

## **Kathy's MCS/ES Info**

### **MCS NEWS**

I know some of you are unable to access or follow MCS news so I want to briefly let you know that there have been some major achievements on the International level this year thanks to the Environmental Health Association of Canada & the Environmental Health Association of Quebec.

1) In March they presented a brilliant report on MCS to the United Nations Committee on the Rights of Persons with Disabilities resulting in MCS being recognised by the UN & included in the UNs report on these Rights.

2) In May they hosted an event to reflect on the above & discuss how to use it to advocate for the next phase of change for MCS. They presented that the UNs inclusion highlights the global acknowledgement of MCS & lays the foundation for advocacy & systematic change to integrate MCS into areas of public policy eg housing, healthcare & employment, & to ensure MCS is incorporated into legislation & accessibility standards.

3) In May, EHAC & EHAQ also hosted the 1st International Conference on MCS to advance scientific understanding, encourage collaborative research & foster systematic change, with experts from around the world who are involved in medicine, research, frontline advocacy, policy making, law & other fields making presentations.

On an international level the goal was to advance recognition & support for MCS. Day 1 focussed on the scientific legitimacy of MCS & then addressed diagnostic challenges & emerging clinical biomarkers that could improve recognition & treatment strategies for MCS. The aim of this evidence-based approach was to consolidate MCS as a legitimate health condition & to advance scientific & medical progress to improve diagnosis, treatment & medical education.

Day 2 focussed on qualitative research including the prevalence, societal impact & policy challenges of MCS. There were also sessions on legal inclusion, public attitudes, barriers to recognition, bias in scientific research, how scepticism has contributed to stigma & limited support. It ended with a panel outlining the next steps in research, policy & advocacy to drive meaningful change.

## DOES FRAGRANCE CAUSE YOU SYMPTOMS?

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Fragrance affects many people & I have many calls about various issues relating to it. It commonly causes symptoms in **MCS sufferers** & for some it can be the initial trigger that causes their MCS. While fragrance may be one of many chemicals which affect you with MCS, some people are sensitive, intolerant or allergic to only fragrance - they have **Fragrance Sensitivity** a condition in itself, characterised by adverse health effects from exposure to fragrance-containing products. Some people think they have MCS when in fact it is Fragrance Sensitivity they have - a mistake easily made because fragrance is used in thousands of consumer products (not just in things like toiletries & cleaning products) & is not always indicated on labels.

ME sufferers can be affected by fragrance through either **ME chemical sensitivity or intolerance** &/or in relation to **ME smell sensitivity** which causes different symptoms.

### What fragrance is:

Fragrances are mixtures of chemicals intended to produce a particular scent. About 4,000 ingredients are used in fragrance manufacturing & a single synthetic perfume usually contains 50-300 ingredients. 95% of the ingredients in fragrances are petroleum-based VOCs that easily evaporate & disperse into the air. Scented products are not only designed to diffuse into the air but also to linger in it & many scented products also contain chemicals to maintain the longevity of the scent. Chemicals emitted from fragranced products also generate secondary pollutants eg formaldehyde.

There is no regulation requiring manufacturers to disclose specific chemicals used to create the fragrances in their products on the list of ingredients as this is considered proprietary information & they can keep their 'recipe' secret. This is supported by the International Fragrance Association (IFRA), a self-regulating organisation representing the interests of the industry that sets its own code of practice. IFRA has a list of fragrance ingredients on its website titled 'the transparency list' which is reviewed every

5 years, but which ingredients are used in the fragrance in a specific product is rarely disclosed on its label - it just states fragrance or parfum etc.

## MANAGING YOUR FRAGRANCE EXPOSURE

### 1) Fragrance free products

Looking for fragrance-free products to use on yourself & in your home can be confusing & misleading as there is no exact definition of which words should be used on labels so there is no consistency among manufacturers. However, below I describe the common use of terms & things you may want to be aware of.

- **Fragrance** may also be listed as **perfume**, **parfum**, **aroma** or **scent**. These all refer to synthetically-created fragrances.

- **Fragrance-free** should be, & is the most likely to be, free of any artificial or natural scents, including essential oils.

However, in cosmetics there is conflict between whether a label's function is to advise of fragrance allergens, or if its to indicate whether a product has a smell or not. This conflict arises because fragrance materials which are allergens may be used in products other than to produce fragrance, eg benzyl alcohol used as a preservative does not create a smell to the product. Whether such a product is labelled fragrance-free therefore varies between countries depending on their viewpoint.

Be aware that a fragrance-free product may get some cross-contamination from fragranced products produced by companies who use the same equipment & airspace for both & do not decontaminate the equipment & the air in the room between making fragranced & unfragranced products. Also, the packaging to be used for unfragranced products may pick up fragrance, as may unfragranced items without airtight packaging that are stored with fragranced ones. Smaller companies who make natural, fragrance-free products for the sensitive consumer market are most likely to decontaminate thoroughly.

■ **Unscented** should technically also be free of any artificial or natural scents, be odourless or nearly odourless & contain no odour-masking ingredients. However, it is often used to describe what should be called de-scented.

■ **De-scented** contain 'masking scents' ie neutral smelling synthetic fragrances that hide the smell of other ingredients. They are full of chemicals just like smelly fragrance so you will still react to them. Alternatively, some unscented products have the same chemicals that are in a scented product but with an additional masking agent to hide the smell.

■ **Scent-free** may also have used masking agents. Those of you who are only affected by fragrance in relation to your ME smell-sensitivity rather than a chemical sensitivity, may find de-scented & scent-free ok to use.

■ **Essential oils**. These can be used in products instead of or as well as a fragrance. Many with MCS react to these. Limonene, Linalool, Citronellol & Geraniol are common ones used which you may want to avoid. Be aware that the labelling of essential oils is not regulated & some seemingly 'natural' oils may also contain other ingredients you may react to.

■ **Natural fragrance** is made in a laboratory from natural ingredients but the combination of these ingredients is not natural.

■ **Natural** or **Free & clear** does Not mean fragrance-free. Products may contain natural scents which you may react to. (If you have MCS also be aware that products sold as 'natural' can contain chemicals too, often hidden in ingredients lists as they have been combined with a natural ingredient to form a semi-natural one).

■ **Environmentally safe/ Eco/ Natural** products usually offer scented or fragrance-free versions of them.

■ Other than for foods, drugs & cosmetics, there is no law that other consumer products have to disclose all ingredients in them so they do not even have to list the general term 'fragrance' in their ingredients.

- Be aware that some products eg air fresheners, which claim to eliminate odours do not actually eliminate the odours but just mask them using chemicals.

## **2) Air purifiers**

These can be very helpful in removing fragrances from the air, particularly after the source is removed. Check which substances an air purifier will remove & consider the purifying process it uses. If you have MCS, a metal or sealed plastic one (ie plastic that doesn't give off fumes) may suit you best & check whether their internal components are encased (or if their fumes pass into the air) & what any filters are made from (fumes from them will be picked up by the air as it passes through).

### **Their Limitations**

- There is only so much air that can pass through a purifier each minute. They do not instantly remove & keep up with a constant source of a chemical & you may react to chemicals faster than a purifier can remove them. Most

specify a room size they are suitable for & choosing one that's intended for a room larger than you intend to use it in will increase its efficiency which helps. If you are not severely affected, using one while being exposed may keep the amount of fragrance in the air to a level you can tolerate.

- Any filter & purifying system cannot remove all chemicals. If there are specific ones you wish to remove, make sure the purifier will do so.

- If you have MCS & tend to become sensitive to things you are regularly exposed to, you may become sensitive to the filter in a purifier (which you could tolerate at first), particularly if you use it constantly.

- Some people with ES cannot use one. Air-purifying paint on walls etc may be an alternative, but do check their ingredients & purification method (some rely on daylight) & be aware some actually release their own VOCs.

### **ME considerations:**

- If you have noise sensitivity check their noise level. Even 'silent' or 'quiet ones' can be noisy once on a setting fast enough to meet your needs. Cheaper ones can rattle.

- If you have light sensitivity, photocatalytic ones have a lamp in them & some of this light is visible on some purifiers. Be aware that the lamp is needed for the breakdown of chemicals so if the purifier has a low-light or off-light option it will not be removing chemicals as efficiently or at all on these settings.

- If you are affected by air movement this may be an issue, particularly on faster settings.

- You may find one which has a remote control useful.

**NB:** Be aware that many air purifiers do Not get rid of chemicals- they may clear particles eg dust or pollen, other things eg mould, bacteria, be sterilisers or only produce negative ions.

### **3)Masks**

If you are unable to use an air purifier or need protection in a public place these may be helpful.

- The lightest & most comfortable are material ones but make sure the mask is for chemical removal (the majority aren't) & that it will remove fragrance. The filter is often a layer within the material & the whole mask will need replacing when it becomes inefficient.

- There are also bulky gas-mask types available, also known as air-purifying respirators. Again make sure it has the correct filter/cartridge to remove fragrance. The filters usually attach to the mask & can be replaced.

- Remember that while a mask protects you inhaling fragrance from the air, it does not protect fragrance being absorbed by your hair & clothes, or at home by your bedding & other items too, so you will need the energy & ability to wash/decontaminate/change these afterwards (& to clear the air in your home if a visitor is not fragrance-free).

- If you can only inhale quite weakly you may find some hard to breathe through as you have to draw the air through the filters.

- If you have MCS you may not tolerate the materials a mask is made from.

#### **4) Buying goods**

- Shops-** Anything bought from a shop usually has fragrance on it- eg from contact with cleaning products used on shelves, from handling by staff & customers, & from the air. The move towards minimal/no packaging is making this more of a problem as the items themselves get contaminated rather than them being fully covered & the worst of it being on the packaging we could dispose of.

- You may find certain shops better than others to use.

- Items from the middle of piles can have been handled less, have had no contact with surfaces & less air exposure.

- Possibly ask for an item from the storeroom or a new box rather than one that's been exposed in the shop.

- Online** -Buying online where items are sent direct from a warehouse may be preferable, but be prepared to try different companies to find a non-smelly one.

- Scent-marketing is used by some companies so a product may arrive in scented packaging which contaminates the item, so do check this. There is currently a petition on [www.change.org](http://www.change.org) about Amazon doing this. If you would like to add your name to it (literally type your name & submit) the link is: <https://www.change.org/p/urge-amazon-to-cease-use-of-fragrance-infused-packaging-and-using-scent-marketing>

- With the increase in policy of many companies to reuse boxes etc, it can be worth requesting a new delivery box or one which has not contained perfumed products. Small, personal & ethical companies are often helpful with this.

## **5) Treatments**

Some people find either low dose immunotherapy (usually privately by an Environmental doctor) or isopathy (homeopathic approach) helpful in reducing or preventing reactions if caused by a chemical intolerance to fragrance.

## **6) Explaining to others & Having Visitors**

Explaining to & asking other people to accommodate your Fragrance Sensitivity (or MCS) can be a very difficult &/or awkward conversation. As I'm sure many of you have experienced, often people don't take in what is said; aren't interested or don't care; disbelieve or think its trivial; become very defensive about what they use & their right to use it; assume a hostile attitude -indignant or resenting that you are trying to influence their personal identity & choices, or see it as you attacking/criticising them. Sadly, some people even deliberately expose you in retaliation. Many people assume or suggest that all you need to do is plug in an air purifier or wear a mask & don't see why you should be imposing on them.

### **It may help to:**

- Bear in mind the above reactions so you phrase & explain things tactfully.
- Consider the person involved, what you need contact with them for & how often you'll be with them to decide the amount of information you give, the way you present it & the requests you make.
- A long list of 'demands' or 'rules' as many see it, is often unacceptable & deters people from visiting or working for you, or not prepared to accommodate any of it - so consider if you could cope if you request just 2 or 3 things that reduce your exposure the most for people you only have one-off or occasional contact with.
- Politely explain your condition & situation well in advance of a visit & when the person can be attentive. It may help if someone does this on your behalf as it shows others take it seriously & also that it is not just you they answer to.
- If you have a supportive doctor, a letter stating your sensitivity & the accommodating needs may make some people be more careful. (There is usually a charge for this type of letter so it can be useful to ask for a 'To whom it may concern' which you can keep/copy to use again).



- When making requests, explain why each request is necessary so they know there is a point to it.

- Guide them on how to fulfil your requests eg. it may not occur to people who are not sensitive that fragrance is in products eg detergent -it just smells of 'detergent' to them. Also they may think that you are just asking them not to wear actual perfume or aftershave, so say if you mean other perfumed things too.

- It can sometimes help if you can show them written information coming from a source other than yourself. This can give it more credibility & reduce the potential personal conflict.

- Explain the limitations of air purifiers & masks, or why you can't use them (egs see above)- it can show that you have considered alternatives to asking them to accommodate you.

- If its possible & appropriate, ask if you can be your carers/tradesman's 1st job of the day before they pick up scent from other places.

- Some people find a carer willing to change into clothes provided (the time taken is part of the care time) & which the person being cared for keeps & washes after each visit. However, any perfume on the carer's skin from their toiletries or from detergent etc on their undergarments gets in these clothes & may not wash out sufficiently to be able to reuse them.

- Disposable Coveralls to throw away after use are an alternative- If you need visitors to wear a disposable coverall you provide over their clothes & hair, ask if they will be prepared to before confirming the visit. (They are not all made from the same materials & also some may be smelly from the manufacturer or supplier, so find one you can tolerate). The coveralls can be very hot to wear so consider turning your heating down to help the visitor be comfortable & accommodating.

- Warn visitors before they come if you will need them to wear vinyl or other gloves to prevent any fragrance/smells on their hands from contaminating you & your home so that they are expecting this. Providing the gloves yourself is usually best.

Unfortunately I know some 25% members & many other MCS sufferers are unable to find carers who will accommodate MCS or even just Fragrance sensitivity.

Attempts to achieve understanding & accommodation isn't helped by the fact that the UK does not officially recognise MCS as an illness, nor is the UK among the countries who are acknowledging the health impacts of Fragrance - even our health service allows fragrance in its environments & on most staff.

### **Health Impacts of Fragrance**

Around 1/3 of the public report adverse health effects from being exposed to fragrance. Apart from any symptoms it produces in conditions such as MCS or Fragrance Sensitivity, it is known that some ingredients used in fragrance exacerbate or cause asthma, migraine, eczema, allergic reactions, sinus & other conditions, that some are known to be toxic & also that some are endocrine disruptors, carcinogens, neurotoxicants, or developmental toxins. Fragrance is also a common trigger for dermatology patients.

### **Recognition of Fragrance Sensitivity**

For those of us with MCS, fragrance is only 1 substance we may react to, but it is encouraging to see that there is a growing movement towards acknowledging its health issues & the accommodation of Fragrance Sensitivity in society around the world. Having less fragrance exposure would certainly make things easier for us.

- **Surveys** of general populations (including in UK) have shown that fragrance hinders access in society, that the majority of people would not still use fragranced products once they knew they emitted hazardous pollutants & that the majority of people would prefer fragrance free workplaces, health care, hotels & other public places.

- **An Online International Study** of people with fragrance sensitivity has recently been conducted in Germany to show the impact of the condition eg. symptoms, limitations it

imposes on lifestyle, quality of life, relationships, accessibility of public places, attitudes towards us etc. It hopes to use it to raise awareness & that it will provide a basis to propose improvements to the situation.

▪**Fragrance-free Policies** operate in various environments in some countries, implemented through voluntary compliance, mandatory compliance or enforcement. Some extend to chemical-free. Most are in Canada & USA where it is often seen as an accessibility issue. Fragrance-free involves both individuals using the space (as fragrance exposure is like secondary smoking exposure- if a person uses it, it impacts those around them too) & the space itself, making spaces accessible to everyone. Some are successful while other places where policies apply are still not always fragrance free.

▪**Disability** -In certain countries Fragrance Sensitivity can be considered a disabling health condition that is covered under disability legislation. It is often classed as an 'invisible disability' as the condition is not immediately apparent to others.

▪**National Fragrance-free Day** The Asthma & Allergy Foundation based in Scotland promotes this annually in June as perfume & fragranced products are one of the biggest triggers for asthma attacks.

**Our grateful thanks to Kathy for this very helpful information. Please see Group Services, pg31 for details of Kathy's MCS/ES Helpline**