Submission on the draft report: "Caring for Older Australians"

Thankyou for the opportunity to present this submission. I've downloaded a copy of your report and note with particular interest the chapter on Catering for diversity – caring for special needs groups. I would like to bring to your attention a particular group who are not listed in this chapter, and for medical reasons are unable to access nursing home care under the current system.

Background

I'm referring to people who suffer from food, environmental and chemical allergies. I belong to this group and our condition is known as Multiple Chemical Sensitivity. In the *New South Wales Adult Health Survey 2002*, 2.9% of respondents reported having been diagnosed with chemical sensitivity and 24.6% of respondents reported sensitivity to chemical odours: Centre for Epidemiology and Research, NSW Department of Health. New South Wales Adult Health Survey 2002 *NSW Public Health Bull* 2003; 14(S-4). http://www.health.nsw.gov.au/resources/publichealth/phb/pdf/adult_health_survey.pdf Some people are so severely afflicted that they are unable to take part in any normal kind of community life.

Implications for Aged Care

The idea of increasing disability with the onset of aging is becoming a cause of increasing concern for people with this condition. Many are on Disability Support, so there are also financial considerations, but that is not my main focus. Ideally, we would like to be cared for in our own homes by family members as we age, but some of us don't have this option and there are some mental and physical conditions which are beyond the coping skills of family. The option of having support in our home by an accredited group (eg Freemasons, Anglicare, etc) poses difficulties in a) the ability to afford such care and b) the fact that anyone coming into our homes on a regular basis needs to be completely fragrance free – including hair, cosmetic and laundry products. Moving into an aged care hostel would be impossible for most of us.

Our Triggers

The things we react to include:

Unfiltered water – both drinking and washing

Laundry detergents

Carpet

Latex or foam mattresses

Synthetic fabrics

Chemical cleaning products (including anything with a masking fragrance)

Essential oils (eg citrus, eucalyptus) used to clean or disinfect

A wide variety of food intolerances – different for different people, but some of us have fewer than 10 "safe" foods

Gas heating

Microwave ovens, mobile phones

Newsprint and glossy paper

Raw timber

New paint work and varnishes

All personal fragrances, including laundry odours, shampoos, hair and body products Fresh flowers and indoor plants

Symptoms can include:

Anaphylaxis

Fatigue – mental, muscular, cardio-vascular

Head – migraine, headaches, dizziness, faintness

Cognitive - brain fog, lack of coordination, disorientation, short term memory loss, speech impairment

Sleep disorder – insomnia, sleepiness

Eyes – itchy, irritable, burning or stinging, runny, light sensitivity, disturbed vision

Ears – itchy, aching, discharge, infection, sound sensitivity

Nose – runny, stuffiness, sneezing, sinus pain, excessive mucus

Mouth – swollen or discoloured tongue, gums or lips, canker sores, blisters, ulcers

Upper Respiratory – coughing, sore throat, hoarseness,

Lower Respiratory - inflamed airways, difficulty breathing, congestion, asthma

Heart – irregular or rapid heartbeat, chest pain, high/low blood pressure

Muscle and joint – aches and pains, spasm, arthritis

Digestive and Gastric – nausea, vomiting, diarrhorea, constipation, leaky gut,

bloating, heartburn, stomach cramps

Urinary/genital – itch, pain, discharge, frequent infections, fluid retention

Weight – excessive weight gain or loss, food cravings

Skin – rashes, irritation and itching, peeling and flaking, hives, acne, bruising,

flushing, excessive sweating

Emotional – depression, anxiety, extreme irritability

Miscellaneous – swollen glands, fever and fluey symptoms

Not only would it be impossible to live in current aged care accommodation, but many of us can't even visit elderly relatives in such places and we ask that you take our needs into consideration in your report.

Ideally it would be good to have separate facilities built for people with this condition, but I realize that this is unrealistic. What I would like to suggest is that 'safe' areas be set aside in existing facilities with more allowances made for individual needs, and better education of nursing staff regarding this condition.

In conclusion, I refer you to the **IEQ Indoor Environmental Quality Project** website: http://www.access-board.gov/research/ieq/intro.cfm

It has the most comprehensive information on making buildings accessible for people with disabilities, including those who suffer from MCS.

Lynne Roberts