

Kathy's MCS/ES Info

RAISING AWARENESS & UNDERSTANDING OF THE CHEMICAL INTOLERANCE/SENSITIVITY SYMPTOM OF M.E.

I have been aware of some lack of awareness within the M.E. community of the Chemical Intolerance/sensitivity symptom. This has included when I have phoned MEA (about other ME things) & some of their volunteers had no knowledge of it or what it means on a practical level, but were interested to learn. To reduce the need for any of us to give so much explanation in future, I contacted the phoneline manager to ask if it would be appropriate & helpful if I wrote an explanation for her to circulate amongst the volunteers. I received a very lovely, enthusiastic & appreciative reply. I have since sent her my written piece which she gratefully received & was about to circulate.

She also commented how very little literature there is on this symptom & if I would agree for my writing to be used to make a leaflet for the MEA literature collection. It has now been sent to the relevant (very busy) departments & hopefully one will be produced in due course. Apart from it helping those who support us to understand how the symptom impacts us, it would also be useful to have an official-looking leaflet to add credibility when we deal with people who question our needs.

Many of us also find that people who are involved with us, eg friends, carers, who are aware this symptom exists, often ask us why we cant use this or that.

As its implications & what the symptom can mean on a practical level are understandably not always obvious to anyone without it, I thought I would use a reduced version of what I sent MEA for our article this time, which may be helpful to show others, particularly for those of you with very restricted communication ability.

WHAT THE CHEMICAL INTOLERANCE/SENSITIVITY SYMPTOM OF M.E. MEANS ON A PRACTICAL LEVEL.

Chemical Intolerance/sensitivity is included in 2021 NICE guidelines as a symptom which someone with ME may have. It is more likely to occur in severe & very severe ME sufferers.

What is it?

Someone with Chemical intolerance/sensitivity will have reactions to synthetic & natural chemicals - they do not have to be things you think of as chemical eg paint, pesticides or petrol, but may be common everyday products eg shampoo (even if unperfumed), plastic, fabrics & newspapers, or natural chemicals & substances. It is Not the same as smell sensitivity which is a different possible symptom of M.E.

Chemically sensitive people can react to things either through inhaling them from the air, absorbing them through their skin, or by ingesting them. They can be sensitive/intolerant to anything, including odourless chemicals, natural substances & mould (which produces toxins).

Although there are lots of eco, environmentally-friendly & natural products available these days, these may still not be tolerated by someone with Chemical sensitivity. Eg they may react to any of the natural ingredients, or may need 0% VOC rather than low VOC, etc.

With Chemical intolerance/sensitivity in ME they may react to one or to a few things, but it is possible that they may become (either suddenly or gradually) sensitive/intolerant to many or even to all chemicals. As with other ME sensitivities, the milder end is relatively easy to manage with, but if very severe it requires major adjustments to live with. Those very sensitive may react to minute amounts of chemical that no one else is aware of.

Those with Chemical intolerance/sensitivity often have or develop Food Intolerance &/or Drug Intolerance which are also stated in the NICE guidelines as possible symptoms of ME. The drug intolerance experienced by Chemically sensitive/intolerant people can include sensitivity/intolerance reactions to any type of drug, eg general anaesthetics, local anaesthetics, medicines, over-the-counter pills, creams & ointments. It is Not the same as certain drugs possibly aggravating ME symptoms.

Symptoms

The symptoms caused from Chemical intolerance/sensitivity & the severity of them varies from person to person. It can cause a very wide range of symptoms & affects different body systems. Examples of symptoms are breathing difficulties, unconsciousness, headaches, stomach upsets, fatigue, weakness, muscle pain,

cognitive problems, co-ordination problems, concentration difficulties, urinary problems, dizziness, collapse, paralysis, rashes, sore throats etc. Everyone is different- there is not a specific reaction to a particular chemical that everyone gets (as many factors can contribute to which symptoms & where in the body symptoms are produced). Once someone has become Chemically intolerant/sensitive, many reactions/symptoms happen immediately or quickly when exposed to a chemical they are sensitive to, but it can be hours or days later.

Managing Chemical Intolerance/Sensitivity

Unfortunately, most conventional doctors have little knowledge about Chemical sensitivity/intolerance & no treatment is available from them. However, to manage this M.E. symptom, Avoidance of chemicals & the things which trigger symptoms is regarded as the most important & beneficial thing to do.

1) Sufferers should not use or be exposed to specific things they react to. If they are only sensitive/intolerant to a few things this is relatively easy to do & they are likely to be able to replace things in their home with a safer alternative that they don't react to. The change may not need to be to a natural product as they may be better with some synthetic chemicals than others. Obviously the more chemicals they react to, the more impact removal of lots of things has on their life & of those they may be living with & the less likely they are to be able to find suitable substitutes.

2) Another aspect of avoidance is to overall reduce the chemical products they use & the chemical materials in their home in order to keep their body's total load more manageable for it to cope with. It is particularly important to make their bedroom as chemical-free as possible.

3) Outgassing (airing) new items before having them around or in use. To explain outgassing - virtually everyone, including people who are not Chemically sensitive are aware of the "new" smell when they buy a new item eg carpet, tv, book, clothing. This is the materials it is made of releasing chemicals. While those who do not have Chemical sensitivity may not notice the smell after a few weeks, a chemically sensitive person may react until all chemicals in it are fully outgassed. They may also react to chemicals outgassing which are odourless, so the smell strength is not always an indicator whether the item is safe for them. Outgassing is usually strongest for the first 6 weeks, but it can take up to 10 years for some substances to fully outgas eg. formaldehyde which is used in a huge range of common items.

It may be possible for outgassing to be done in a spare room the sufferer never uses, but if more severe, will need to be well away in eg a clean garage or shed. Those with ME physical limitations may need help with this.

4) New items often also require repetitive washing, steaming or other decontamination which someone with ME physical limitations may need help with.

Understanding the impact of Chemical intolerance/sensitivity on someone with ME.

Depending on the level of Chemical intolerance/sensitivity, this symptom of ME can further restrict a persons ability, both physically & mentally depending on the symptoms it causes & can cause further losses in their life.

It is likely to further reduce their quality of life by, for example:

- restricting hobbies which involve materials they can not tolerate eg arts & crafts, reading books or magazines; restricting environments they can be in such as public places & buildings, or even their own garden (eg if neighbours laundry is drying, a neighbours window is open with eg fragrance or cleaning product fumes coming out, weedkillers have been used nearby, there is building work in their area, or the general pollution of outdoor air);

- restricting physical & social contact (if affected by other peoples clothing materials, or the laundry products &/or toiletries they use etc);

- being unable to replace items when worn out eg a tv, phone, hoover, bedding or other items because of materials they are made from; 2nd-hand items are often not an alternative as they will have chemicals from the previous owner on them;

- even their best-tolerated clothing & bedding may cause them symptoms;

- possibly being unable to have adequate heating- they may not tolerate gas for fires or central heating, the paint, cables or components of electric & other heaters, or smoke from open fires;

- restricting use of aids to help with M.E. symptoms because of the materials used in them eg blackout blinds, eyemasks, ear defenders, stairlifts, wheelchairs;

- restricting access to medical care including surgeries, hospitals, dentists, chiropractors etc by either not being able to tolerate the environment &/or not being tolerant to medication or treatment; it may not be possible to use drugs to help with their other M.E. symptoms either;

- preventing small comforts like being able to have a thinking of you card beside their bed;

- draining their limited energy & abilities on the extra mental & physical tasks involved to live with Chemical intolerance/sensitivity, so there is less or none left for using on other essential tasks &/or on anything pleasant.

If the Chemical intolerance/sensitivity is very severe:

- they may have to live in isolation, with no visitors or carers indoors.

- they may be unable to have windows open.

- If they have very severe ME & are totally dependent on help but also have severe Chemical intolerance/sensitivity, carers are likely to make them ill with chemical sensitivity symptoms.

- Living without what would normally be called "essential items" can be the only option for some sufferers of this symptom.

When ill with ME & Chemical intolerance/sensitivity it can often feel that the sufferer has to exacerbate one in order to manage the other eg have symptoms of chemical

sensitivity by using a carer or aids they react to, compared to pain, exhaustion & collapse from physically trying to live without them. It can be a difficult decision how to balance this & will be individual to each person, depending largely on which symptoms are less serious or which they 'prefer' to suffer.

Chemical intolerance/sensitivity with the accommodations it can require, often puts strain on relationships, particularly with those the sufferer lives with & if severe.

Examples of the needs & alterations someone with Chemical intolerance/sensitivity may have to make

Depending on the severity of someone's Chemical intolerance/sensitivity, their reactions & the number of substances they react to, they may need to make changes to accommodate it. These are usually relatively simple & unimposing for people with milder sensitivity or milder severity of symptoms, but can be very challenging for those severely affected.

- They may need to use specific products.
- They may need to change their toiletries, laundry detergent & household cleaning products - avoiding fragranced products may be sufficient or they may need to use natural &/or organic ones. They may need natural sanitary protection to avoid synthetic material, plastics &/or adhesive.
- They may need to wear clothing made from natural materials eg cotton & linen, &/or avoid bleaches, dyes or finishes such as crease free, stain resistant etc. Severely affected may need to use undyed organic material. They may need to avoid elastic. Tolerable footwear can be very difficult for some to find with the materials & glues used in them.
- Bedding, including mattresses may need to be made of natural materials, with no fire retardants or other treatments/finishes.

- They may need laundry done by hand if they are very sensitive to rubber so cant have laundry put in a washing machine.

- They may be unable to have normal repairs done to their home because of the materials used. They may need to work out an inventive alternative & hope they can find a tradesman willing to do it that way. For those who rent they hope that their landlord is accommodating although they may be unable to be due to legal requirements.

- They may need visitors & carers not to have used fragranced toiletries or detergent, nor have residues of other chemicals on their clothes, hair or possessions. Some people may need them to change into specific clothes kept for them or to wear a disposable coverall. Carers & visitors may need to wear protective gloves supplied by the sufferer.

- Visitors may be asked to use a certain chair, which may have a protective cover on it, &/or be asked to leave their coat or belongings outside or on a protected surface so as not to contaminate the home.

- They may need to use air purifiers. It is important to realise that air purifiers have limitations eg someone may react to chemicals faster than an air purifier can deal with them, an air purifier does not get rid of everything which may affect someone, some people can not tolerate the filters. In addition they may be unsuitable for someone with ME eg too noisy for their noise sensitivity, too much air movement, photocatalytic ones may be too bright for their light sensitivity. For severely Chemically intolerant/sensitive sufferers they are most useful to clear air after a source of chemical has been removed, but for the less severely affected they may help to keep levels tolerable. In addition, air-purifying masks may not be an alternative option if they are unable to tolerate the materials it is made from or not be able to breathe strongly enough to draw the air through the filters.

- They may only tolerate specific food or organic foods. They may need to avoid processed foods & additives.

- They may react to tap water & need bottled natural mineral water or spring water to drink & cook with, or use a water filter or purifier (if tolerated). They may need a water purifier (if they can tolerate the filter) for bathing water.

- They may react to plastics, cardboard or other wrappings, &/or the chemicals absorbed/adsorbed to them from a shop or warehouse & need to decant shopping straight away out of its packaging into their own storage containers.

- They will need to research in detail the ingredients & composition of products- whether toiletries, clothing, furniture, furnishings, home maintenance etc. & then carefully test anything. Finding things that they can tolerate can take months or even years & be frustrating, despairing, exhausting & costly.

- They may be unable to tolerate a public environment. They will usually need to have had it checked out first.

- Those whose ME does not make them totally housebound may need to keep specific clothes to wear when they go out (washing doesn't always remove everything they may absorb) & to be fully covered, including their hair & hands. Most need to change & bathe & wash hair afterwards & this can prevent them being able to go out if they don't have energy or help for this as well as the energy for the trip itself.

- They may be unable to tolerate a doctors surgery or hospital with the chemicals used & from other people, & need home visits. Or those less severe may need to reduce the exposure when attending a surgery eg a time when few other people are there or before cleaning products have been used that day. In hospital they may need their own room with their own bed sheets, where they are away from other peoples clothing, toiletries, air fresheners etc & can possibly plug in their own air-purifier.

- They may not be able to use public transport &/or have difficulty travelling in a car from the materials of the car or engine fumes coming through air vents or exhaust or other fumes with the window open.

- Chemical intolerance/sensitivity can make someone housebound even if their other ME symptoms don't.

- They may experience financial strain. It can become very expensive for those who need to eat organic food, buy quality nutritional supplements; use natural &/or organic toiletries, bedding, clothes etc; have bespoke items made (using materials they are least affected by), or bespoke repairs done to their home, &/or purchase suitable one-use protective gloves/coveralls for themselves &/or carers regularly. They may also need support about the fact that their unusual costs are a necessity, (not an eco-choice) if being financially assessed for social care.

Daily living with Chemical intolerance/sensitivity can become complicated, very time-consuming, & physically & mentally demanding. Those with ME, particularly if severe may need help both with the extra physical tasks & with the research. In addition those who have limited communication ability may need someone to explain & ensure understanding by carers, landlords, tradesmen, medical staff & others. Emotional support is also important.