MCS Tips by Kathy

I know that many of you will have had MCS for years & found ways of coping & things you can use. Unfortunately, I expect there are some of you who have recently developed MCS & are still trying to work things out so here are a few TIPS which you may find helpful, but remember- we are all different.

1) While well people think there are lots of eco & natural products available now, these still contain chemicals - some natural & some not, so while they may be better for some to tolerate than non-eco products you may react to them.

2) Hypoallergenic & ' for sensitive skin' does not always mean suitable for MCS & chemical free (these can often come up during a fragrance free search of natural toiletries)

3) Check ingredients on natural products like toiletries & cleaning products. There may be some that you know you don't tolerate. Also while they may be completely natural & fragrance free (ie have no deliberate fragrance, herbs or essential oil added) some of their ingredients may be very smelly & depending on the amount in them be intolerable for your smell sensitivity.

4) Metal, glass & ceramic are often the safest materials for items, as they are very inert themselves, they can be washed & they do not absorb chemicals from the air like softer materials do. However check & be aware of any paint or coating on metal e.g. Chrome Effect is a coating & not chrome.

Frosted glass can be made in different ways - either sandblasting or acid etching. I only know this from learning the hard way -although the acid is washed off after the process I was unable to keep the item.

5) If buying wooden items then hard wood (eg maple, beech, oak) is usually better than soft woods (eg pine) if you have MCS. If avoiding varnished wood be aware that bare wood has a smell, at least until it "settles", so see which wood is best for you.

6) Natural materials are generally considered more suitable than synthetics for people with MCS. Undyed organic cotton is probably the most popular. It does have a strong smell when you buy it which can stop people from keeping it but this does reduce a lot with washing.

Soaking it in hot water with bicarbonate of soda (if you are ok with this) for an hour or so & then rinsing & washing & drying it helps reduce the smell a lot. You may need to do this several times. If so, drying in between is an important part of the process. (you may need to avoid the room the soaking & drying is being done in).

Special MCS Feature

The reality of living with very severe MCS

As if we haven't had more than enough disbelief over ME, those of us with MCS have to deal with even more of it about our MCS.

While things on that front are improving in regard to ME, unfortunately MCS is a long way behind in its recognition & acceptance.

I have experienced much overall disbelief & scepticism about my MCS , & have often been treated as if I am just difficult or crazy.

I am also used to people criticising or questioning what I do to protect myself & how I live. Eg Some telling me it's not necessary to do this/that - well really, how do they know? They aren't the one reacting & have no way of measuring pain or my other unseen symptoms. OCD accusations can get thrown around, & if my actions were taken out of my MCS context I'd probably be agreeing.

I am always baffled by the comment "but surely it can't make you that ill & it's better to have this item/that care than live without it". Well, obviously the symptoms are worse to live with than living without it is, or I'd have it wouldn't I! I am still trying to figure out why many people don't then stop to consider how horrific living with the symptoms caused must be if they are worse than what the person thinks is unacceptable to be living without - but not many people seem to process that.

There's also the disbelief to cope with from people who do believe in MCS but not the extreme level of it I have and the minute amounts of chemical that affect me. They seem to accept that if they can either smell something, or see something like wet cement which they can't smell, then they can assume there's something there for me to react to, but when its quantities they can't detect, it causes difficult situations &/ or disbelief.

Then there's been times when those closest to me (who do believe MCS) have said "you/ we never used to 'have to' do that", or "this product's always been ok for you". They can forget (or in early days, not know) that we can get worse, more sensitive to each thing or sensitive to new things & it can be very difficult for us to ask them & for them to accept more restrictions/hassle to accommodate us.

I have also had difficult moments when they don't consider or (understandably) can't comprehend what its like to feel constantly ill & living for decades with so many symptoms- ME, MCS & other conditions. I (like I'm sure all of you) have a multitude of symptoms I suffer daily, many of them constant. Sometimes I could possibly endure a lesser symptom/reaction if I had less overall, but it can be the straw that breaks the camel's back & it's hard for a well person to see beyond each symptom on its own.

At some point with ME, even if only for DWP forms, we have to deal with doctors & their attitudes towards MCS. MCS is not officially recognised as an illness in the UK & finding a GP who is supportive of ME & also accepts (or is at least open-minded about) MCS & that it is a physical illness is not at all easy. After several years I finally found a GP sympathetic to ME & fortunately he has been supportive to my severe MCS too , but I've still had dreadful experiences with other NHS staff.

After all we lost through ME - jobs, friends, hobbies, independence etc, with MCS we lose even more. (I am writing this in the context that my MCS became severe after my ME did).

I live without many basic things which a well person would consider essential these days, eg washing machine & drier, a flushing loo (a long story, but I pour jugs of water down instead), a complete set of clothes, adequate heating, proper meals (food intolerance), a simple pain killer etc. I have hardly anything that isn't absolutely essential to existence. Fortunately for myself I was never a materialistic person who wanted "stuff". However, sentimental items contaminated with years of normal home atmosphere from before my severe MCS had to be boxed up & put in a shed when my MCS became very severe & I am sad they can't be around me. Less sentimental stuff was just thrown away.

I, like most people with severe or very severe MCS can't have open windows. Air, (unless possibly if you're remote) is a "chemical soup" & we can't necessarily use an air purifier (which have limitations anyway).

I remember when I was eventually diagnosed with ME, I bought a book about it. It had 1 page on chemical sensitivity (which I'd never heard of at the time) & said that very sensitive people can be affected by fumes from factories even 30 miles away if the wind blows from that direction. I thanked goodness that I didn't have that symptom. Now, when I open the door to take shopping from my mum I know, from specific symptoms I get to particular chemicals, that someone down the road has been using paint, or there must be builders using cement, or the council has been using weedkiller on the village green about a mile away etc. I can't see these activities but if I ask mum I'm always right.

I am unable to make many repairs to my home, certainly not indoors & live with a hole in my bedroom ceiling covered only with kitchen foil from where a pipe leaked in the loft. I can't have a normal repair (because of materials required), & it's not worth the symptoms & contamination afterwards of having someone else come in to do it (assuming they even agreed to an inventive suggestion). I have a precariously rotten window frame currently held together with glue outside but don't want to replace it until it actually falls in because of my serious symptoms to the sealant. Having repairs or replacements done takes much research & planning well in advance, & a lot of explaining & discussion with the person who will do it as they usually can't do it , &/or use their usual products, how they normally would. Finding someone willing to accommodate this can also be difficult.

In my lighter moods I often laugh in an 'if only they knew' way at the thoughts of the panic or "stress" people are in when their kettle stops working or something . All they have to do is go to a shop or order online & buy a new one - no problem!

In my experience with severe MCS, finding a product (whether household, clothing, toiletries or anything else) that you can tolerate can be an exhausting, frustrating, despairing & costly process which can take literally years of searching. And sometimes when you finally find something, the next time you need it it's become unavailable or changed so that you react to it, & you have to start looking again - & go without in the meantime. Many items (even those I think are keepable) require a lot of washing/airing or more complicated procedures before they can be left around or used, & my ME doesn't give me the physical ability for doing this much so I am restricted to only essential items in this way too.

My choices on whether to have something or go without (assuming symptoms aren't so serious that I have no choice but to go without) depends on the symptoms, the severity of them & how much I need/ want the thing in relation to my suffering of the symptoms.

With severe ME & very severe MCS our most difficult choice is probably over whether to have care indoors. I experience a particular one, & there is no medic to turn to about them. Living alone there's no one to comfort me or even know what I am going through.

I think the mental & emotional strength & energy we need every day to cope with this sort of thing is rarely considered by others & it can be exhausting.

I now live alone, as many very severe MCS people end up doing. (My husband & I having had to separate after us managing years of my very severe/extreme MCS together).

Not only do I try to get by without indoor care but for the same MCS reasons, I am not able to have any visitors indoors. It's not just about surviving while people are actually in my house but also the chemical "contamination" they leave behind in the air & on things.

Although I can no longer have visitors indoors, I'll describe what it was like when I occasionally did. This was before my MCS was so severe & when my ME was at a level to manage a few minutes very occasionally & when my husband was here to help.

Fumes from visitors clothes, hair & possessions waft into the air (this may be from chemicals that got settled on them from their homes & outside & in the car etc while travelling here too, not just the actual clothes & toiletries themselves). All these not only made me ill, (often with such intense symptoms that I couldn’t enjoy the occasion) but also settled in my own hair & clothes & things in my home. After the visit, the things, myself & my husband, & our clothes then needed to be washed (often many times over) & air purifiers moved around to get rid of the fumes (if they were actually chemicals they dealt with). My ex did all these jobs. With my ME I couldn’t have done it myself. The fumes from disposable coveralls and gloves caused symptoms too if we all wore those.

In addition, however careful people try to be, they usually contaminate something by touching or putting something down without thinking. Before learning the hard way we ended up having to cut out a section of our kitchen worktop & throw away chairs & other items visitors had contaminated that we couldn’t decontaminate sufficiently afterwards. And with my MCS we couldn’t replace these things.

Having learnt from these incidents, if we then had an occasional visitor, my ex would move things out of the way, cover everything else & we kept visitors just inside the kitchen door on chairs we otherwise kept in a non-smelly shed. We kept specific clothes for use with visitors, after having some ruined & I used to cover my hair. We washed & used purifiers afterwards like before.

Severe MCS adds hugely to the isolation & lack of physical contact I had with ME on its own (even compared to many years when my ME made it very restricted) as I can’t have even my parents indoors - though we would all love that!

I see my family on days (about 2 a month) when I can get downstairs. I sit in my lounge & they sit on the patio outside & we chat through the closed patio doors. Later, my mum (who avoids chemicals as much as she can in her own life for my benefit, & comes in clothes she keeps only for coming to me & washed in the detergent I use) brings my shopping which she passes through the kitchen door at arms length. Wearing gloves we hold hands for a few moments, if I can possibly survive the outdoor air any longer - I suffer for hours or longer afterwards anyway from the air while she passed shopping in, though I am next to an air purifier there. That’s the extent of physical or face to face contact I have.

I find the combination of severe ME & severe MCS awful. It often feels that I can’t help one because of the other. Living with MCS, without the help of mod-cons (that I cant tolerate) & with the precautions I have to take, is very physical & time consuming. If I want to protect myself & make it possible to live with my level of MCS, then I have to exacerbate my ME. The alternative is to look after my ME & be poisoned.

I hope that by sharing this, it may give some of you with MCS comfort and confidence to do what you need to, & let you know that you are not the only person who is disbelieved, going through these types of things or living in poor or unusual conditions.

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