# Why Does Lupus Impact Memory?

by BARBARA LEECH

## Coping With Lupus and Memory Loss

I decided I would write about lupus and memory loss for this post. I was excited, because this is something that is near to my heart and one of my week-to-week challenges.

I was totally ready to share something important and perhaps, just perhaps, make a difference to someone going through the same feelings, wondering if they were losing their mind and if they were the only one.

Then, as if on cue, I forgot to write it.

You may laugh, but I am certain many of my fellow warriors can relate. My memory has been at its very worst lately. I can't remember basic things and unless I have reminders written down all around me, I feel lost, frustrated, and at times, embarrassed.

I am a responsible, relatively intelligent person — a former reporter and newspaper editor. I used to have a mind like a steel trap. I remembered faces and stories and leads and deadlines. Heck, I remembered how to spell words rarely used and when it was appropriate to use a comma. We overuse them you know.

Well, I used to know, but now not so much.

### The Things I Forget

With lupus affecting seemingly everything in my body and who I once was, I can look at instructions or a name or the correct way to spell a word, turn away from the page and it is gone. Vanished from my mind like I did not in fact just look it up.

I forget my PIN number to my bank card, my zip code, and most recently, even my own last name. Yes, I actually went up to the pharmacy counter last week to ask for my lupus medications, said my first name and then drew a blank.

My maiden named popped into my head, which makes no sense since it hasn't been that for 30 years. I panicked. Then my married name from my first husband popped into my head and I was even more panicked, and to be honest, slightly disgusted.

Then my remarried name, which has been mine for nine years, finally came to me and though I am sure it was only 20 or 30 seconds that I was stuck, it was enough pause that the pharmacist was looking at me questioning if I was who I said I was. Embarrassing!

It is moments like that, or when I am mid-sentence and I can't think of the words I need to say, that I really feel like lupus has robbed me of so much more than anyone knows. I mean, you can tell someone you are having

memory issues and they say, “Oh I know, I forget things all the time lately.”

But they mean they forget to pick up their dry cleaning or forget to buy milk on the way home. I mean I will be driving and suddenly not remember where my turn signal is or where I am going or how to get there.

I have actually had moments of complete panic while driving when I suddenly realize nothing looks familiar. Eventually, minutes later, something I see jogs my memory and it comes back to me, but it is the most frightening feeling until it all returns.

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 on a different day, 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 what even I don’t fully understand.

*Next page: Lupus and memory loss survival tips.*

**Memory Loss Survival Tips**

Since I know I am not alone, I thought I would share some lupus and memory loss survival basics with you.

- **I write down every appointment and all my to-dos.** I keep it all in one location. 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 onto my calendar.
- **Post-it notes supplement the monthly planner for immediate tasks that need my attention, items I need to get, and even who I must call (and when) each day.** I might actually miss a call, interview, or deadline if it is hidden in my planner, so I put up little yellow flags to remind me. 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. I 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 the next day.
- **I leave my medication in its prescribed dose for the day out on the kitchen counter.** I often will not remember if I did or did not take something, so the weekly containers that have little doors for each day of the week are my salvation.
- **While shopping, I always have a list I have created and worked on, so it hopefully contains everything needed.** If my kids are with me, I ask them to help me with their strong memory skills and don’t let mommy forget the milk or yogurt or tomatoes, for example. I give them three or four items each to be in charge of remembering. They feel proud they helped and I can count on not forgetting the really important items.
- **I have pickup times and locations for my children posted on my refrigerator like I might do for a babysitter.**
- **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 for an appointment or work meeting.

- **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. I also write a post-it and stick it on the coffee pot so I see it first thing and then I set an alarm either on my phone or the timer on the stove, 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.

Finally, I try and cut myself some slack and realize I am not losing my mind, it is just part of this horrible disease.

None of it is permanent — eventually the lupus fog clears and I remember. I am just denied access for a period of time.

I try and find little ways to hide it as much as I can from the outside world, but honestly, other people need to cut me some slack too. If it was cancer causing this, there would be sympathy and assistance offered.

I realize now that I deserve the respect of patience. I will remember eventually and I do not forget appointments or other important things on purpose.

Acceptance of this part of lupus is hard to find, even within yourself. Once you do, you work around it, work to hide it a bit and realize you are doing the best you can.