Caring for Yourself While Caring for Others

by BARBARA LEECH

Being a Caregiver When You Have Lupus

I am sitting in my mom's hospital room listening to the steady beep of the heart monitor and watching the rise and fall of her chest, praying that it continues to do so. I take a deep breath that burns and realize I have not eaten anything since 10 a.m. It is now 8 p.m. and my body and mind are exhausted.

I ache and am shaking from the overzealous air conditioner that's pumping cold air into the room. As I have lupus, I am normally very diligent in guarding my health and activities. I take care of myself with healthy foods, plenty of water and proper rest.

The past 48 hours have not been normal and I realize that, on top of everything else, a flare is imminent.

Right now I am caring for someone else, not just my children, my husband or my home, but for my two elderly parents — one in a hospital bed, and one pacing the halls.

Sadly, my mother is not able to advocate for herself and my father simply doesn't know where to begin. I know that I have to be here to relay the symptoms she's displaying, the doctors' findings (blood sugar at 520, a blood clot in her leg and tests indicating stress on her heart) and explain how her health has spiraled downwards very quickly. There has been a steady parade of doctors, all of whom ask us to start from the beginning.

I look at the blood pressure reading and it is 110/35 — nope, I am not going anywhere.

I finally look in the bag my husband packed for me as I ran out the door. It contains supplies to help keep a flare at bay and I hope that they will work, now that I have remembered that I must also care for myself.

Inside My "Care for Others and My Lupus Bag"

Inside the bag I find exactly what I need to keep lupus under control:

- **A bottle of water with lemon slices.** Staying hydrated and flushing out the body does wonders for inflammation and how I feel.
- **Bags of healthy foods.** Organic sweet potato chips, crackers, celery sticks and organic peanut butter in a single serving pouch for dipping. In the lunch bag with an icepack are some broccoli florets, carrot sticks and a healthy salad.
- **My kindle and headphones.** When I need a break I can read or listen to relaxing music.
- **My medications, pain relievers and vitamins.** In my pack you'll find a multi-vitamin, B-12 for energy, and fish oil.
- **A note from my husband.** It says, "You are a good daughter. Remember to take care of you."

He thought of everything that I had forgotten. In this situation and as a caregiver, someone with lupus *must*

remember to take care of themselves or they could end up in the hospital as well.

Lupus can steal our ability to navigate through these types of life events and diminish our strength and energy, but we must put up a good fight, even when the focus is on someone else’s health and wellbeing.

The best advice I can give: take care of yourself. Don’t skip meals or medications and try and allow yourself time to rest. It can be hard to do, but it’s worth the effort.