

These guidelines are intended to provide information to people who are likely to visit a person with MCS. The guidelines cover a description of what MCS is, how it comes about and what you can do to help. These are aimed at family, friends, professionals and service providers.

At all times remember that chemically sensitive persons are very sick because they have been poisoned. The reactions are real, they are not imagined. Always treat a chemically sensitive person with dignity and respect because their value and worth as a human being is deserving of that. Treat them as you would like to be treated yourself in that position.

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SECTION 1. Why are these guidelines so important?

The Problem with chemicals

Toxic chemicals are becoming more prevalent in our everyday life; they are everywhere and can be detrimental to all who come into contact with them. All pregnant women need to exercise care when choosing products as some chemicals can affect the unborn. Children and people with chronic diseases and illnesses such as allergy, asthma, eczema, chronic fatigue syndrome/fibromyalgia, cancer are more susceptible to chemical exposures. People who have already developed a chemical sensitivity can react much more strongly to chemical exposures. MCS sufferers are affected to the point where they have had to change their whole lives in order to exist.

Most people with MCS have difficulty obtaining medical help, this includes being transported in ambulances, attending medical facilities and close contact with medical professionals wearing fragrances, ingredients of medications. A lack of understanding of the disease within the medical profession further complicates obtaining viable medical treatment. For example even oxygen delivered through plastic tubing and devices can be a problem.

Levels of pesticides and fragrances in hospitals and on staff are a major deterrent to a chemically sensitive person seeking medical assistance. In an emergency medical help may be very difficult to acquire but sometimes it can be needed and the only person who will know when this outweighs the risk is the person with MCS. Be guided by what they say - this is necessary.

We are all different! The severity of reactions and types of chemicals that affect MCS individuals varies enormously. If you have ever had a headache, sinus attack, watery eyes or rash from a particular perfume, deodorant or cleaning product etc you have had a small taste of how a chemically sensitive person suffers. But for those with MCS the whole world seems to be full of 'irritating' and toxic substances. This is why they endeavour to create and maintain a safe haven at home, specific to their own personal requirements. This is done by trying to eliminate as many contaminants as is humanely possible.

It has in many cases taken years for someone with MCS to clear their homes of products that contain chemicals that adversely affect their health. This is no mean feat, try maintaining a home without being able to use commercially available paints, wallpapers, cleaning products, insulating products etc. Even after years of dealing with the challenges there are difficulties. The home of a person with MCS may be their only SAFE HAVEN from chemical exposures. ***Please respect this space; it has often taken a long time to make it happen.***

If your visit brings with it a number of chemical contaminants, the person may:

Become total disabled, Suffer an asthma attack that is difficult to resolve as the person cannot use medications normally used to treat attacks, Have a major life threatening reaction (anaphylaxis)
Experience a permanent deterioration in their health, a greater degree of sensitivity to chemicals, and probably to an even larger range of products and chemicals.
Be afflicted by pain, disorientation, discomfort, migraine etc.

If you have any questions about chemical sensitivity and the needs of the person you are planning to visit please ask – **BEFORE YOU VISIT.**

Why It Is Important to maintain Social and professional contact

Remember MCS is a debilitating disease that interferes with all aspects of life and isolates sufferers from normal community structure. Social contact is especially hard and can be very demoralizing.

Chemically sensitive persons need personal assistance and company. Some are very isolated. People visiting need to be very careful with their chemical avoidances. If this is not possible it is probably better not to visit at all.

Support from family and friends is always appreciated particularly as it so difficult for 'normal' people doing normal everyday things and using normal products NOT to be contaminated in some way. This can be despite their very best efforts.

Support from professional services is also essential and includes health & allied services, building and household maintenance. As the MCS community ages, the need for aged care services increases and this includes home care providers. While help with cleaning the house maybe required, the headache, breathing problems etc that result from exposure to caregivers fragrance and other chemicals clinging to skin and clothing is definitely not.

If you represent an organisation providing services to a chemically sensitive person, please observe the precautionary measures recommended and ensure that any chemically sensitive individuals you visit are given the first appointment in the day to ensure that no contamination has occurred from previous appointments.

These guidelines may seem extreme but they are vital to someone with MCS. The only chance that some people with MCS get to be seen at their best is when they are not being exposed to chemicals. This may only be achieved in their own safe haven. These havens are not always perfect but they are all chemically sensitive people have and it is necessary for them to protect this place from contaminants brought in by other people.

After visiting someone with MCS you may reconsider what you thought was vital and could save yourself a lot of money spent on Personal Care and Cleaning Products. It may be beneficial to your health to visit a chemically sensitive person in their chemical free environment. You never know maybe your sinus or headache might clear up during the visit!!

We thank in advance those who take these guidelines seriously. It is very much appreciated.

SECTION 2 About MCS

How does MCS develop and who gets it?

There seems to be no age barrier to developing MCS. Indeed the prevalence of childhood

allergies, food intolerances and other sensitivities are increasing. (Poulos, M L et al. 2007)

The exact mechanism of MCS is still debated, but can arise following **SENSITISATION** from

- 1) a single large dose from an **occupational** exposure, **domestic/school** exposure (eg pesticide treatment, home renovations) or **environmental** exposure (eg mosquito treatments, chemical fire), or
- 2) long term exposure to lower levels of chemicals arising through an occupational, domestic/school, or environmental exposure.
- 3) A combination of 1 and 2.

Once sensitization occurs, AND FURTHER EXPOSURES ARE NOT ELIMINATED, the condition can worsen and the number of chemicals that cause adverse health reactions increases until the number and variety are such that the person can no longer live what is considered a 'normal life'. This is known as the 'spreading factor'.

The only known way to deal with MCS is avoidance. This has become a nightmare because of the insidious nature of the chemicals and a community acceptance that these products are both safe and necessary.

Chemical sensitivity is a recognised disability by the Australian government JobAccess Disability Advice Initiative (http://jobaccess.gov.au/Advice/Disability/Pages/Multiple_Chemical_Syndrom.aspx) and the Human Rights and Equal Opportunities Commission (www.humanrights.gov.au). The right of the chemically sensitive to clean air and a safe environment is enshrined in International

Human Rights Charters.

What are the symptoms of MCS ?

People with MCS are unable to tolerate even small amounts of chemicals that are present in the environment – air, water, the food they eat, medications and many consumer products. Following exposure to certain substances, people with MCS will suffer a number of symptoms related to many organ systems. A few examples are

- Respiratory – shortness of breath to severe breathing difficulties,
- Gastrointestinal – nausea, vomiting abdominal pain,
- Skin – rashes, itching etc,
- Neurological – difficulty concentrating, mood swings, headache.
- Musculoskeletal – pain, stiffness,

For more information on Chemical Sensitivity see the ASEHA Leaflet Series – *Chemical Sensitivity – Is there a problem?*

And other ASEHA articles that can be found through the website MCS Information Page.

www.asehaqld.org.au

SECTION 3 Chemicals and Products of Importance when visiting MCS

What chemicals produce adverse health effects in MCS?

Over the last few decades of technological advances, both the number of chemicals in use and the amount of industrial and consumer products that contain them have increased. Chemicals includes solvents, those found in pesticides, herbicides, cigarette smoke, petrol and diesel fumes, chemicals in plastics, printing inks, paints, food additives, colours, fragrances, preservatives to name a few. A person with MCS can adversely react to such chemicals and products containing them.

Everybody is exposed to this huge mixture of chemicals in their occupational, domestic and recreational life. Biomonitoring studies indicate that people are absorbing and retaining chemicals they are being exposed to in the environment; it is not just a problem for those with MCS. The difference in MCS is that these chemical sensitivities are severe to the point that it destroys the ability to have a normal life. This normal life includes such things as, being able to work and earn a living, go shopping, go to school, attend medical and other health facilities, socialise, playing in or attend sporting events, entering a shopping mall. Even buying food and normal everyday products such as toilet paper, shampoo, soaps etc is difficult. Try finding a consumer product that does not contain amongst its many ingredients - fragrance.

The individual chemicals aren't the only problem; the mixtures of chemicals in any one product combined can be many times more toxic than that calculated for each one individually. Some examples of the mixtures in consumer 'fragranced' products are discussed below. Insecticides may contain amongst ingredients a chemical that blocks the enzyme used by the insect to detoxify the active ingredient. This may not be at levels expected to affect human adults, but for someone with MCS who is already unable to deal with the toxin the combination usually exacerbates the problem.

In the context of visiting someone with MCS, the following products and chemicals are of major importance:

- Perfumes/Fragrances in Personal Care Products
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- Laundry detergents containing scents/fragrances
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- Pesticide contamination on clothing or from clothing treatments, insect sprays, pesticide

bracelets and anklets

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- Industrial chemicals which are ubiquitous and used in large variety of products Eg Formaldehyde.

- Contamination maybe present on clothing from laundry detergents, fabric treatment or dry cleaning, shoes, accessories such as hand bags.

Perfumes and Fragranced Products

For the majority of MCS sufferers components of fragrance and fragranced products can cause debilitating symptoms. Fragrances and fragranced products are a major detriment to building access and the provision of services to persons with MCS.

Fragrance and fragranced products are extremely difficult to avoid. They contribute to indoor air pollution and can cause **sick building syndrome (SBS.)** SBS can cause headaches, irritation to the throat, eyes and nose, dizziness, poor concentration and memory recall, fatigue and chemical sensitivity.

There are numerous types of synthetic and 'natural' fragrances used in consumer products. Synthetic musk compounds are cheap and used widely. 'Natural' Essential oils are volatile compounds that can also trigger reactions in chemically sensitive persons (they are also used as industrial solvents). The 'inert' chemicals present in cosmetics, fragrances & fragranced products (eg solvents, colours, fillers & preservatives) are also a major source of exposures but this time 'hidden' in the ingredients list. Some are known to be sensitizers and allergens.

Fragrances are also specifically designed to last and because of this they will linger on cloth materials and take weeks, months, or even years to fully dissipate.

Common Fragranced Products

- Perfumes, Aftershaves
- Deodorants
- Cosmetics
- Tissues
- Household Detergents
- Laundry Products
- Toilet paper
- Some stationary
- Hand creams
- Suntan lotions/Sunscreens
- Talcum powder
- Air Fresheners
- Deodorising products
- Garbage bin liners

For more information on fragrances see the ASEHA Leaflet Series – *About Fragrances, Did you know!; Indoor Air Pollution* and *Allergy and Your Skin*

Pesticides

Uses for pesticides have also increased and now include garbage bin liners, in paints, in wallpaper as well as insecticide sprays, baits, lawn and garden treatment. Pesticides and herbicides are used in public buildings, access areas, parks and road verges, during summer

months the use of these chemicals significantly increases. For more information on pesticides see the ASEHA Leaflet Series – *Pesticides – They're Everywhere*.

Industrial/ Ubiquitous chemicals – Example formaldehyde

Formaldehyde sensitivity is common amongst MCS individuals and the chemical is ubiquitous – it is used in building products, clothing, perfumes, glues, fabrics. Many internal furnishings are made from chipboard which outgases formaldehyde, especially in kitchens. For more information on environmental toxins see the ASEHA Leaflet Series – *Impact of Environmental Toxins on Children* and the ASEHA article *Formaldehyde in Clothing*.

Why is using your own discretion in choosing suitable products not a good idea?

Ingredient labels don't always help to avoid chemical sensitisers.

Consumers generally rely on product labels to assist them to make an informed choice, but labels are not necessarily helpful in this regard as not all ingredients are listed. Here are some pitfalls to consider as ***all of these types of products will cause adverse health effects in individuals with MCS***

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Fragrance and other consumer products may consist of formulations that are trade secrets and are not required to be listed on the ingredient label.

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Other Ingredients not required to be listed on labels are those in concentrations lower than one percent.

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Products can *still* be labeled 'unfragranced', 'fragrance free' or 'unscented', if the 'fragrance' is used as a masking scent. Surprisingly some 'fragrance free' labeled products will have fragrance in the ingredient listing.

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Reading all **ingredient** labels carefully is essential. Some products e.g. paints, are labeled 'hypoallergenic' or 'low allergy', these may contain

less

solvents or additives but they are not entirely eliminated. There is no guarantee that products with these labels are safe for someone with allergy or chemical sensitivity.

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Fragrance is not the only problem for MCS and just because something is fragrance free does not mean it is safe. A prime example of this is the new insecticide spray Aeroguard that is 'fragrance free'. Without a good understanding of MCS a 'visitor' may use this product thinking it would be acceptable, after all it's fragrance free – but this would be a disastrous mistake!

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If in doubt about any products always ask before you visit. Do not trust your own instincts

SECTION 4 So what can I do?

Tables 1 and 2 provide a basis on where to start. You can check through the lists of things that can result in an adverse reactions and eliminate a large proportion of contaminants. As these are generalized guidelines final recommendations should be sought from the person with MCS. Everyone is different.

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The best way to avoid a problem is to consult with the person with MCS you are planning to visit for guidance.

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Not all chemically sensitive individuals react to the same chemicals; these vary from person to person as do the type of reactions experienced.

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These guidelines can be less daunting when the list of safe options is considered.

The information you may require from them includes

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Specific chemicals and products that will trigger a reactions;

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Precautionary measures you need to take to ensure that your visit does not cause any adverse health reactions;

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A written list of tolerated products that are safe for you to use for the visit and where you can obtain these;

General precautions to be taken for all MCS individuals

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Refrain from wearing any **perfume or fragranced products**. The person you are visiting may have an exquisite degree of sensitivity and while you may not detect any odour, it is possible that your presence can trigger a severe reaction. Even a mild odour can trigger major health problems.

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Do not bring any personal care products or other unnecessary items into the house when you visit.

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NEVER rely on your own judgement as to whether a product is safe to use or not, ask the person you are planning to visit.

If you are a *regular* visitor to a chemically sensitive person it may be best if you always use the same products the chemically sensitive person uses and leave a change of clothes there so that you can shower and change when you arrive. These can be laundered by the chemically sensitive person to ensure they are not a problem.

Remember at all times you may be using a product that can threaten the life or welfare of a severely sensitive person so **please** adhere to the tolerated products list and instructions given. If for some reason this is not possible, then alternative arrangements should be made to ensure the safety of the individuals with MCS.

The scent from fragrance or fragrance containing products linger on clothing and body (hair) for several days after use and will be discernable by the chemically sensitive person you are planning to visit. You need to use products from the list provided for several days prior to the visit.

Table 1. PERSONAL CONTAMINANTS CHECK LIST

Check List

What To Avoid

Alternatives

Personal Care Products (PCP's)

Perfumes and commonly used fragranced products

“ toilet soap and other toiletries,

“ skin care products, including pharmacy products,

“ ‘natural’ fragrance or essential oils,

“ cosmetics,

“ sunblock,

“ aftershave,

“ deodorants,

“ toothpaste,

“ hand and hair care products.

“ Pesticide treated anklets and bracelets.

The categories below -	Hair	,
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Remove any pesticide treated bracelets or anklets for several days prior to visit

Do not use any spray or roll on personal insect repellents prior to visit.

Hair

Hair care products include	hair colouring	,	m
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Prior to your visit, shower thoroughly and wash your hair in water only or with tolerated personal care

Do not visit a chemically sensitive person if your hair has been permed in the last month unless you have

Hands

Fragranced hand care creams and products.

Nail polish should be avoided for several days prior to your visit as it contains

Do not use fragranced hand care products for several days prior to visiting.

Hand care products can be replaced with unfragranced sorbolene or aqueous cream.

Cotton gloves may be worn as a precaution to ensure that there is no odour on your hands from frag

Deodorants

Most **deodorants contain fragrance** or other harmful components.

Deodorant chemicals can be absorbed into clothing

Bicarbonate of soda (all supermarkets) and crystal rock or crystal liquid deodorants are safe choices.

Some unfragranced underarm deodorants are available from supermarkets, pharmacies and health food stores.

Cosmetics

Cosmetic products maybe fragranced or contain other substances that can ca

Do not use any skin care products, moisturisers, foundation of any type, face powder, lip gloss or lipst

Medications & therapeutic products

Some **nasal sprays** contain oils and other ingredients

Liniment and other **medicated creams.**

Please check with the person you are visiting whether any products you are using are problematic.

Breath

The odour from the **toothpaste** or b

Bicarbonate of soda or calcium powder should be used in place of toothpaste on the day of your visit.

Do not chew mints or other sweets that will leave any odour on your breath.

Breathe fresheners should also be avoided several days prior to the visit.

Clothing

New clothing may be treated with **formaldehyde** for a variety of reasons

Laundry detergents contain fragrances that persist on the clothing for a long time and can 1. cause immediate acute reactions, 2. result in longer term problems from the absorption of the chemicals onto the persons furnishings and 3. outgas and persist in the indoor air environment.

Clothing that has been stored in **moth balls**, these contain naphthalene.

Dry cleaned clothing as the solvent used is very toxic to chemically sensitive individuals.

Some fabrics such as wool and synthetic materials can also trigger reactions.

Clothing that has been worn during **pesticide or herbicide applications**

100% cotton clothing is the safest fabric to wear during the visit. Organic cotton is best as it is not treated

Most supermarkets now stock laundry detergents that are labelled fragrance free, but this does not always guarantee the product will not contain hidden scents. If you decide to purchase these products check with the person you are visiting.

It is best to wash the clothes you plan to wear in bicarbonate of soda at least three times prior to the visit

Shoes/ handbags

Do not wear shoes or carry a bag **shoe cleaner** treated with any **or** **p**

Leather and **new** **s**

Handbags and wallets are always **contaminated with scented or perfume products** because many who

Leave your handbag in your car to ensure that you do not cause any reactions.

A microfibre or old cotton bag is more suitable.

Pets

If you are bringing your pet for the outside is washed with fragrances, shampoo or treated with pesticide

All	Flea collars	- Herbal flea collars should be treated
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Make sure the dog has not been patted by someone wearing fragranced hand care products when the

If you use a flea collar ensure that you have removed it for several days prior to the visit. If you can s

Printed material

Many with chemical sensitivities **print sensitive** and will be affected by the s

Some paper is treated with **pesticides** , s

Always ensure that any printed material you need to bring to the visit is contained in plastic sleeves.

If you need to write details on paper, ensure that you have a lead pencil rather than an ink based pen

Others

Table 2. ENVIRONMENTAL/ PRODUCT CONTAMINANTS (AVOIDING CONTAMINATION PRIOR TO CONTACT/VISIT WITH MCS PERSON)

Check List

What To Avoid

Alternatives

Shopping

If you have been shopping for a **chemically sensitive person**, ensure **shopping bags** are not contaminated with fragrance.

Sometimes shop assistants use **fragranced** **hand cream** t

Supermarket plastic bags can have strong plastic fumes and some are now perfumed.

Always ask the **chemically sensitive person** for a purse or plastic bag in which to return the change from

If possible **food/grocery items** should be delivered in cotton bags or a plain cardboard box, preferably

Until a **chemically sensitive person** can advise what is tolerated, precautionary measures are necessary

Travel

Public transport. Your clothes, skin, hair and bag are likely to have been contaminated

Own car. New cars outgas

Public Transport: Weather permitting, an outer coat that can be removed and left well out

Own Car: After removing all fragranced products it is best to let the car air well.

Places to avoid prior to your visit

Avoid visiting a petrol station on the day of your delivery or visit

Make your visit the first thing of the day.

Avoid these places prior to your visit, do it on the way home or the previous day.

Occupation

If your occupation is for example

Gardening, you may be contaminated with pesticides & herbicides etc;

Welders use solvents;

Farmers use many chemicals – crop and livestock;

Those working in **public areas** – clothing, skin contaminated with

These chemicals can contaminate clothing and footwear.

Please do not wear clothes, coats or shoes that may have been worn during working hours and become

Others

SECTION 5 References and More Reading

Further information about chemical sensitivity is available on ASEHA's website. Information is also available on fragrances, allergy, pesticides, the adverse impacts of toxins on infants and other related topics. For a detailed review of MCS See *MCS A 2006 Review of the Evidence*. This review lists a number of scientific and medical references, and websites used in the production of these guidelines. ASEHA website www.asehaqlld.org.au

ASEHA QLD Inc is a support group for individuals with allergy, food and chemical sensitivity. It is a volunteer organisation that offers information, encouragement and support to individuals with allergy, food and chemical sensitivity, chronic fatigue syndrome, fibromyalgia and attention deficit hyperactivity disorder. ASEHA engages in systems advocacy and occasional individual advocacy.

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