



Health Care Consumers' Association Inc
100 Maitland Street, Hackett ACT 2602
Phone: 02 6230 7800
Fax: 02 6230 7833
Email: adminofficer@hcca.org.au
ABN: 59698548902

HCCA Response to the Review of the Canberra Hospital and Health Services (CHHS) Multiple Chemical Sensitivity Clinical Procedure

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Contact: Darlene Cox
Executive Director
02 6230 7800

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The Health Care Consumers' Association (HCCA) provides a voice for consumers on local health issues and also provides opportunities for health care consumers in the ACT to participate in all levels of health service planning, policy development and decision making. HCCA involves consumers through consumer representation, consultations, community forums, and information sessions about health services and conducts training for consumers in health rights and navigating the health system.

In 2008, State and Territory Health Ministers endorsed the Australian Charter of Healthcare Rights. The Charter was developed by the Australian Commission for Safety and Quality in Health Care and applies to all people receiving, seeking or delivering health care in all settings in Australia. The Charter was adopted in the ACT in December 2009. HCCA believes that a shared commitment to the Charter will improve the safety and quality of health care for all consumers. Our submission to the Review of the Canberra Hospital and Health Services (CHHS) Multiple Chemical Sensitivity Clinical Procedure is strongly based on the principles and values inherent in the Charter.

The HCCA welcomes the opportunity to provide feedback on the Canberra Hospital and Health Services Clinical Procedure for the care of patients with Multiple Chemical Sensitivities (MCS). We acknowledge the importance of providing quality patient-centred care to individuals living with MCS and commend CHHS on their commitment to MCS patients reflected in having such a clinical procedure.

In particular, we stress the importance of effective communication with MCS patients and opportunities for patients to participate in their own health care, as well as mechanisms to provide feedback on the services they receive. This submission includes some suggestions we feel would further enhance the effectiveness of the CHHS Clinical Procedure for MCS.

This submission has been developed in consultation with our members, in particular with Alexa McLaughlin, who has valuable knowledge and experience in this area.

Health Care Context for Sufferers of MCS

People with MCS get a wide array of complex symptoms from low levels of exposure to chemicals, where these levels would not generally cause symptoms in most people. People who suffer from MCS may have multi-system illnesses as a result of

exposure to a wide variety of environmental chemicals. Diagnosis is often difficult as the existence of and a definition of MCS are not universally agreed. There is also inadequate understanding of causes and effects and how to measure them.

HCCA understands that patients with MCS often become frustrated with health care providers as a result of poor communication and a lack of understanding. Frustration is often experienced by clinicians as well. This can lead to scepticism and a failure to acknowledge and accommodate, to the patients' satisfaction, the difficulties and distress caused by MCS.

Whilst reflected throughout the MCS Clinical Procedure, a more up-front statement of commitment to MCS patients that recognises the need for developing awareness, sensitivity and respect for the needs of MCS would add value to the document. Such a statement would contribute to improving the relationship between CHHS and MCS patients and their carers, demonstrating respect for the individuals' condition and needs, in accordance with the Australian Charter for Health Care Rights.

1. General comments

HCCA notes the good practice of the internal evaluation that has been conducted as part of the review of this policy, including a literature search, review of data and consumer feedback, as well as improvements to ensure readability and consistency with other CHHS policies and procedures.

Consumer feedback has indicated that a number of people living with Multiple Chemical Sensitivities who have been hospitalised at The Canberra Hospital since the protocols were in force have expressed concerns during and after treatment. This is a small number of people but we consider there to be value in monitoring their experience of hospitalisation.

In addition, the procedure provided for review has been difficult to negotiate as it has not been made clear where the changes have been made from the previous version.

It could also be useful in future procedural reviews to undertake to provide some reasoning for the changes made, especially where there is an evidence-base on which the change is made.

Members have indicated interest in reading the internal evaluation of the existing procedure, including citations for any new material uncovered.

One member expressed concern that:

“the main effect of this is to reduce important safeguards for people with MCS, remove evaluation and not do any community outreach”.

However, feedback was positive on the improvements made to the new overall layout of the document, especially with the movement of the care pathways to appendices. We are firmly of the view that when policies and procedures are revised

that the changes are made clear and reasons given for the changes. There are a number of changes which we do not support, especially as the reasons for the changes have not been made.

A key improvement that could be made to the document to ensure its focus on providing quality patient-centred care to individuals living with MCS would be to include modifications to the following paragraph from 'The Patient Experience' (p6), such as:

“Mistrust can be experienced by MCS patients based on prior experience. There can be frustration for both patients and the staff caring for them. Some reasons for this may include lack of knowledge of and belief in MCS by staff as well as the lack of confirmed diagnostic methods and treatments. Mutual respect and compassion can enhance the relationship”.

being moved to the overview as this kind of focus and understanding from staff has the potential to significantly improve the care and experience of patients with MCS.

We note that the scope of the procedure is the Canberra Hospital and Health Services, but the focus of the procedure seems to be emergency presentations and hospital admissions (including planned admissions) – essentially The Canberra Hospital Campus. There is a lack of information included about clinical procedures for MCS patients in CHHS community settings, this could be clarified in the procedure itself.

2. Specific Issues/ section of policy/ consultation paper for review

2.1 - Section 2 - Pre-admission Considerations (page 4)

Due to prior negative experiences, patients with MCS who are not aware of this document may therefore not volunteer information about their condition. Consumers therefore suggest that all patients be asked if they have MCS and the response be recorded.

In the first dot point, the admitting team is responsible for meeting with the MCS patient, and 'where possible' has been added in. For a planned admission, we suggested that meeting with the patient well before the admission could be strengthened to say 'wherever possible', recognising that there may be cases where this is not possible. Perhaps an alternative to meeting with the patient could be a phone call with the patient to ensure an understanding of their pre-admission needs, documenting of all their sensitivities and the severity of their symptoms.

2.2 - Section 3 - Emergency Presentation (page 5)

The first two dot points in this section, referring to liaising with the patient's GP and isolating the patient in a clean room, now say 'if possible', rather than 'wherever

possible' (previous version). We consider the previous wording of 'wherever possible' to strengthen the importance of these activities for patient-centred care.

The change made to the next dot point from 'ideally' to 'Subject to the clinical requirements of managing the condition necessitating admission' was commended as a good change that improves clarity and understanding. This could also be prefaced with "wherever possible".

2.3 - Section 4 – On Admission (page 6)

See earlier comments on 'The Patient Experience' under 'General Comments' in this submission.

The following has been inserted as the last dot-point under 'Risk Assessment' –

"If the patients' reaction is to cleaning products, environmental services are to be contacted to ensure that the room is prepared with *neutral detergent*, prior to the patients admission".

We suggest that 'neutral detergent' should be defined in the document as a starting point, and that consideration be made to the use of simple cleaning agents, such as water, sodium bicarbonate and vinegar for MCS patients, particularly those with a longer-stay admission.

2.4 - Section 5 – Care During Admission (page 6-11)

A change has been made to the first heading in this section from "Required for admission of all patients with MCS" to "Equipment that may be required when caring for a patient with MCS". A consumer commented that they would prefer the original heading. The new title could be confusing in that if only some of the equipment may be required, it is not clear as to who will make the decision, when it will be made, and how the appropriate equipment will be chosen. This could be improved to ensure the appropriate decision making processes about equipment can be undertaken.

The list of equipment has had two additions:

- "fragrance-free cleaning products" – which has replaced "Low irritant cleaning products (i.e. Sodium bicarbonate)". We are interested to know what the reason for this change is and suggest that it is not adequate, particularly since fragrances are not the only irritants for people with MCS.
- "Chlorhexidine wet box" – needs to be defined, noting that Chlorhexidine is a broad spectrum antiseptic extensively used in healthcare environments. There should be some explanation about the possible sensitivity of MCS patients to Chlorhexidine. According to the [Guidelines on the Perioperative Management of Patients with Suspected or Proven Hypersensitivity to Chlorhexidine¹](#), a

¹ PS60 Guidelines on the Perioperative Management of Patients with Suspected or Proven Hypersensitivity to Chlorhexidine, Australian and New Zealand Anaesthetic Allergy Group (ANZAAG) of the Australian and New

“chlorhexidine free box” would contain a copy of the facility’s chlorhexidine free register. It would also contain chlorhexidine free alternatives for common procedures, such as skin antiseptics prior to intravenous cannulation and surgical procedures, lubrication jelly for indwelling catheter insertion and a chlorhexidine free central venous access device. It is useful that the dot points details where the “Chlorhexidine free box” is available to staff.

In addition, consumers have reported difficulties with equipment brought from home, such as air filters. It appears that policy requires that all such equipment should be tested by an electrician and that this can only happen once a month. This should be highlighted to patients so that they can organise this.

Under the heading ‘Patient Accommodation’ (p7), the following dot point has been deleted from the previous policy (and we suggest that this information clarifies an important issue and should be included as modified):

“Note Many MCS sufferers are sensitive to non-perfumed substances making them far more difficult to identify and manage sensitivities to perfumed substances (i.e. perfume, scented hygiene products etc.) are well understood because these are the sensitivities that people with MCS can readily identify. On the other hand, some components of laundry detergents are not perfumed and yet have been associated with severe hypersensitivity.”

On page 9 in information relating to the transport of the patient for treatment outside of the patient’s room, the following information has been taken out:

“coordinate the plan of care with all other hospital departments the patient may be transferred to for treatment and, whenever possible, arrange to have the patient to be treated in his/her room.”

This statement adds value to the procedure and improves the focus on patient-centred care – we suggest it remains incorporated in the document.

Under the heading ‘Initial Cleaning’ on page 9, a dot point has been removed stating:

“time is to be allowed for the room to air”.

We suggest it is appropriate for this to remain included in the procedure.

In the section beginning on page 9 entitled ‘Daily Cleaning of an MCS patients’ room should be minimal but include:’, a change has been made to include dusting with a clean cloth moistened with *neutral detergent*. A comment was made that this was previously a cloth moistened with *water*, and that this was the preferred method for patients with MCS. Other dot points that were deleted but were felt to add value to the procedure include:

Zealand College of Anaesthetists (ANZCA), 2015
{accessed September 2016: <http://www.anzca.edu.au/documents/ps60-2015-guidelines-on-the-perioperative-manageme.pdf>}

- "Use Sodium Bicarbonate for tubs, sinks and toilet", and
- "Wet laundry should be removed from the room immediately after use."

Under 'Dietary Requirements' on page 10, the following statement was removed:

- Patient meal trays should be removed from room immediately on completion of meal.

A comment was made that this statement should be reinstated in the procedure.

We are interested to know the reason for these changes between the existing procedure and this draft procedure. Should there not be compelling reasons for these changes we suggest that they should be reversed.

Under the heading 'Medications' beginning on page 10, it was suggested that the second sentence read:

Standard ingredients of medications should be known as MCS patients *may* react to both naturally occurring and artificial substances including but not limited to: colouring agents, preservatives, sweeteners, flavourings etc. *(to add in 'may')*

It is not necessarily conclusive that all MCS patients react to both naturally occurring and artificial substances in relation to medications.

Under the heading 'discharge' on page 11, feedback indicated that the additions to the list of things that visitors should be advised not to do was helpful. It would also be helpful to advise visitors not to bring flowers or other items emitting volatile substances into the patient's room.

For consistency, we suggest that the first section be modified to:

"All visitors should be as free as possible of:

- perfume or scented hygiene products
- aerosol products such as hairspray
- laundry soaps, fabric softeners, deodorants, shampoo, hair lotions, make-up, hair mousse, gels and bath soaps (which can all contain perfume or masking fragrances and deodorisers, and should be avoided by visitors to patients with MCS)
- new clothing which has not been laundered to remove chemical residue
- clothing which has been freshly dry-cleaned
- having smoked cigarettes prior to visiting or wearing clothing impregnated with smoke.

In addition, the final list under this heading of things that visitors should be advised to do has had removed a statement regarding using protective clothing. Feedback from members suggested that this may still be relevant and could remain incorporated in the document.

2.5 - Section 6 – Discharge (p11)

Under 'Evaluation of Care', the patient can now 'request' a social worker to participate in the discharge planning process, which is more empowering for consumers than the previous wording of 'supported', emphasising the patient's important role as part of their healthcare team.

A significant portion of text has been deleted from this section, as follows:

“Evaluation

Outcome Measures

- All incidents related to care of patients with MCS are reported via the Clinical Incident Reporting System (Riskman).
- There is evidenced compliance against the 'CHHS MCS - Care of Patients' SOP.
- There is reported positive satisfaction from consumers with the care provided by the CHHS as reflected in the 'CHHS MCS - Care of Patients' SOP.

Method

- All incidents related to patients with MCS are reported via the Clinical Incident Reporting System (Riskman). Incidents are reviewed and corrective actions are reported and managed via relevant departments in line with continuous quality improvement processes.
- Teams overseeing the care will, in consultation with the patient (family/carers) review and evaluate the care provided against the 'CHHS MCS - Care of Patients' SOP.
- All MCS patients will be provided with a consumer feedback form to facilitate further improvements. Patients will be encouraged to identify themselves as an 'MCS' patient on the form (they will have the option of not doing so). This feedback will be managed by the Quality and Safety Unit - Consumer Feedback & Engagement Team and clinical care team members and management.”

Feedback from consumers suggested that this information may not have been implemented in the past and was critical to include. We suggest that this information be re-incorporated in the document.

The paragraph on 'Discharge Planning' (p12) is a good addition to the document to remind staff of the importance of discharge planning for patients with MCS.

2.6 - Implementation Section (p12)

Whilst a range of suggestions have been made for the implementation and dissemination of the MCS Clinical Procedure, there is value in circulating information in the community. It would be good to include information on the ACT Health website as well as undertake targeted communication such as consumer briefings. HCCA would be interested to work with ACT Health on this.

2.7 - Related Policies, Procedures, Guidelines and Legislation (p12)

There are a number of deleted policies/procedures that have been deleted at page 12, we question whether these policies could remain included, (or could you advise why they have been removed).

- “Adverse Drug Reaction Reporting SOP TCH11:005” (this has perhaps been superseded by the CHHS Medication Management Policy?)
- “Latex Allergy – Patients SOP TCH11:037”
- “Personal Protective Equipment SOP TCH11:034”
- “Waste Management Policy CED10-046”

2.8 - References (p12)

It would be good to again check the list of references for standard referencing formatting and to ensure active links.

In particular, the following addresses are correct but the links don't work:

www.aessra.org/

<https://www.nicnas.gov.au/chemical-information/information-sheets/factsheets-on-specific-topics/multiple-chemical-sensitivity-review-factsheet>

In addition, the link for document 5, Fitzgerald, should be:

[http://sacfs.asn.au/download/Fitzgerald%202008%20EHJ8\(3\).pdf](http://sacfs.asn.au/download/Fitzgerald%202008%20EHJ8(3).pdf)

And the link for document 11, *Guidelines for South Australian hospitals*, should be:

<http://www.sahealth.sa.gov.au/wps/wcm/connect/a7da1b004754557a8a71fa2e504170d4/MCS-HospGuidelinesLicensed.pdf?MOD=AJPERES&CACHEID=a7da1b004754557a8a71fa2e504170d4>

Further, the author for item 6, *When the Hospital Makes You Sick*, is Catherine McIver.

Concluding remarks

Please do not hesitate to contact us if you wish to discuss our submission further. We look forward to seeing how the consumer feedback from our submission is

incorporated in the final procedure. Given the nature of suggestions we have provided, we would welcome the opportunity to comment on your final draft prior to it being implemented.