Tips for Attending and Enjoying Events With Lupus

by ANNA SCANLON

Enjoying Important Events With Lupus Despite Pain

Being chronically ill often means missing out on important events like weddings and birthdays. I know this all too well, having dealt with SLE since 2005 and having missed out on countless special events.

I think the one that hurt the most was missing my grandmother's funeral back in 2010, but because I was so sick with the worst flare I ever had there really isn't much I could have done.

The thing about having lupus is there will always be people who just don't understand, even people in your family. There will be people who accuse you of not coming to events because you don't want to, or exaggerating your symptoms to get out of things.

While there is no doubt some people might actually do this, the majority of us are upset when we have to miss out on big events with family and friends, and skepticism from others doesn't help.

However, us lupies are often able to attend these important events — and sometimes even participate, such as serving as a bridesmaid, godparent or other position of honor.

Here are some tips I've compiled for attending (or declining, if necessary) in good graces.

Communicate About Your Illness

When I was first diagnosed with lupus, I was incredibly embarrassed to tell people I had the illness. Instead of saying anything, I would often wait until the last minute to tell people — until the disease was causing a problem.

But for most people, this sort of behavior will make them wonder why you didn't tell them in the first place, and even question the authenticity of your statement.

I suggest you always *always* tell people you suffer from SLE so they know there is possibility you may not be able to attend all their events or participate to the full extent. This way, last minute hurt feelings will be minimized. A true friend (or genuine family member) will understand the limitations of your illness.

Prepare Yourself For the Event

If you're going away for the event, it is especially important that you are prepared. If you're going to be exposed to the sun, make sure you have packed sunscreen, a hat and anything else that may protect your skin in the sun, since lupus and the sun don't mix.

Make sure you have all of your medication, including pain medicine. Sometimes I even take cold packs to place on my joints if they start swelling or hurting, which you can do in a break from the festivities or if you can sneak off

to your hotel room for a few minutes.

Sometimes parties and family events can be draining (lots of socializing and sometimes even dancing!) so you want to make sure that you can enjoy the festivities as much as possible without pain. You aren't going to have fun if you are trying to grin through severe pain, nor will you be as sociable as you would like.

Accommodation

If you are going to celebrate an event away from home and need to book a hotel, consider a few things before you do so. Firstly, booking a hotel close to the event is going to be your lifesaver, especially if the event is taking place over several days.

If you can't book a hotel on the premises of the party, staying a few minutes' drive or walk away is ideal. This way if you're not feeling so great during the event, you can steal away and take a quick nap or have a refreshing bath to perk you up.

You may find having a couple of hours to yourself will make it much easier for your health to tolerate and for you to have fun.

Mobility Aids

Although many people with lupus don't need help getting around, sometimes it can be a lifesaver if you're expected to walk a long way. Some people may find this embarrassing, but you have to look at it as a way for you to enjoy the event to the maximum. Most people will be more than understanding of your need for the devices.

These devices can include mobile wheelchairs, crutches and walkers. Many places, like amusement parks, offer a service in which you can rent a wheelchair for the day, which will most definitely help for destination celebrations. This way, you can still join in on the fun without having to sacrifice your joints or your energy.

Pacing Yourself and Scheduling Ahead

I do like to take vacations "by the seat of my pants" when I'm with immediate family, very close friends or with my partner.

But when I'm at an event like a wedding, I really like to know when and where things are happening. This allows me to better prepare for travelling with lupus by planning to schedule in naps or set up my sleep schedule so I know exactly when to get in bed so I will have enough sleep so I can be ready for the next day's events.

It also allows me to segregate my clothes and accessories (such as sun screen, extra water and hats) so I'm prepared for everything the day has in store.

Bigger events, like weddings, will have schedules already laid out. However, for things like family reunions or big birthday celebrations, usually the person in charge has an idea of how the day (or days) will pan out. Speak to them beforehand and get a loose itinerary.

If You Can't Make It

Sometimes, despite your best efforts, you still won't be able to make it to a big event. It is awful and is upsetting for you and those who wanted you to share in the special event.

But instead of being caught unprepared, you can always make gestures to ensure those throwing the event know how much you sincerely wanted to come.

I always make sure I buy presents and cards well in advance, so if I am unable to attend, a family member or

friend can pass it on as well as my regards.

Recently, my great-aunt celebrated turning 100 years old and I was unable to attend. However, knowing this was the case, I created a video message for her to let her know I was thinking of her and wishing her a happy birthday.

These small gestures can mean the world to people, especially if you are missing a big life event like a wedding or big birthday.