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Re: Review of Clinical Procedure for Idiopathic Environmental Intolerance / Multiple Chemical Sensitivity

The Health Care Consumers' Association (HCCA) is a health promotion charity and the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation, and consumer and community consultations,
- training in health rights and navigating the health system,
- community forums and information sessions about health services, and
- research into consumer experience of health and social care.

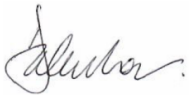
HCCA is a member-based organisation and for this submission we consulted broadly with our members, including our Quality and Safety Consumer Reference Group. We received feedback from a number of consumers, including those with lived experience of Multiple Chemical Sensitivities.

HCCA welcomes the opportunity to provide consumer input to the Canberra Health Service review of the Clinical Procedure for Idiopathic Environmental Intolerance/Multiple Chemical Sensitivity (IEI/MCS). We acknowledge how important it is to provide quality, patient-centred care to individuals with IEI/MCS and commend the commitment of Canberra Health Services (CHS) to having a clinical procedure for this purpose.

We particularly highlight the importance of effective communication with consumers with IEI/MCS, and opportunities for shared decision making in health care, as well as mechanisms for providing feedback on care received.

Our submission, along with a copy of the procedure including comments and tracked changes, is attached.

Yours sincerely



Darlene Cox
Executive Director
14 February 2020

HCCA Submission:

Review of Clinical Procedure for Idiopathic Environmental Intolerance / Multiple Chemical Sensitivity

Submitted 14 February 2020

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Review of Clinical Procedure for Idiopathic Environmental Intolerance / Multiple Chemical Sensitivity

General Comments

Consumers with IEI/MCS can experience a range of complex symptoms from even low levels of exposure to chemicals and other triggers, such as light, sound, touch/feel, and smell, where these levels of exposure would not generally cause symptoms in most people. Those suffering from IEI/MCS often experience multi-system illnesses as a result, and diagnosis is often difficult as there is not a universally agreed definition for this condition.

HCCA recognises that consumers with IEI/MCS can become frustrated with health care providers, due to poor communication and a lack of understanding about their condition and symptoms. Health professionals can experience similar frustrations. This can lead to scepticism and a failure to acknowledge, to the patients' satisfaction, the difficulties and distress caused by IEI/MCS. There is a need to continue to need to develop awareness, sensitivity and respect for individual experiences of this condition. This is an important area of care in which to recognise the role of shared decision making, in line with both the National Safety and Quality Health Service Standards[1], and the Australian Charter of Health Care Rights[2].

In our submission to this procedural review we provide some suggestions for further enhancing the effectiveness of the CHS Clinical Procedure for IEI/MCS.

We commend CHS on having made the Clinical Procedure for IEI/MCS publicly available, but acknowledge that while it can be found online through a Google search with the correct terms, it is not easily located at www.health.act.gov.au. It is important that this be rectified, in terms of communicating the clinical procedure to consumers.

We also think there is value in making available a fact sheet for IEI/MCS patients to share with visitors and/or their health professionals, around the details provided at p13 of the procedure.

There is no mention in the procedure of the intention of Canberra Health Services to communicate the review and updated procedure to staff, once this is complete. We suggest that this be considered as part of the process of continuous quality improvement.

[1] https://www.safetyandquality.gov.au/standards/nsqhs-standards
[2] https://www.safetyandquality.gov.au/australian-charter-healthcare-rights

A Consumer Story

This case study, provided by one of our consumers during consultation, and with permission to be shared, highlights that the definition of Idiopathic Environmental Intolerance **needs to be expanded to include not just chemical or physical agents but also sound (frequencies not just volume), smell, light, touch, etc.**

I have an extreme hypersensitivity to sound which does not have a simple identifiable label and my medical specialist has defined it by its symptoms and tests: Central & Sympathetic Nervous System with low Parasympathetic drive over-reaction to a physical reaction caused by high & low sounds, and sound vibration. Sound or vibration trigger > SNS response > further lowering severely compromised PNS > body overreacts to amount of chemicals SNS produces = swelling throat muscles, constricting airway; random loss of muscle tone; intense pain; and other symptoms.

My inability to breathe is often mistaken for a panic attack instead of an anaphylactic reaction. I can not use an Epipen as it is the amount of chemicals my body (SNS) produces that causes a reaction. The pain and other symptoms can resemble a stroke or heart attack and admittance to Emergency Departments exacerbates symptoms. Hospitals by their nature have equipment producing sounds which set off or intensify a reaction.

In relation to this draft document my comments are based on attendance at emergency, and outpatient departments, with little or no acknowledgement of my hypersensitivities and misdiagnosed as panic or anxiety without the appropriate treatments administered.

My most recent attendance to an Emergency Department was two weeks ago following a fall during the night and breaking my foot, and then later on coping with a hypersensitivity flare-up which was not understood nor appropriate action taken.

The ambulance and night doctor and nurses were considerate of my sound, hyperalgesia, and allodynia conditions (didn't use bp machine as the bing noise would have caused anaphylactic response). My husband would normally have been with me however as the night staff accepted my hypersensitivities I felt reassured so he was able to reorganise elderly family members who were still in an evacuation centre now without a carer. However the day staff responded to my reaction to the high-pitched sound from an oxygen pak as panic, and I was told to expect emergency departments to be noisy. Not only did I have broken bones and other injuries but also compromised breathing, and a total body pain condition that had also been exacerbated. The situation I have described was during a natural disaster emergency when priorities change and availability of resources are limited. ***The point I am making using my situation is that hypersensitivities extend beyond chemicals and my comments throughout this draft reflect all environmental triggers – and all staff need to be aware of a patient's condition, and the immediate response required.***

Comments on Specific Sections of the Clinical Procedure

Purpose

This section mentions common triggers, it would better read 'common and more nuanced triggers'. A consumer commented that:

> *More nuanced/subtle incitants/triggers should also be considered, not just the most obvious/common. With MCS there is no one size fit all to what a person may react to. Also, 'chemical overload' needs to be considered whereby someone might not necessarily react to exposure to one chemical at a particular time but if also exposed to one or several more chemicals/triggers or certain foods, even days later, it could push someone into reacting – a domino effect.*

Alerts

We received consumer feedback that it is important for staff, when providing care to a consumer with IEI/MCS, to remember that exposure to triggers may not only result in considerable distress but that it can also exacerbate multiple conditions – so that concerns must be taken seriously and modifications to the environment undertaken wherever possible. It should be noted that the exacerbation of any conditions may not have a diagnosable label, but be defined by the symptoms.

Section 1 – Background, triggers, and common symptoms for IEI/MCSAlerts

On p2 of the procedure, there is mention of 'environmental chemicals'. We suggest the addition of 'including chemicals from natural sources'. A consumer told us that there is a common misperception that *if it is natural, it cannot harm you – hence 'natural' needs to be spelt out.*

Further in this section on p2, it would be worthwhile amending the sentence about debilitating symptoms of IEI/MCS to read 'The symptoms experienced by consumers are diverse and reported symptoms can, in some cases, be highly debilitating both physically and/or psychologically'. A consumer commented that a

> *.. person can appear to be psychologically fine overtly but psychological reactions are evident to person themselves and/or to others who might notice that the person is not quite like their usual self [not necessarily evident to staff within a health service who may not be familiar with the 'usual self' of a particular consumer]. These psychological reactions are just as debilitating as physical ones.*

Additional triggers to the 'common triggers' list on p3 include:

- *fragrances (natural as well as artificial), aftershaves, haircare, essential oils, cosmetics, body sprays, hand creams/lotions, face/body moisturisers, newly applied nail polish*
- *home laundry detergents, fabric softeners/conditioners*

- *moulds*
- *bathroom/toilet air fresheners and/or deodorisers*
- *scented toilet paper*
- *plastics [remembering that whether new or old they can continue to outgas]*
- *sound, light, touch**

**Syndromes such as fibromyalgia, chronic fatigue, chronic pain can be exacerbated by environmental hypersensitivities* making standard approaches to treatment less effective.*

Common symptoms of exposure to incitants (p3-4)

We suggest removing 'depending on the degree of exposure'. A consumer told us that in their experience

> *The degree of exposure doesn't always determine the severity of symptoms. Exposure, even for a minute or less, can cause quite severe reactions. Also, reactions aren't always immediate. They are frequently delayed and may not manifest until many days after exposure.*

A consumer also noted that it may not only be exposure to incitant chemicals and/or substances that might affect those with IEI/MCS, triggers can also include sound, light and/or touch.

We also suggest adding in that '*It is important to keep in mind that these symptoms are not always immediate but can be delayed, even up to a week after exposure'*. The list of common symptoms should add in the following additional symptoms:

- respiratory symptoms*, not to be confused with panic or anxiety attack*
- '*migraine'* along with headache'
- *'mood swings'* along with irritability and depression
- *blurred vision*
- *low tolerance to stress*
- *sleep disturbance*
- *light and noise sensitivity*
- *reduced tolerance to other known triggers (incitants) and also to otherwise tolerated substances*
- *heightened sense of smell*

The paragraph about the severity of symptoms could add that:

> *It is important to note that after exposure symptoms frequently cannot be mitigated and take their natural course regardless. The duration of symptoms due to exposure is unpredictable and can continue for several days, if not longer.*

However, while this can be the case, it is still worthwhile making every effort to remove an offending substance for a consumer with IEI/MCS.

The final paragraph in this section discusses 'mutual respect'. We suggest that it is important to add the following information (below), as consumers with IEI/MCS are

more vulnerable to a changed environment, and the same high anxiety they experience with reaction to substances can also lower their tolerance for other incitants.

> *It is, however, important to be aware that consumers' reactions to substances commonly cause fight/flight/freeze responses so consumers' capacity for 'mutual respect' etc. could be compromised as a result. In addition, the high anxiety/stress of being (or the prospect of being) in an environment in which consumers are particularly vulnerable to exposure can also trigger fight/flight/freeze responses which in turn will impact on consumers' capacity for 'mutual respect' etc.*

Section 2 – Preparation for Planned Hospital Admission

We suggest that the sentence about meeting with consumers before the admission date be expanded to read"

> *In advance of the admission date, the admitting team is responsible for coordinating a meeting with consumers with IEI/MCS where they will discuss a respectful partnership and create a personal care plan.*

It is important to recognise that notice of the meeting should be given well in advance for consumer with IEI/MCS so that there is time for the consumer to collate their needs in a less stressful environment. The ideas of mutual respect from the previous section also apply well to the concept of a 'respectful partnership' between consumers and health professionals.

One of our consumers told us, in terms of documented alerts in ACTPAS for IEI/MCS (described at p5), to ensure that we highlighted that:

> *The 'My Health Record' isn't reliable [for complete health information on a patient with IEI/MCS, it can give an]: incomplete patient profile for conditions, treatments, medications, pathology, integrative therapies.*

Section 3 – Unplanned Presentation

In this section, we suggest adding in the possibility of liaising with a consumers' specialist, not necessarily just their GP, to be able to get a thorough picture of health. It would also be good to add that, where consumers with IEI/MCS are hypersensitive to light or sound, consider arranging a clean and isolated room that helps enable minimal exposure, where practical. If no such room is available, it is advisable to choose an area that is away from the general waiting room, and to advice reception about the special needs of the consumer.

It seems likely, on this basis, that consumers with IEI/MCS may perhaps end up being accommodated out of the usual clinical area relevant to an admission. A consumer suggested acknowledging this in the procedure, in recognition that consumers who are outliers (in terms of not being co-located with other similar patients) may inadvertently be neglected or missed in specialist rounds. We suggest noting this as a risk factor.

In the paragraph that covers the area where a consumer with IEI/MCS should be treated (wherever possible in an area that is not close to certain possibilities of exposure to triggers), these should include:

- areas being remodelled or renovated *or being cleaned with sound-producing equipment*
- *cleaning product storage and supply areas*
- *printers/toners*

Additionally, under the requests for 'all staff and visitors entering a consumer's area', a dot point should be added around ensuring that any clothing worn underneath the gown put on before entering is perfume/fragrance free, and that any sounds from devices or watches are silenced.

Section 4 – On Admission

In the section about Risk Assessment, it is documented that 'staff are to confirm specific chemical sensitivities with the consumer'. This is not always possible for consumers with IEI/MCS. A consumer highlighted to us that

> *[It's] not always possible for consumers to produce a conclusive list of chemical sensitivities, so provision of a full list should not be relied upon. Wisest course is to avoid all chemical substances if possible and err on the side of caution. Also, exposure to a chemicalized environment could sensitise consumers to otherwise tolerated substances. The same applies to being in a stressful environment whereby consumers' tolerance to otherwise tolerated substances could be seriously compromised.*

In the same vein, staff are asked to 'identify exposures that have caused such reactions in the past' – we suggest adding 'if possible'. A consumer told us that

> *Identifying exposures that have caused reactions can be quite complex and certainly not straightforward. Consumers can be exposed to a myriad of incitants simultaneously. Therefore, pin-pointing which exposures caused "such reactions in the past" can be very difficult, if not impossible.*

We also propose it is important to add to the documenting of 'chemical sensitivities', the possibility of other sensitivities such as sound, light, touch/pressure and smell.

Section 5 – Care during Admission

In the section on 'consumer accommodation', it is important to add to the list of dot points about where consumers with IEI/MCS should <u>not</u> be accommodated, the following

- *rooms that are used for cleaning product storage or supply*
- *rooms that are used for food preparation where gas cooking equipment is used ie. gas stove/oven, gas cylinders*
- *rooms that contain printers or where pen markers, glues or toners are stored*

- is being remodelled, renovated or repaired, or *near areas that are being renovated*

When preparing the room for a consumer with IEI/MCS (p8), the procedure asks staff to give consideration to a consumer's area/room/bed signage to warn staff and visitors of potential triggers/incitants. We suggest adding to this list to include beeping on phones/devices/watches.

In the section on p8 that mentioned perfumed and non-perfumed substances, it is important to all that perfumed substances include all scented/fragranced products, both chemical and natural), and scented cosmetics.

We note that while the statement is made that 'Exposure to non-perfumed substances can be difficult to identify and eliminate' – this is why erring on the side of caution is crucial for consumers with IEI/MCS.

In the section on 'Notification of Support Services', we suggest adding to the list of cleaning requirements that

- *rubbish bin liners/receptables are to be fragrance free*

In the section on 'Equipment that may be required when caring for a consumer with IEI/MCS, we suggest adding to the list

- bottled drinking water – *preferably filtered drinking water*

In the section on 'Staffing considerations', we suggest adding to the list of needs not to wear, use or be exposed to

- *hand creams/lotions, face/body moisturisers, aftershaves, body sprays*
- *all clothing that has been impregnated with perfume due to habitual perfume use by the wearer*

In the paragraph below these dot points, we suggest it is important to reiterate that all garments worn under theatre scrubs should be fragrance free.

There are a series of dot points on page 10 about how all staff can care for a consumer with IEI/MCS. These should include

- be familiar with the consumer's condition and what incitants or allergens the consumer is affected by. Different consumers may react to different ranges of incitants *but not always be able to identify all of them*
- when the consumer with IEI/MCS is allocated a single room ensure that the door of the room is kept closed at all times *and that the gap between door and floor is minimal*
- not permit any flowers, plants, newspapers, *magazines,* or chemically treated or perfumed paper in the consumer's room unless the consumer advises that this is acceptable
- *ensure rubbish bin liners/receptacles are unscented*

In the section on 'Dietary Requirements', we suggest the following additions:

- Bottled water, *preferably filtered water*

- *Eating/drinking utensils that have washing up detergent residue thoroughly rinsed off*

In the section regarding Medication (p11-12), we suggest adding that the consumer could also react to fillers and the shell of capsules, for example.

In the section about 'Ongoing Care Requirements', we suggest adding the need to:

- *Dust with a damp cloth – if not using neutral detergent*

We also suggest that 'highly' fragrant should be removed – it is enough to just avoid 'fragrant' cleaning products. A consumer told us that from their experience

> *Products do not have to be "highly fragrant" for a consumer to react. Any fragranced/scented product should be completely avoided if possible.*

In the section with direction for 'Visitors', we suggest the following dot points

- *hand creams/lotions, face/body moisturisers, aftershaves, body sprays*
- *all clothing that has been impregnated with perfume due to habitual perfume use by the wearer*
- *newly applied nail polish, newly applied acrylic nails*
- *should avoid making physical contact with a person wearing fragranced/scented products prior to visiting consumer with IEI/MCS.*
- *avoid phones/devices/watches which beep, or play music, electronic sound*

It may be worth considering making these instructions for visitors into an Attachment to the Clinical Procedure, or saved as a co-located document, that can be used as a printed or emailed fact sheet to provide to those who are intending to visit consumers admitted who have IEI/MCS. A document like this would then be easily accessible for consumers to send to family and friends to share.

Evaluation

It would be worth clarifying here that while the number of complaints may be used as a measure. The consumer feedback received through the Consumer Feedback and Engagement Team may give a more descriptive view of the consumer experience. This qualitative data might better reflect the compliance or effectiveness of the clinical procedure for IEI/MCS, in reflecting the actual experience of consumers with this condition, as opposed to the simple calculation of number of complaints or incidents entered into RiskMan.

Related Policies, Procedures, Guidelines and Legislation

We note that p9 refers to the need to have electrical equipment tagged within CHS. As such we suggest adding the related policy on Non-Clinical Electrical Equipment, particularly where consumers' own equipment is used in the health service setting.

Search Terms

Please add ‘reaction, reactions’ to the list of search terms.

Concluding comments

Thank you for the opportunity to provide feedback to the consultation process for this review of the Clinical Procedure for IEI/MCS. HCCA looks forward to seeing how our consumer feedback is incorporated and we would be glad to discuss any aspect of our feedback in more detail. Thank you for the opportunity to put forward consumer views on these issues.