

This letter is from Kylan Clayton. Please read it and put this information to good use in helping Kylan with his disability. ~~ Chuck

Dear Friends and Colleagues,

As many of you know, I have a chronic health condition called Multiple Chemical Sensitivities (MCS) which means that I cannot be in contact with a wide range of chemicals without suffering enormous health consequences. This letter is to let you know a bit more about my (dis)abilities, the effects of chemicals on my body, to let you know what you can do to ensure that the classrooms and workspaces (including workrooms and hallways) we share are accessible and safe for me. I have also included a list of resources for you.

Information on my (dis)abilities and some of my experiences with them:

Like many people, I developed MCS as a result of two other related illnesses: Fibromyalgia Syndrome (FMS) and Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) (also known as Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS). Not nearly enough is known about these syndromes, but their symptoms closely resemble other immune and autoimmune disorders such as Lupus, Multiple Sclerosis, and HIV/AIDS. CFIDS and FMS both cause an enormous amount of physical pain. Part of the “fatigue” in CFIDS is fatigue to such a degree that it causes excruciating pain. (“Fatigue” doesn’t really describe the reality of the experience). One weekend I got what seemed like a horrible achy flu and couldn’t get out of bed. I never got better. Few people seem to recover from CFIDS and FMS, though some experience periods of remission.

Because these are autoimmune disorders, my immune system lost the capacity to protect my body from the toxins present in almost everything we use in our current society. Scented products contain poison substances that my body cannot fight. When I’m exposed to chemicals, my symptoms can include:

- Dizziness
- Disorientation
- Forgetfulness & confusion
- Nausea
- Stomach cramps & spasms
- Migraines
- Sore throat and nose
- Stabbing pain in my ears
- Muscle cramping
- Lung pain
- Rage attacks and depression (Many chemicals destroy your central nervous system, and intense emotion get triggered in that process).
- Nerve misfires (kinda like pinched nerves) and stabbing pains
- FMS flare-ups and increased CFIDS symptoms
- There just ain’t no way to say it nice, folks: the feeling that someone is ripping me apart at the groin

These symptoms can last several days or sometimes weeks.

MCS becomes less manageable and more dangerous the more I’m exposed to chemicals. Many people with MCS cannot live near other people or in houses at all. Many people MCS die from liver failure and anaphylaxis.

Of all of the illness I’ve acquired over the last two years, MCS has been the most difficult to negotiate because toxins are so prevalent in this country. People who do not experience MCS have difficulty imagining that products that they use everyday could injure or kill another person. Here are some of the products I can’t be around that people use on a daily basis:

- Perfumes, colognes, aftershave and essential oils
- Scented soaps
- Scented detergents
- Scented deodorants
- All fabric softeners
- Petroleum-based or derived products
- Hairspray, gel, and other hair products
- Cigarette smoke (including residual smoke)
- Bug Repellents

I also can't read newspapers or telephone books without wearing gloves and a mask.

What You Can Do to Insure Accessibility and Avoid Giving Me Chemical Injuries

In truth, avoiding toxic products is better for *all* of us and for the environment. It also ensures that people with MCS, autoimmune disorders, HIV/AIDS, allergies, asthma, and Gulf War Syndrome (to name a few disorders) are able to have access to the same buildings and events as temporarily able-bodied people. When people wear scented products it's as if I am using my wheelchair (which is damn cute, by the way) and the classrooms or workplaces are blocked by stairs. So, not wearing scented products is not only a health issue, it's an issue of access and social justice.

So, in order to ensure that the spaces I'm in are safe and accessible, please refrain from wearing any of the products that I mentioned above. There are several safe, non-toxic alternatives for personal hygiene that are just as effective as toxic options. Make sure that your personal products say "fragrance free," not just "unscented." ("Unscented" often means there is a masking scent used to cover-up the scent of the products.)

Because of the risks involved if I'm exposed to chemicals, please don't take offense if I let you know that a product you're wearing is making me sick, or if you are asked to sit in another section of the classroom because you forgot to make sure you were fragrance free before coming to class, etc. Please understand that it's against my "home training" to approach people about their personal habits; I do so in a spirit of good will and to ensure safety and accessibility. Also, please remember that MCS is a progressive illness, which means that a product that doesn't make me sick one day may bother me the next.

Thanks for your understanding, y'all. While MCS is a difficult condition to live with, your respect and cooperation helps me immensely. Don't hesitate to approach me with any questions.

Thanks
Kysten E. Clayton

RESOURCES:

Here are some suggestions. You should be able to find these and more at any health food store or online:

Guide to Less Toxic Products: <http://www.lesstoxicguide.ca/index.asp?fetch=household>

Soap:

- Dr. Bronner's Soap -- Unscented Baby Mild (available as a bar soap or a liquid soap)
- Kiss My Face ORIGINAL Olive Oil Soap (green label -- others contain fragrance)
- Green Mountain Soap
- Kiss My Face Fragrance Free Moisture Soap

Shampoo/Conditioners:

- Pure Essentials Fragrance Free Shampoo & Conditioner

Lotions/Moisturizers:

Nature's Gate Fragrance-Free Moisturizing Lotion
Alba Botanicals Fragrance Free Lotion
Olive Oil, or any vegetable oil

Laundry Detergents:

Seventh Generation Free & Clear (without dyes and fragrances - NOT the regular Seventh Generation)
Seventh Generation Non-Chlorine Bleach – Free & Clear
Ecover Natural Laundry Wash Ultra
Ecover Laundry Bleach

Hair Products:

Autumn Harp's Un-Petroleum Jelly
Magick Botanicals hair gel
Naturade AloeVera 80 Fragrance Free Styling Spray
Lily of the Desert Aloe Vera Gel (If kept in the fridge, it will have the same texture as hair gel.)

Deodorant:

Kiss My Face Fragrance Free Active Enzyme Natural Stick or Liquid Rock Roll-On

Sunscreen:

California Baby Sunblock or Sunscreen No Fragrance

Shaving:

Kiss My Face Fragrance Free Moisture Shave

Other Resources:

Chronic Fatigue Ruled Cause of Death: <http://news.bbc.co.uk/1/hi/uk/5112050.stm>

E Magazine's Photo Essay on folks living with MCS: <http://www.emagazine.com/view/?1003>

Peggy Munson's CFIDS/MCS Site: <http://www.peggymunson.com/cfids.html>

Greenpeace UK's "The Chemical Home":
<http://www.greenpeace.org.uk/Products/Toxics/chemicalhouse.cfm>

Center for Disease Control and Prevention's Guide to CFS: <http://www.cdc.gov/cfs/>

CFIDS Association of America: <http://www.cfids.org>

BBC: "Chronic fatigue gene signs found" <http://news.bbc.co.uk/2/hi/health/4702515.stm>

Skin Deep: A safety assessment of ingredients in personal care products:
<http://www.ewg.org/reports/skindeep>

william maria rain-shadid's "chemicals in the midst: accessibility, toxicity, and living with chemical injury": <http://www.pscap.org/db/>

The EPA's EnviroMapper and EnviroFacts (look to see toxin producers in your neighborhood!) and other toxic fun right in your own backyard!: <http://www.epa.gov/epahome/commsearch.htm>

I Remember Me (film): <http://www.irememberme.com>

Stricken: Voices from the Hidden Epidemic of Chronic Fatigue Syndrome edited by Peggy Munson