

# EXECUTIVE SUMMARY

Multiple Chemical Sensitivity (MCS) is a highly controversial condition and one that raises many concerns. The condition is not recognised by the medical and scientific community as a specific disease in Australia. There is not only a lack of consensus on an appropriate term and case definition but no definitive diagnostic test exists for MCS. The overlap between MCS symptoms and other illnesses such as Fibromyalgia and Chronic Fatigue Syndrome also presents difficulties for diagnosis.

The Committee heard that MCS is, however, a medical term in common use and is described in the 1999 Consensus diagnostic criteria on MCS as a chronic condition with symptoms occurring in multiple organ systems, that recur in response to low levels of exposure to a range of chemicals and improve or resolve when these chemicals are removed. Characteristic symptoms can include headaches, burning eyes, nose or throat, concentration or memory lapses, nausea, muscle pain, dizziness, breathing problems and fatigue.

Due to the lack of consensus on MCS and its overlap with other illnesses, it is difficult to accurately determine how many Australians have the condition. Surveys conducted by the Department of Health in SA in 2002 and 2004 suggest that 0.9 percent of the population may have MCS, while an estimated 16.4 percent may experience some chemical sensitivity. Interstate and overseas research has shown that up to 6 percent of the population may have MCS, with between 10-25 percent experiencing sensitivity to chemicals.

The Committee heard from 22 witnesses and received 167 written submissions from a range of individuals and organizations across Australia and overseas. A diverse range of views on various aspects of the condition was presented.

A defining feature of the evidence presented, which includes research papers and reviews of the literature on MCS, is the polarisation of views on the cause and mechanisms of MCS. Some arguments claim that the issue of chemical causation in MCS is itself contentious and that the condition has a purely psychological basis. Other arguments propose that MCS is an immunological or toxicological disorder.

A fundamental division in the medical and scientific community concerns whether chemicals are indeed the cause of MCS. Research supports both the view that chemicals can cause or trigger MCS symptoms, and the argument that there is no objective evidence to establish a link to any specific chemical or group of chemicals as the cause of MCS. At this point in time there is no evidence to conclusively support any one theory.

Research that associates a great many chemicals with initiating or eliciting MCS symptoms cannot, however, be ignored. Of these chemicals, some research indicates that herbicides such as Glyphosate, pesticides, solvents, and sterilisers, have been associated with the condition. Evidence presented to the Inquiry suggests that once MCS symptoms are established, common chemicals in everyday products such as perfumes, aftershave, and deodorants, as well as in paint and household cleaning products, can trigger symptoms. MCS symptoms can also be exacerbated by environmental agents such as tobacco smoke, vehicle exhaust and electromagnetic radiation (EMR).

Given the lack of consensus on the condition, the Committee heard that the medical profession has not yet been able to identify and recommend an effective treatment regime. Evidence suggests that the condition can, however, be managed if sufferers receive understanding, information about their condition and how best to manage it, and support from medical practitioners, family, friends, colleagues in the workplace and the general public.

The Committee heard that a number of regulations and authorities are involved in managing chemicals at the Federal, State, and Local Government level. Different chemicals are assessed and registered under a number of different schemes and some 144 separate pieces of Commonwealth, State and Territory legislation cover the management of chemicals for environment, community, and worker's health and safety.

The wide range of chemicals thought to be associated with MCS and the lack of consensus on the cause of the condition presents difficulties with regard determining the appropriate regulatory action that needs to be taken to address issues raised by MCS. Evidence presented questions the adequacy of the current regulatory environment and suggests that a nationally co-ordinated review and response, as well as further research on the affects of chemicals associated with MCS, is needed.

The Committee heard that the need for greater collaboration between State Government Departments and authorities and Local Government is also required. This would enable uniform best practice measures for chemical use and for minimising chemical exposure to individuals with MCS, to be identified and adopted, particularly by Local Councils.

While Germany is the only country to formally recognise MCS as a medical condition, the disorder is nonetheless recognised by a diverse range of authorities in many countries overseas, but predominantly in the United States and Canada. A growing number of hospitals and health care facilities have adopted MCS related policies and protocols which recognise the health problems experienced by people with the condition from exposure to a range of chemicals, including fragranced personal products. MCS guidelines on Scent-Free policies in particular, have been introduced in workplaces and public spaces as part of OHS policies and Disability Action Plans.

The Committee heard that regardless of whether MCS is recognised as a disease, individuals fulfilling the diagnostic criteria for the condition can suffer significant illness and disability. Evidence has established that MCS is recognised as a legitimate disability and disability access provisions for people with MCS have been made by authorities overseas, and to a lesser extent in Australia. The lack of medical recognition of MCS has, however, prevented some sufferers from having their condition recognised as a disability.

The debilitating nature of MCS symptoms can cause social isolation and great hardship to individuals, their partners, and family members. A key issue emerging from the evidence is the lack of recognition of MCS, which not only has implications for diagnosis and treatment but also raises issues regarding appropriate ways of responding to the needs of those with this complex and little understood condition. These needs include financial assistance through Commonwealth income support programs and worker's compensation schemes, access to adequate health care and support services, and to education and affordable and appropriate housing.

A wide range of measures to raise community awareness, educate medical professionals, and reduce the impact of chemicals on sufferers, ensuring greater access to health service providers and public and community facilities, were proposed to the Inquiry.

Evidence presented strongly suggests that there is a need for further research to enable a better understanding of MCS, particularly in relation to cause, management, prevalence and the cost burden to the community. A little understood impact of MCS is on the fertility of sufferers and further research on this aspect of the condition would be a valuable addition to the body of evidence on MCS.

The Committee has made a number of recommendations in this report based on close examination of the written submissions and oral evidence presented. These recommendations recognise the need to build on existing structures and resources where possible.

The Committee wishes to acknowledge and thank the many individuals who provided evidence to the Inquiry. In particular we wish to thank individuals with MCS, for providing personal accounts of the difficulties they encounter in living with this complex condition.

# COMMITTEE RECOMMENDATIONS

For the Multiple Chemical Sensitivity inquiry the Committee has made the following recommendations.

## SECTION 1

### **Prevalence**

#### Recommendation 1

That the Department of Health (DoH) monitors the prevalence of MCS in SA and compiles comparative data on the incidence of MCS to enable trend analysis.

### **General Recommendations**

#### Recommendation 2

That the Department of Health (DoH):

- 2.1 coordinate and consult with relevant professional bodies, organisations and community groups in the production of an Information Sheet outlining the current position of Multiple Chemical Sensitivity, including working definitions and symptoms commonly associated with the condition;
- 2.2 coordinate the dissemination of information on MCS to a wide range of organisations and groups including medical practitioners, local Councils, and the general public, through appropriate information distribution channels.

#### Recommendation 3

That the Department of Health (DoH) convene an MCS Reference Group including representatives of relevant Government departments and agencies including PIRSA and the EPA, professional bodies and organisations, community groups, and Councils nominated by the Local Government Association, to maintain ongoing communication and provide up-to-date information on developments in the MCS debate.

## SECTION 2

### **The Role of PIRSA and Chemical Trespass**

#### Recommendation 4

That the PIRSA Chemical Trespass Coordinator continue to provide assistance to people with MCS in addressing instances of chemical trespass as they arise.

### **Chemical Use and Local Government - Local Government and MCS**

#### Recommendation 5

That the MCS Reference Group convened by the DoH work to develop best practice guidelines to enable local Councils to establish No-Spray Registers that identify MCS sufferers, and those with chemical

sensitivities generally in local communities. To assist in informing these guidelines, best practice models of No-Spray Registers currently used by Councils should be identified.

## **Minimising the Impact of Chemicals - Guidelines for Best Practice**

### Recommendation 6

That PIRSA:

- 6.1 encourage all relevant bodies across SA to adopt and implement best practice guidelines for administering chemicals;
- 6.2 advise local Councils through the LGA, on best practice in the use of chemicals and in working with local communities to implement best practice measures, particularly in relation to No-Spray Registers;
- 6.3 ensures that all Councils clearly understand their legal obligations with regard chemical use, as outlined under Control of Use legislation.

## SECTION 3

### **Recognition of MCS as a Disability in Australia**

#### Recommendation 7

That the DoH collaborates with the Department for Families and Communities (DFC) and other appropriate agencies and organisations, with the view to exploring practical measures that could assist in addressing disability access issues experienced by MCS sufferers, in relation to public facilities and services in the community.

## SECTION 4

### **The Need for Further Research**

#### Recommendation 8

That the Minister for Health place MCS on the Australian Health Minister's Advisory Council agenda to ensure that a co-ordinated national approach is taken to addressing emerging issues, including the need for:

- 8.1 a national review and evaluation of the medical literature in relation to the status of MCS, with a view to:
  - 8.1.1 guiding further research into the cause, management, impact on fertility, and prevalence of the condition; and
  - 8.1.2 contributing to the formulation of an ongoing national research agenda.
- 8.2 a Federal Government commitment to funding a national research agenda on MCS;
- 8.3 a national position statement on MCS.

## **Policies and Protocols for Safe Access to Health Centres**

### Recommendation 9

That the DoH:

- 9.1 urgently resumes its review of existing MCS hospital protocols with the view to introducing guidelines to provide greater access to chemically sensitive patients requiring medical services. To assist with this task, the DoH is encouraged to continue to investigate and monitor intrastate and interstate protocols and procedures such as the Royal Brisbane Hospital draft MCS protocols, and other relevant overseas protocols on MCS;
- 9.2 Convene a working group of representatives from relevant Government departments and agencies, health service providers, and community organisations, to consider developing appropriate protocols and procedures that enable greater access to health care services for people with MCS.

## **Measures to Minimise Chemical Exposure in the Community**

### Recommendation 10

That relevant State Government Ministers:

- 10.1 lobbies the Federal Government to conduct ongoing research with a national focus on effective alternative measures for weed control, including identifying herbicides with lower toxicity than those currently in common use;
- 10.2 ensures that local Councils are informed of the findings of Federal Government research on alternatives measures for weed control;
- 10.3 lobbies the Federal Government to consider undertaking a review of the adequacy of the current chemical regulatory structure and assessment processes in addressing issues raised by people with MCS with regard chemical use, including the adequacy of health and safety labelling information on chemicals associated with MCS.

## **Extending Existing Support Services to Accommodate MCS Sufferers**

### Recommendation 11

- 11.1 That the State Government's Minister for Disability lobby the Federal Government to consider providing some Federal assistance for essential aides and items to assist people with severe disabilities arising from MCS symptoms in managing their condition.
- 11.2 That the DoH consult with existing service providers such as the Southern Chronic Illness Links Network, with regard extending its existing support services for people with chronic illnesses to support people with MCS across South Australia.

# Summary

MCS can be a debilitating condition that causes great hardship for many sufferers, their partners and families. The Committee acknowledges the many individuals with MCS who came forward to share their very personal accounts. It is clear from these accounts that MCS is very real and that many individuals experience considerable suffering, particularly in light of the lack of recognition surrounding this condition.

It is apparent to the Committee that MCS not only impacts on the health of sufferers but on their ability to remain actively involved in the world around them. The Committee recognises that many sufferers become socially isolated in an attempt to safeguarding themselves from the harmful affects of the wide range of chemicals, present in indoor and outdoor environments, that may trigger MCS symptoms. MCS leads many to retreat from their work, lose social contact with friends and family, and experience great stress and psychological suffering. Research into the social and economic costs to society of MCS have yet to be carried out, however, evidence presented to the Committee suggests that the burden on the health and welfare system in particular, may be substantial.

The Committee believes that there is a clearly identifiable need for further research to determine cause, management, prevalence and the cost burden of MCS to the community. Further work is also needed to address what appear to be gaps in the assessment processes for chemicals nationally, particularly in the area of health and safety information and labelling. The Committee was concerned that very little is known about the effects of chemicals on the fertility of MCS sufferers and believes that research into this area should be undertaken.

In tackling the many issues arising from the MCS debate, the Committee is of the view that a nationally coordinated approach is required. It acknowledges that while States can and must contribute their expertise, State efforts alone would not provide the necessary overarching national position, and an ongoing, clearly defined research agenda.

It is apparent to the Committee that the inadequacy of research surrounding many aspects of MCS frustrates attempts to address and resolve emerging issues. The lack of recognition of the condition by the medical and scientific community prevents agencies such as WorkCover in SA from recognising MCS. It also frustrates the process of ensuring that those with a genuine disability arising from MCS receive much needed financial and practical support.

The Committee believes there are a number of ways in which MCS sufferers can be supported until the medical status of MCS is clarified. It is the intention of the Committee that the recommendations presented pave the way toward greater dialogue, understanding and accommodation of the condition, and greater compassion and support for sufferers.

Hon Gail Gago MLC  
Presiding Member