



What you need to know before visiting a person who has MCS

I can't wait to get together, it has been so long since we last sat and chatted over a cup of tea. Life sure has changed in many ways since we last visited with each other, hasn't it?

For me, interacting with other people is one of the hardest and most stressful things for me to deal with these days while having a difficult to control illness. Even well meaning people can cause me to have what may have started out as a "good day" into a life threatening medical nightmare or disaster. Jeesh... when I think about it, I have to run as fast as I can to stay in place on most days. As if living with such a difficult health situation is not bad enough, it is often equally difficult for me to ask others not to make me ill in my own home by using various chemicals/products that seem completely harmless (to them). This causes an entire other set of issues due to isolation, alienation, resentment and even friends & family avoiding me because being in my company or visiting me is simply not "convenient" for my would be guest.

If you are planning to visit me at my home for a few minutes, hours, or for and extended over night stay, here are some basics, which may help make our visit enjoyable and lessen the chances of my becoming too ill to enjoy our visit as well as lessening your chances of feeling hurt, bad or embarrassed for contributing to my illness.

After all, breathing is a necessity, chemicals and fragrances on ones body, hair and clothing are not. Hence, my health and ability to breathe in the company of another person is NOT negotiable. The truth of the matter is I have never really been in the company of another person who made me sick... it was the chemicals they had on their body, hair and clothes that has gotten my health to the compromised point in which it is today.

There are not any products that I am not neurologically reactive to. It is just a matter as to how reactive or sensitive to them I am and how ill a specific product will make me.

So, please leave them all at home.

Those "all natural" fragranced products are not safe around me either. While some products are worse than others, all WILL make me sick to some degree, probably too sick for you to even come into my home or to enjoy your company.

These are just some basics, but better to ask me than to assume.

Personal hygiene Simple rules-of-thumb:

If the word perfume or scented (natural or otherwise) is on the label of your product, don't use it before you come to visit me at my home ... Yes, even your breath mints, gum and mint toothpaste smells could knock me for a loop as would bug sprays and "body sprays."

Things you probably cannot smell affect me and make me pretty sick; after all, it's the chemicals not the odors that make me sick, so ... just ask if you're in doubt.

Cosmetics have exemptions from labeling laws, they are literally allowed to state they are fragrance free, when they in fact do have fragrances in them referred and often labeled as "masking fragrance" which is used to cover up the smell of the product itself. Obviously, chemicals are chemicals and fragrance is fragrance, if it's in there it will make me very ill.

Shampoo

All brands you can buy in a supermarket have fragrances in it, even baby shampoo. Please do not "drop in" after you have just come from the salon or you have just shampooed or colored your hair. This will make me sick.

If you will be staying over night at our house, I will supply the guest bathroom with "safe" products (ones that do not make me ill) for you to use while visiting, including: toothpaste, shampoo, conditioner, lotion, soap etc.

Please DO NOT bring any of your own personal products into my house.

Soap is like shampoo. The worse offenders to me are Dial Soap and ALL other "deodorant/scented" soaps. Safer alternatives are easily available like Neutrogena Fragrance Free soap or Basis soap. Again, ask me and I will help you out here.

Keep in mind that the soap you may wash your hands with in a public rest room or in an airplane before you get to my house will make me sick because chances are good that this soap will contain a perfume /fragrance.

Currently the ONLY soap that is safe around me is Neutrogena Fragrance Free Facial soap which we also use as a GREAT shampoo bar and Kiss My Face Fragrance Free Pure Olive Oil bar.

Deodorant

Most all deodorants have fragrances or "masking fragrances" and other harmful chemicals in them. A good alternative is the crystal sticks, or any of the chemical free varieties. Try Arm and Hammer UNSCENTED or ask me which deodorant would be ok for you to use while you are visiting me at my home.

Hand cream & Lotions

There does not seem to be any safe hand creams for people chemically sensitive. **Best to leave yours at home.** I have some nice "safe" lotion bars that are great even for your face.

Perfumes, fragrances, colognes, lotions, after shave, hair care products, nail polish and/or remover etc...

I've Just got to say NO!

Lotions, hair gel, hair spray... Amazing how much stuff people pour on their body, hair and laundry

every day, isn't it? Please do without these products around me, in our home or when visiting.

Clothing... What to avoid:

DO NOT WEAR --- Any/all clothes washed in any scented (natural or synthetic) detergents or bleach, this will make me sick. So will clothing that has "Fabreeze" OR "Bounce" on them.

DO NOT HAVE ON --- Freshly polished nails (same day)... the same goes for "just" colored or permed hair.

Hands which were washed with a bar or liquid soap, which has fragrance or germicide in it will make me really sick.

New clothes – new fabrics are treated with formaldehyde and formaldehyde makes me terribly sick.

DO NOT WEAR --- Dry-cleaned clothes

DO NOT WEAR --- Moth balled clothes

DO NOT WEAR --- **ANY Clothes which have EVER been previously washed or dried with fabric softener / dryer sheets of any kind...**

This is the worse for me and will make me very sick.

Bears repeating:

DO NOT WEAR --- **ANY Clothes which have EVER been previously washed or dried with fabric softener / dryer sheets of any kind...**

This is the worse for me and will make me very sick.

Do not pack (if you will be staying overnight) or wear clothes that have been in the closet next to other clothes, which have "lingering" perfume/cologne/aftershave smells, fabric softener smells, deodorant smells or detergent smells.

Overnight guests

Needless to say, I do not use any fragranced detergent, softeners or laundry/cleaning products. I wash clothes in borax and/ baking soda; it works well even for dirty work clothes. Chances are good if you are staying over for more than a couple of days, you will need to do a load of laundry. Any clothing previously washed and/or dried using products that contain fragrances cannot go into my machines or come into the house for that matter. Even if they were washed and dried last month, fabric softeners and dryer sheets leave a permanent lasting waxy film that sticks on your clothing and machine FOREVER -- this will make me very ill.

If you have any questions about any of this... please ask **BEFORE** you come to visit.

Save yourself from an uncomfortable and perhaps embarrassing situation.

When you keep "forgetting," I get one of two messages:

Either you don't believe I'm really sick or you don't care.

I never get the message you just forgot.

PS... MCS is NOT an allergy or an "allergic" reaction to "smells" or "perfume-fobia." It is a serious and very difficult to manage highly reactive neurological disorder triggered by chemicals (fragrances are chemicals) . I am obviously much more neurologically/chemically sensitive now than I probably was the last time we saw each other, but this doesn't mean we can't enjoy each others company and have some fun, it just means I need to be more careful to avoid triggering a

negative reaction.

On a more personal note about MCS:

If I were to tell someone that I had Cancer or Multiple Sclerosis, that person I'm talking to can accept this in a detached and somewhat impersonal way. The issue usually does not personally challenge the other person.

Now if I tell this person that perfumes, every day household chemicals, scented soaps and fabric softeners make me horribly sick to the point of disabling, since he/she most likely use one or more of these products regularly, the issue is immediately personal.

**And if all of this seems too overwhelming for you to remember,
then try this simple formula:
Pretend this happened to you and you are having to write this to
send to your friends and family!**