

***Some points for managing your hospitalisation By Dorothy M. Bowes\* June 2004.***

*Facing hospitalisation and surgery can be very daunting for individuals with allergy, food and chemical sensitivity. Some individuals are so sensitive, that leaving their homes puts them at risk of exposure to substances to which they are sensitive. Such individuals will not always allow themselves to be transported to hospital, as it is a hazardous environment for them. Normal things in the hospital such as chemicals used for infection control, flowers in wards, visitors wearing fragranced personal care products and carpets can provoke allergic or chemical reactions. Further these can all be recycled via the air condition system to produce poor indoor air quality. When faced with a health crisis, the need for a clean environment is paramount for a full and rapid recovery.*

Following a complaint before the Human Rights and Equal Opportunities Commission the Royal Brisbane Hospital acknowledged the existence of Multiple Chemical Sensitivity (MCS) by devising protocols for dealing with such patients in the hospital (Queensland Government. 2002). While recognising MCS, these protocols also acknowledge there are measures the hospital can take to mitigate some of the problems caused by chemicals and allergens in the hospital environment, along with their duty of care to MCS sufferers

Until now, disability access to hospitals for MCS sufferers has been a problem, central to which has been the failure of the health care system to accept MCS as a legitimate disability. Recent events have put the MCS protocols devised by the Royal Brisbane Hospital to test, with some surprising results.

Recently, a patient with allergy, food and chemical sensitivities asked for the protocols to be applied and was successful in this endeavour. This patient's problems had been not been taken seriously by the treating GP some years previously and the problem became serious requiring hospitalisation for emergency lifesaving surgery.

Many doctors do not take MCS patients seriously because of a belief system that has become entrenched in the health care system and allied services. Patient claims of chemical illness and injury are usually discredited with the emphasis placed on psychological diagnosis and treatment instead. This injustice, was headed by the Chemical Manufacturers Association which encouraged the formation of a coalition of manufacturers of pesticides, soaps and detergents,

along with medical associations, insurance companies, the aerospace industry, automobile manufacturers and others who 'have an interest in placing environmental illness (MCS) in its proper perspective' (Hileman, B. 1991). This has happened in spite of material safety data sheets and credible scientific data to support chemical illness and injury/sensitivity, including our own [Worksafe Standard](#).

MCS is now synonymous with Chronic Fatigue Syndrome (CFS) in many medical practices and is thought to be a symptom of depression or some type of somatisation disorder (all in your mind). Once this goes onto medical records, it is almost impossible to be taken seriously and get proper health care. The end result of this can be a life-threatening cancer or some other severe illness requiring surgery and intensive treatment that would be avoidable if a proper diagnosis was made early in the course of the illness.

MCS is a recognised disability, which makes disability access to health care facilities a right. The Royal Brisbane Hospital have recognised their responsibility to provide disability access for individuals with MCS. And should you require hospitalisation in the Royal Brisbane Royal Women's Hospital, these protocols will provide you with some protection, but do not go far enough. If the hospital will not apply the MCS protocols, MCS is also recognised by the Human Rights and Equal Opportunities Commission (HREOC) and provided for in the Disability Discrimination Act. Complaints of disability discrimination can be made to HREOC. (Personal correspondence) [www.humanrights.gov.au](http://www.humanrights.gov.au)

Testing the Royal Brisbane Hospital MCS protocols revealed they can be applied and:

- Should provide access a single room as a public patient
- special needs surrounding allergy, food and chemical sensitivity should be met
- special medication needs observed i.e. allergy, sensitivities and previous adverse reactions
- disability access to a fragrance free environment must be provided if these cause disabling symptoms
- disability access to a pesticide free environment should be provided if these cause disabling symptoms

At all times refer to the application of these protocols as disability access.

While all of this should be possible, the experience was that the fragrance free, pesticide free environment is not possible and there is no food suitable for MCS sufferers available from the hospital kitchen i.e. no organic, preservative or additive free food available. If you suffer severe reactions to food contaminated with additives, pesticides and other chemicals, you will have to provide your own food. If you are sensitive to carpet, there is no such thing as a room without carpet and the hospital air quality was sufficiently poor to provoke severe reactions in a short space of time (almost instant).

## **PREPARING FOR YOUR HOSPITALISATION**

***The following list will assist you to develop your special needs:***

Ask for the MCS hospital protocols to be applied - you should have a copy of these and may need to produce them. Should you experience problems with this, contact the Executive Director of Medical Services.

Ask your primary health care practitioner i.e, GP, Environmental Medicine Practitioner, Allergist to contact the hospital to ensure the hospital takes you seriously. Dialogue between these is desirable for the choice of a suitable anaesthetic and instructions re medications. It may also become essential if problems arise.

Ask for the first appointments on days you have to attend the hospital for tests, diagnosis, explanation of procedures

Ask for the first appointment in the operation theatre to avoid a build up of anaesthetics, fragrances worn by staff and disinfectants

On the pre-surgery visit ask for the following to be present at the consultation: nurse in charge of special needs, anaesthetist, senior pharmacist, dietitian, physiotherapist, social worker or necessary therapists.

Ensure the senior pharmacist is involved and all medication prescribed is done in consultation with the pharmacist and yourself. If in doubt, contact your primary health care practitioner.

Ensure the dietitian is available prior to hospitalisation in case home-prepared food has to be provided. Not everybody has family support to ensure assistance with this so time prior to hospitalisation is of the essence. It would be advisable to contact your own dietitian re suitable food for the recovery period.

A list of allergens, food and chemical sensitivities, known reactions to medications and medical aids must be compiled and provided to the hospital. This must be in writing and test results to document these should be provided if available.

## **Disability Accommodation Needs:**

Allergy to dust mite, mould, pollen and fragrances preclude a patient from a shared ward or a carpeted room. Ask for a single, uncarpeted room. This should be routine for allergy and MCS sufferers.

If you are allergic to fragrances, all staff dealing with you must be fragrance free.

While the hospital is a cigarette smoke free environment, it is not a fragrance free environment. The fragrance free issue is the same as the cigarette smoke issue. Fragrances are composed of some very nasty toxic substances e.g. neurotoxins, carcinogens.

Ensure you are not tended by a smoker

Ensure the room does not contain any fragranced air fresheners, tissues or other fragranced products. You may need to take your own tissue products.

Ask for synthetic substances in your room to be minimised , especially plastics

Be aware that the hand washing disinfectant in the room above the hand basin will be perfumed. Staff may need to wash their hands prior to entering the room if an unfragranced disinfectant cannot be found.

An air filter is likely to be essential if you are bothered by indoor air contaminants. You need to organise this with the hospital prior to admission. If you have to provide your own, they will want to test it first to ensure that it all right to plug into the hospital electrical system.

Check to see if the hospital can provide filtered water - otherwise provide your own.

If you are allergic to latex, ensure latex gloves are not used in you presence or by staff dealing with you

While the hospital is a cigarette smoke free environment, it is not a fragrance free environment. The fragrance issue is the same as the cigarette smoke issue. Fragrances are composed of some very nasty toxic substances e.g. neurotoxins, carcinogens. More information on fragrances can be found at [www.fpinva.org/](http://www.fpinva.org/)

Some patients have asked for a fragrance free hospital environment and this has not been observed. This has resulted in legal proceedings being initiated and some cases have been successful. In the long term, as more people are successful with legal proceedings and the processes of the Disability Discrimination Act, this will bring about necessary change.

***Things that need to happen when hospitalisation occurs***

The staff member responsible for overseeing the hospitalisation should be present during the admission process

The Executive Director of Medical Services who is responsible for overseeing the application of the MCS protocols should be identified and his/her contact details given to the patient should problems arise

All staff members need to be fragrance free when dealing with the patient

The list of allergens, sensitivities and adverse reactions to medications and medical aids must be on the Allergy & Alert Sheet at the front of the medical records. [Health Information Template](#)

As medical records are not always locatable, extra copies of the Allergy & Alert Sheet should be available at various locations in the hospital e.g. pharmacy, with the patient at all times, in the patients room with the medical charts. ASEHA advises that spare copies of these should be available from you at all times and with you wherever you are in the hospital. The hospital may object on the grounds of confidentiality but your safety is paramount and overrides any confidentiality issues. In plain talk - you need to make sure these are available. You cannot trust the hospital to do this as things sometimes take time to be moved around the system.

A single uncarpeted room should be provided. That room should not have been recently treated with pesticides, fragranced products, strong disinfectants or detergents.

### ***Provision of information***

Successful hospitalisation is a two-way process and there are things you need to do to ensure that problems are minimised:

Ensure your primary health care practitioners contact details are known to the hospital for emergencies

Provide the hospital with a list of your allergy, food and chemical sensitivities and the reactions they cause. Provide test results if available.

Provide a list of known problems with medications and reactions caused

Provide a list of known problems with medical equipment e.g. plastic tubing, corn based dextrose, adhesive tape

It may be necessary to test adhesive tape and suture material prior to surgery to find suitable materials

If you have a history of an occupational exposure and acute poisoning, provide this as well.

Provide a list of known health problems

Stress the need for the hospital staff to consult with you as to whether or not something is likely to cause a reaction. They should consult with you before procedures and use of medicines, topical application of creams etc. If in doubt, or if you are not conscious, they should contact your primary health care practitioner.

Many individuals with allergy, food and chemical sensitivity do not carry a list of their allergens, food and chemical sensitivities with them, nor do they routinely provide these to GPs or other treating practitioners they consult. It is preferable that a full list of allergens, food and chemical sensitivities is compiled for your health care practitioners. Some thought should also be given to registering your list with [Medicalert](#) so that in the event of an accident or some other emergency, a list is accessible.

## **References:**

**Queensland Government. 2002.** Royal Brisbane and Royal Women's Hospital and Health Service Districts.

**Hilemann, B. 1991.** Multiple Chemical Sensitivity. Chemical and Engineering News. July 22:226-42.

**Personal Correspondence. 2004.** Human Rights and Equal Opportunities Commission. Disability Discrimination Commissioner.

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