

CARE AND FEEDING OF AURORA LEVINS MORALES

AN ACCESS GUIDE

Thank you! If you're reading this document, it's because you've invited me somewhere, to do something interesting, and are about to spend a few minutes learning how to help me stay healthy during our time together. I live with a long list of physical challenges, some of which are just uncomfortable and some of which can be life threatening. I have many years of experience handling them, and am the best possible expert you could have, to help you set things up well for me. The most important thing to understand is that because of a genetic liver condition, a challenged immune system, and several neurological conditions, including epilepsy, my body can react very strongly to physical or chemical conditions that would be fine for someone else. In order to be safe, healthy and able to participate in what we're planning, I need to avoid the highest risk problems and give my body maximum support so I can handle the rest.

SITE SAFETY

My body reacts in extreme ways to many common chemicals, combustion fumes, mold, dust, and smoke. I do carry a facemask, but it's hot and uncomfortable to wear for long periods, and doesn't fully protect me. Portable air filters can also help, but in most situations it's not practical to bring one. So it's important that any room I'll be in, be cleaned with unscented and non-toxic products, be free of mold, and not be heated with gas or propane. Most cleaning staff people don't understand what's meant by non-toxic and scent free, so it's helpful to over them specific suggestions. **Hard floors, tables and counters can be cleaned with a solution of water and white vinegar, with unscented Dr. Bronner's castile soap, or with plain water.** Products like Simple Green or products with citrus or lavender oil are non-toxic, but very highly scented, and will make me sick. **Glass surfaces can be cleaned with rubbing alcohol.**

Carpeted rooms are more challenging. New carpet (and new paint or vinyl flooring) outgases formaldehyde and other volatile compounds that affect my nervous system and can provoke seizures. Older carpets can hold dust and mildew. Most carpet shampoos are toxic and often scented, and steam cleaners smell like those products even if plain water is

used. It's best for me to avoid carpeted rooms, but if we can't, then **the room should be thoroughly vacuumed a day before my arrival, and not shampooed.**

PERSONAL PRODUCTS

Most people use dozens of personal products that are loaded with fragrances and potentially toxic chemicals. Asking people to be scent free at an event is challenging. People can have strong emotional attachments to their favorite shampoo, cologne or laundry product, and don't understand how seriously ill these products can make someone like me. Fabric softeners can have as many as 500 different chemicals in them, including 28 identified carcinogens and 19 neurotoxins. Because my brain has already been injured, and because my liver can't get rid of toxins very efficiently, sitting next to someone whose clothing was washed with Downy, or dried with a dryer sheet, can make me lose control of my limbs, be unable to speak clearly, make muscles in my arms and face start twitching, cause shooting pains in my legs, and even provoke full blown migraines, or seizures in which I could get injured.

How willing people are to leave their chemicals at home depends on many factors, not all of them rational. The easiest thing to do is avoid putting on perfume or cologne, for at least 24 hours before seeing me, but lotion, sunscreen, shampoo, conditioner and deodorant are usually heavily scented, too, and tend to get all over people's clothing. The next easiest is to consciously decide to use unscented soap, shampoo and conditioner, and skip the deodorant or use baking soda instead, and to not wear anything recently laundered. However, fragrances are engineered to last, so they often stay on clothing for weeks. The steps that take the most commitment from people and provide me the best protection are to wash what they plan to wear around me in unscented laundry soap and baking soda, and to use only unscented hand soap, shampoo, conditioner, lotion and deodorant. (This is actually good for them as well, and for our environment.)

At the site, any built-in soap dispensers should have signs on them saying DO NOT USE, and unscented soap should be available. If people will be staying overnight, there should be unscented shampoo and conditioner available in the showers. Any "air fresheners" or other scent dispensers should be taken out of the bathrooms as long before my arrival as possible.

I should sleep in an uncarpeted room, and NO LINENS should be put on the bed. If possible, the mattress should be wiped down with rubbing alcohol to remove laundry product chemicals. I'll bring my own linens and pillow. In some cases, I may bring a camping pad to sleep on. There should be no smoking or incense burning anywhere near me or anywhere I'll be.

EPILEPSY 101

Flash cameras can trigger seizures, so no one should use flash in any room that I'm in. Turning my head won't protect me. I can generally tell if I'm at risk for a seizure and take steps to prevent it. There should be a designated person who'll be my buddy if I need to stop a seizure from happening. It should be someone calm and attentive, who can follow my directions without asking a lot of questions.

If I have a seizure aura, it will become hard for me to talk or to understand what's said to me. Only one or at most two people should stay with me, and everyone else should go about their business. The best thing is for me to a) get to a quiet place where I can lie down, 2) take ½ to 1 mg of lorazepam, which I carry in my backpack at all times, and 3) possibly eat an emergency snack (I'll be able to nod or shake my head about whether I want this, also in my bag,) and 4) cover my eyes—have as little sensory stimulation as possible. Someone should stay with me until I'm certain I've stopped the seizure

My seizures are very infrequent. As of this writing, I've had one in the last four years. But it could happen.

If I have a seizure—DON'T PANIC. Make sure my head is protected. Do NOT try to put anything in my mouth, or restrain my limbs. Don't let a crowd gather. I will go rigid, convulse for less than a minute, and then be semi-conscious and confused for 20-45 minutes. PLEASE DO NOT CALL AN AMBULANCE! There is no reason for me to go to an emergency room unless 1) I fall in such a way that I injure my head or neck, or 2) I actively convulse for longer than 5 minutes, which has never happened. It's normal for my breathing to sound strange, and for there to be blood on my mouth from biting my tongue. Do not try to "bring me round" but let me regain consciousness slowly, at my own pace. I'll be confused, won't remember what happened, and will need to be told many times. Once I'm more or less lucid, I'll be in a lot of pain from the muscle contractions. I take arnica, (in my bag) and if it's bad,

ibuprofen. I'll need to change my clothes and go to bed. My seizures affect my memory and thinking, and cause pain throughout my body for as long as a week, so it's really a lot better to prevent them.

FOOD

I have many food intolerances and allergies. Most important to avoid: wheat products of all kinds, corn and corn products, cow milk and dairy products, eggs, red meat, commercial chicken, spinach, shellfish, eggplant, potatoes, peppers, tomatillos, and tomatoes. My liver can't tolerate pesticides, so I try to eat only organic produce, and if that's not possible, to stick to the ones that are least affected—root vegetables, plantains, avocados... If we'll be eating out, I do best with Thai, Japanese and Puerto Rican or Cuban restaurants. If we're at a facility that provides food, the best options for me are usually fish, rice and vegetables or salad. I can also eat beans if they don't have tomato sauce or meat in them. Usually, the easiest thing is to bring my own food to supplement what the cooks prepare. I travel with protein powder, canned fish, wheat free crackers and pasta, miso and goat cheese.

If my hosts will be preparing the food, it's helpful to go over the menu in advance, so I know how much to bring, or, if it's not too complicated, to work together to come up with meals I can eat.

If I have a strong allergic reaction, I need to take Benedryl and possible use an epi pen, both of which I carry in my backpack.

REST

Because of my multiple chronic illnesses, (I haven't mentioned Lyme and CFIDS) I experience a tremendous amount of fatigue, so it's very important that I get enough rest, and that I'm able to sleep at night. Travel is hard on my body, and I need extra rest to compensate. If I'm performing or speaking, I need to lie down by myself for at least an hour before I go on. If I am at a workshop or meeting, I may need to withdraw to my room for a while. If at all possible, I should have my own room, where I can be sure of scent free and quiet environment, can rest privately when I need to, and can set up my noisy C-PAP machine, to help me breathe at night. My room should be away from areas where people will be gathering late at night.

COMFORT/PAIN RELIEF

I have chronic inflammation in all my joints and muscles because of the build up of toxins caused by my liver condition. I also have spasms in my muscles because of neurological damage from a stroke and other conditions. This means that unfortunately, it's usually painful for me to hug lots of people, shake hands, or share a couch or mattress with anyone else. It's also painful for me to sit in hard chairs, bend to pick things up, or carry anything heavy. In meetings, classes or workshops, I do best if I'm able to lie on a couch, mattress or pad, with cushions, or sit in a soft, reclining chair.

CELEBRATION

In spite of all these challenges, and make no mistake, they're big and difficult ones, I have a rich and rewarding life, and enjoy being with people like you, to think, work and create. We live in a society that doesn't support the sick and disabled very well. We often have to struggle very hard, in the face of indifference or active hostility, to get our basic needs met, much less to have the same access you do to work, social lives and creative outlets. The struggle for survival and for access can be exhausting and discouraging, and sometimes we just don't have the energy to do it by ourselves. Without the support of people like you, I would not be able to travel, participate in face-to-face community, or work with you.

Thank you for reading this message, and doing everything you can to make it possible for me to be with you at our upcoming event.

Warmly,

A handwritten signature in cursive script that reads "Aurora Levins Morales". The signature is written in black ink on a light-colored background.

Aurora Levins Morales