically backup everything I should remember with a hard copy.

Reducing Brain Fog

So what can a lupus warrior in the long-term do to ease the stress and fear of the fog?

Eat Healthy, Regular Meals

I find that if I have not eaten, it is harder to concentrate and I am definitely more prone to one of these lupus brain fog episodes. Your lupus diet menu should be healthy, nothing processed or full of additives or dyes.

I have noticed a correlation between having a glass of wine in the evening and experiencing brain fog the following day. Not only is alcohol not good for a flare, but it seems to disturb my clarity for at least 24 hours.

Use Backups

If I have to follow directions to get somewhere, I find that planning it out with reminders on paper is better than relying on my memory. I also use my GPS when I am feeling a bit lost to serve as a backup so I don't miss a turn.

As I said before, I use post-it notes on my desk to serve as reminders of important dates, my to-do list and upcoming deadlines and assignments. I even use it to remember people's names that I have a meeting or appointment with.

Choose to Stay Close to Home

If I am really foggy brained I don’t drive. Not driving is not ideal in many cases, but if I don’t feel safe behind the wheel it is a choice I have to make.

Living with lupus has many hidden challenges, including brain fog and memory issues. It can feel like there is something seriously wrong with your mind when you cannot remember something basic. Talk to you doctor about the issue to rule out anything else, but know this is a common issue for those with lupus — you’re not the only one!