



Parliament of South Australia

Inquiry into Multiple Chemical Sensitivity

**Twenty Second Report
of the
Social Development Committee**

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ESTABLISHMENT AND COMPOSITION OF THE SOCIAL DEVELOPMENT COMMITTEE

The Social Development Committee was established pursuant to sections 13, 14 and 15 of the *Parliamentary Committees Act 1991* proclaimed on 11 February 1992.

Membership of the Committee

Hon Gail Gago MLC (Presiding Member)

Hon Terry Cameron MLC

Hon Michelle Lensink MLC

Ms Frances Bedford MP

Mr Joe Scalzi MP

Mr Jack Snelling MP (to 1/6/05)

Hon Trish White MP (1/6/05→)

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FUNCTIONS OF THE SOCIAL DEVELOPMENT COMMITTEE

The functions of the Social Development Committee are laid out in section 15 of the *Parliamentary Committees Act 1991* and charge the Committee —

- (a) to inquire into, consider and report on such of the following matters as are referred to it under this Act:
 - (i) any matter concerned with the health, welfare or education of the people of the State;
 - (ii) any matter concerned with occupational safety or industrial relations;
 - (iii) any matter concerned with the arts, recreation or sport or the cultural or physical development of the people of the State;
 - (iv) any matter concerned with the quality of life of communities, families or individuals in the State or how that quality of life might be improved
- (b) to perform such other functions as are imposed on the Committee under this or any other Act or by resolution of both Houses.

TERMS OF REFERENCE

The motion referring this inquiry to the Social Development was moved by the Hon Sandra Kanck MLC in the Legislative Council on Wednesday 14 May, 2003. A motion was carried on 9 July 2003 that ~

The Social Development Committee should inquire into and report on Multiple Chemical Sensitivity, with particular reference to:

1. Which chemical or chemical compounds are responsible for the majority of symptoms of Multiple Chemical Sensitivity and how exposure to them can be minimised;
2. The effect of chemical exposure on human fertility;
3. The comparative status in other countries of Multiple Chemical Sensitivity as a diagnosed medical condition;
4. Best practice guidelines in Australia and overseas for the handling of chemicals to reduce chemical exposure;
5. Current chemical usage practices by Local Government and state Government Departments and changes that could be made to reduce chemical exposure to both workers and the public; and
6. The ways in which south Australians with Multiple Chemical sensitivity may more effectively access sources of support through Government agencies;
7. Any other related matter.

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.

BACKGROUND TO THE INQUIRY

On Wednesday 14 May 2003, the Hon Sandra Kanck MLC moved a motion in the Legislative Council that the Social Development Committee investigate and report on Multiple Chemical Sensitivity (MCS). In referring the matter to this Committee Ms Kanck noted that she had received a 'large amount of correspondence' in relation to the condition, including a letter from Dr David Suzuki which in he referred to MCS as:

*"...an area fraught with controversy within the medical community. I can understand why doctors regard mcs with suspicion. They like dealing with direct cause effect relationships and mcs is not that simple. Personally, I am absolutely convinced mcs is real, that it is serious and probably just the tip of the iceberg."*¹

The motion was supported by members of both major parties and independents, and was carried on 9 July 2003.

The Social Development Committee commenced hearing evidence for this inquiry on 4 August 2004 having first completed Inquiries on the matters of Obesity, Supported Accommodation and Postnatal Depression which had previously been referred to it.

METHODOLOGY

A range of methods and techniques were used in the conduct of this Inquiry. These included advertising the terms of reference in *The Advertiser* on Saturday 19 June 2004 and targeting individuals and organisations, including South Australian and Commonwealth government Departments and agencies, considered to have a particular interest in or expertise on the matter.

In response to these advertisements and invitations, the Committee received written submissions and heard evidence from academics, health professionals, government officers and support groups, as well as individuals with MCS.

In total, 167 written submissions, including a petition of over 1000 signatures submitted by the SA Task Force on MCS, were received. The Committee heard oral submissions from 22 people including representatives from three key State Government Departments and agencies, the Local Government Association, MCS support groups and individuals with MCS, and medical professionals, including two expert witnesses from NSW. A list of submissions including the names of those witnesses who gave oral evidence is provided at the end of the report.

The Committee heard its first oral submission for this Inquiry on 4 August 2004 and completed its hearings on 1 December 2004.

¹ Legislative Council Hansard 14 May 2003

SCOPE OF THE INQUIRY

This Report broadly examines MCS in relation to the stated Terms of Reference of the Inquiry. Due to the specialised nature and breadth of research on MCS, the Inquiry did not undertake to assess its validity. The Committee has sought to present a brief overview of the debate with the view to providing direction on how best to address emerging issues.

In compiling this report, the Committee has primarily drawn on the written and oral submissions that it received. The large number of submissions from many overseas countries and from across Australia, presented a wide range of information that has helped inform the Committee on the debate surrounding MCS, the key emerging issues, and practical measures that could be implemented to address the concerns of people with the condition. Additional information was also sourced, however, due to the broad scope of the Inquiry, this was limited by necessity.

A key focus of the Inquiry has been to recommend strategies and approaches that specifically assist people with MCS in South Australia. Where possible the Committee has undertaken to build on and enhance existing partnerships, structures and resources. It has, however, also sought to advance the debate by ensuring that further research is taken under national leadership to provide a strong evidence based approach to addressing the issues raised by this complex condition.

STRUCTURE OF THE REPORT

The report is divided into four main sections which address the Inquiry's Terms of Reference.

Section One: Introduction provides an overview of the debate surrounding Multiple Chemical Sensitivity (MCS). The following areas are discussed:

- A. Terms and Definitions
including the historical background to the emergence of MCS;
- B. Symptoms
- C. Diagnosis
including issues regarding diagnosis of MCS in South Australia; and the link between MCS and other recognised illnesses;
- D. Causal Mechanisms
including an outline of theories of causal mechanisms, and at risk groups;
- E. Prevalence
including prevalence of MCS in South Australia; and
- F. Treatment/Illness management

Section Two: Chemicals and MCS considers:

- A. The Chemical Causation Debate
including arguments for and against chemical causation in MCS; and chemicals associated with the condition;
- B. Chemical Use and the Regulation of Chemicals

including a discussion of the Federal, State and Local Government regulatory environment; and

- C. Measures for Minimising the Impact of Chemicals.

Section Three: The Comparative Status of MCS considers:

- A. The current status of MCS as a diagnosed medical condition in Australia and overseas, and
- B. An overview of the policies, protocols and position statements that reflect its status.

Section Four: The Impact and Implications of MCS considers:

- A. The Impact of MCS
On the health and wellbeing of people with the condition; the social and economic impact on the lives of sufferers and those close to them; and the broader ramifications of the condition. A particular focus will be on the impact of chemicals associated with MCS on human fertility; and
- B. Issues Arising from MCS
The central issues surrounding MCS are identified and ways in which these issues may be addressed through policies and practical interventions that offer support for those with the condition are outlined.

SECTION 1: INTRODUCTION

A. TERMS AND DEFINITIONS

Introduction

There is no single accepted definition of MCS and over the years several terms have been used to describe the condition. It is noted that all proposed definitions differ by some key criteria and that the syndrome has engendered over 20 names since it was first described.² They include Ecological Disease; Environmental Stress Syndrome; Environmental Illness; 20th Century Disease; and MCS. More recently the World Health Organisation's International Program on Chemical Safety recommended the name Idiopathic Environmental Intolerance (IEI) be used in place of MCS.³

Historically, a number of developments have given rise to the wide array of terms used to describe patterns of hypersensitivity to chemical exposure.⁴ These terms are associated with developments within medical science and within a wider social context.

HISTORICAL BACKGROUND

The Emergence of Clinical Ecology

The Inquiry heard that the symptoms characterising the disorder known as MCS are not new or unique. Dr Robert Loblay, a clinical immunologist with the Department of Clinical Immunology at the Royal Prince Alfred Hospital in NSW, informed the Inquiry that historically these symptoms have been recognised as a range of illnesses to which various diagnostic labels have been assigned.

⁵ Dr Loblay explained to the committee that:

"...this is not a new problem. Similar problems were described...in the 1880s by the American physician George Beard...He had chronic fatigue syndrome, or what we would call chronic fatigue syndrome these days but was called neurasthenia at that time...The idiosyncrasies he described, particularly with external irritants, are very typical of the sorts of things that trigger off symptoms in people with what is called MCS now."

*"In the early decades of the 20th century, these phenomena became bound up with things other than neurasthenia, that is, a whole variety of diagnoses which kept changing from decade to decade, depending upon the particular focus of medical interest at the time."*⁶

According to Dr Loblay, the concept of "20th century allergy", in which the current understanding of MCS is based, is inextricably linked to the emergence of Clinical Ecology, the "non-mainstream quasi-medical subculture," that spawned it.⁷

² American College of Occupational and Environmental Medicine (ACOEM), Policies and Position Statements- Multiple Chemical Sensitivities: Idiopathic Environmental Intolerance, www.aceom.org, p1.

³ Smith, S (NSW Parliamentary Library Research Service), A Review of Multiple Chemical Sensitivity (Paper prepared for the Hon A Corbett MLC), 23 October 2001, p2 & Fitzgerald, written submission, p17.

⁴ Smith, S (NSW Parliamentary Library Research Service), A Review of Multiple Chemical Sensitivity (Paper prepared for the Hon A Corbett MLC), 23 October 2001, p2.

⁵ Loblay, R.H., Allergic to the 20th Century, Australian Family Physician Vol. 22, No. 11, November 1993, p1986.

⁶ Loblay, oral evidence, Hansard, pp169-170.

⁷ Loblay, op.cit., p1987.

Clinical Ecology is a non-recognised medical specialty, and while clinical ecologists began calling themselves environmental medicine specialists in the mid 1980s, the theories and practices that form the basis of their approach are still not recognised by many professional bodies, among them, the American Board of Medical Specialties.⁸

Dr Mark Donohoe, a medical practitioner and proponent of Environmental Medicine from NSW, was one of several witnesses to explain to the Inquiry that the condition that came to be known as MCS was first described in a systematic way by Dr Theron Randolph and others in the 1950's.

*"They described polysymptomatic patients whose illness was clinically associated with exposure to a broad range of synthetic chemicals, including pesticides, petrochemicals, solvents and irritant chemicals such as chlorine and formaldehyde."*⁹

They also observed that humans were unable to adapt to these exposures, and the development of responsiveness to extremely low concentrations after sensitisation, factors which came to characterise MCS.¹⁰

In the late 1950s Randolph coined the term "ecologic illness" to describe what he saw as a new disorder.¹¹ Randolph, initially a board-certified allergist,¹² adopted the term to describe his practice and its focus on environmental incitants, and to avoid use of the term allergy.¹³ In his written submission to the Inquiry, Dr Donohoe explained that a rift developed between traditional allergists and clinical ecologists practicing within the discipline of allergy. The changing definition of allergy and discoveries within the field contributed to this rift.¹⁴ According to Dr Donohoe:

*"This has led to a widening gap between the medical and public meaning of the term "allergy", and massive confusion in the discussion of adverse reactions to foods and chemicals."*¹⁵

Factors Influencing the Rise of Clinical Ecology

In his submission Dr Donohoe explained that the term allergy as originally coined by Baron Clemens Freiherr von Pirquet in 1906 was defined:

*"...as "altered reactivity" of the host on second or subsequent occasions of exposure to any environmental agent."*¹⁶

This early definition embraced both immunity and hypersensitivity. In 1925 European allergists influenced their American colleagues to redefine allergy in the context of antibodies and antigens.

⁸ Ashford, N. and Miller, C., Chemical Exposures- Low Levels and High Stakes (2nd edition). Van Nostrand Reinhold, New York, 1998, p21.

⁹ Donohoe, M. (Dr.) (Fellow of the Australian College of Nutritional and Environmental Medicine), Public Submission Request for Modification to the International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM), 2002, pp3-4.

¹⁰ Smith, op.cit., pp2-3.

¹¹ Loblay, R.H., Allergic to the 20th Century, Australian Family Physician Vol. 22, No. 11, November 1993, p1987.

¹² Ashford, N. and Miller, C., op.cit., p17.

¹³ Ibid., p19.

¹⁴ Donohoe, written submission, p1.

¹⁵ Ibid., p1

¹⁶ Ibid., p1.

Randolph and other allergists objected, preferring to call this development the “immunologic theory of allergy,” but the new definition prevailed. Clinical ecology, which was concerned with heightened reactivity of unknown aetiology, did not fit under this new definition.¹⁷

With the discovery of IgE antibodies¹⁸ in 1967, it is believed that the credibility of allergy as a speciality was enhanced, as it provided allergists with a scientific basis for their practice. Consequently it is argued, clinical ecology, which did not have such a basis, was dismissed by some allergists. It has been suggested that:

...the observations of clinical ecologists, irrespective of their validity or clinical utility, were excluded from allergy, in part because IgE did not appear to be involved.”¹⁹

As clinical ecologists continued to apply their concepts of environmental illness they distanced themselves further from traditional allergists. Randolph and other likeminded allergists founded the Society for Clinical Ecology in 1965 as it became apparent that the field of allergy no longer accommodated the work they were carrying out. In 1984 the Society changed its name to the American Academy of Environmental Medicine.²⁰

Over time allergy and clinical ecology continued to develop and define their separate paradigms. These developments and the paradigms out of which they have arisen have also come to ascribe different meanings to the term “sensitivity.”²¹ The Convenor of the SATFMCS, Mr Peter Evans told the Inquiry that:

“...there is a ...conflict in the medical profession around the terminology... They cannot agree on the terminology – sensitivity means something different to a clinical ecologist to what it means to an allergist.”²²

It has been argued that toxicologists also view the issue of chemical sensitivity quite differently to clinical ecologists and allergists, and that each of these separate specialities operates under different disease paradigms.²³

The emerging environmental consciousness of the 1950s in the US was also significant in that it provided the preconditions for clinical ecology. This consciousness was precipitated by widespread changes in chemical production, consumer products and building design.²⁴

Dr Loblay informed the committee that the work of Rachel Carson was particularly influential during this time.²⁵ Carson, a trained biologist and scientist published *Silent Spring* in 1962. Based on research she had conducted during the 1950s, she wrote about what she saw as the “reckless

¹⁷ Ashford, N. and Miller, C., op.cit., p20.

¹⁸ IgE Antibodies are described by the Health Scout Health Encyclopaedia as a type of immunoglobulin made by the body which are implicated in allergic reactions: <http://www.healthscout.com>.

¹⁹ Ashford, N. and Miller, C., op.cit., pp20-21.

²⁰ Ibid., p21.

²¹ Ibid., p8.

²² Evans, oral evidence, Hansard, p88.

²³ Ashford, N. and Miller, C., op.cit., p8.

²⁴ Ibid., p10.

²⁵ Loblay, oral evidence, Hansard, p170.

and irresponsible poisoning of the world” by the widespread use of chemicals and chemical compounds.²⁶ Carson observed that:

*“The contamination of our world is not alone a matter of mass-spraying. Indeed, for most of us this is of less importance than the innumerable small-scale exposures to which we are subjected day by day, year after year. Like the constant dripping of water that in turn wears away the hardest stone, this birth-to-death contact with dangerous chemicals may in the end prove disastrous. Each of these recurrent exposures, no matter how slight, contributes to the progressive build-up of chemicals in our bodies and so to cumulative poisoning.”*²⁷

DEFINING MCS

While there is no consensus on the case definition of MCS, several definitions are consistently used and referred to in the literature. In addition to the definition proposed by Randolph and other allergists in the 1950s, the most commonly used definitions are those proposed by Dr Mark Cullen, Professor of Medicine and Public Health at Yale University, and the diagnostic criteria stated in the 1999 Consensus Criteria.

The Inquiry was informed that the term multiple chemical sensitivity was first proposed in 1987 by Dr Mark Cullen,

*“...as the appropriate name for a disorder characterised by the triggering of symptoms in different organ systems of an individual by exposure to environmental chemicals at concentrations below those usually considered toxic or harmful.”*²⁸

Cullen outlined seven major diagnostic features of the syndrome:

- The disorder is acquired in relation to some documentable environmental exposure(s) insult(s), or illness (es)
- Symptoms involve more than one organ system
- Symptoms recur and abate in response to predictable stimuli
- Symptoms are elicited by exposures to chemicals of diverse structural classes
- Symptoms are elicited by exposures that are demonstrable (albeit of low level)
- Exposures that elicit symptoms must be very low, by which we mean many SDs²⁹ below average exposures known to cause adverse human responses
- No single widely available test of organ system function can explain the symptoms.³⁰

²⁶ Carson, R., *Silent Spring*, Hamish Hamilton Ltd, Great Britain, 1963, p.x.

²⁷ *ibid.*, p143.

²⁸ Donohoe, M. (Dr.) (Fellow of the Australian College of Nutritional and Environmental Medicine), Public Submission Request for Modification to the International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM), 2002, p4.

²⁹ SD's or Standard Deviations are calculations based on a statistical formula that are used as a measure in science. Source: <http://www.yourdictionary.com/ahd/s/S0702200.html>.

³⁰ Graveling, R.A., Pilkington, A., George, J.P.K., Butler, M.P. and Tannahill, S.N., A Review of Multiple Chemical Sensitivity. *Journal of Occupational and Environmental Medicine*, 56, 1999, p73-74.

It has been observed throughout the published literature on MCS, that the Cullen criteria are the most extensively reported.³¹

Several submissions to the Inquiry refer to the ‘MCS: A 1999 Consensus’ criteria in offering a working definition of MCS. In 1989 five consensus criteria were identified in a multidisciplinary survey of 89 clinicians and researchers in the United States, with extensive experience in but widely differing views of MCS. In 1999 a 6th criterion was added.³² The Consensus was adopted to standardise and enable diagnosis while medical research continued to investigate the aetiology of the signs and symptoms of MCS.³³ The MCS Consensus criteria describe what they refer to as Environmental Illness as:

- A chronic condition
- with symptoms that recur reproducibly
- in response to low levels of exposure
- to multiple unrelated chemicals and
- that improve or resolve when incidents are removed
- with symptoms occurring in multiple organ systems.³⁴

The working definition of MCS presented to the Inquiry by Dr Jim Fitzgerald, Principal Toxicologist in the South Australian Department of Health’s Environmental Health Service, is based on the Consensus criteria. Dr Fitzgerald informed the Inquiry that MCS

“... is often defined as a chronic condition with symptoms that recur in response to a chemical odour and sometimes in response to what is believed by the sufferer to be a low-level chemical exposure in the absence of an odour with symptoms improving or resolving when the chemicals or perceived chemicals are removed.”³⁵

The 1999 Consensus also informs the SA Task Force on MCS (SATFMCS) definition of MCS. Mr Peter Evans, Convenor of the Taskforce told the Inquiry that:

“These criteria are used internationally, and we recommend that they be adopted as a basis for diagnosing MCS in South Australia.”³⁶

Emerging Issues regarding Terms and Definitions of MCS

Individual submissions to the Inquiry indicated a preference for use of a range of terms and definitions. The Inquiry was advised that the use of the term MCS was contentious. Dr Fitzgerald explained to the Inquiry that:

³¹ Smith, S (NSW Parliamentary Library Research Service), A Review of Multiple Chemical Sensitivity (Paper prepared for the Hon A Corbett MLC), 23 October 2001, p5.

³² Multiple Chemical Sensitivity: A 1999 Consensus, Archives of Environmental Health (signed by 34 signatories), Vol. 54, No. 3, May-June 1999, <http://www.mindfully.org/Health/MCS-1999-Definition.htm>, p1

³³ *ibid.*, p1.

³⁴ *Ibid.*, pp2-3

³⁵ Fitzgerald, oral evidence, Hansard, p17.

³⁶ Evans, oral evidence, Hansard, p71.

“Many professionals are not comfortable with the term ‘multiple chemical sensitivity’ since it denotes that chemicals are the sole causative agents... As a result, many other terms for MCS are used – for example Idiopathic Environmental Intolerance, ecological disease, environmental stress syndrome, 20th century syndrome; and the Gulf War syndrome is included in this list as well.”³⁷

The Inquiry was informed that a proposal to rename MCS Idiopathic Environmental Intolerance (IEI) was put forward in 1996 at the Berlin workshop convened by the World Health Organisation’s (WHO) International Program on Chemical Safety.³⁸ The name change was recommended on the basis that the term makes an unsupported judgement on causation, does not refer to a clinically defined disease, and is not based on accepted theories of underlying mechanisms nor validated clinical criteria for diagnosis.³⁹

While there was some support for the change of name, agreement could not be reached. Dr Mark Donohoe informed the Inquiry that the proposal to rename the condition:

“...has not really had an effect on the common nomenclature of the syndrome, which continues to be known and indexed in Medline under “multiple chemical sensitivities MCS.”⁴⁰

Nevertheless, references are made to IEI in the literature and in evidence presented to the Inquiry. In a submission received from the Plastics and Chemical Industries Association (PACIA) the Inquiry was informed that MCS is more correctly termed Idiopathic Environmental Intolerance.⁴¹ In the report prepared for the PACIA submission by Australian toxicologist, Dr Roger Drew, it is argued that:

“... the issue of chemical causation of MCS is open to serious question, and indeed the preponderance of objective scientific data strongly indicates chemicals are not the cause of MCS.”⁴²

Dr Drew further argues that :

“...the designation IEI should displace the term multiple chemical sensitivity as well as other labels such as chemical intolerance because these terms suggest unproven causation and physiological mechanisms.”⁴³

In other evidence, the Committee heard that while some support the view that the term MCS is misleading and should be abandoned, they also reject the term IEI, proposing their own definition. Research conducted by Dr Robert Loblay has led him to conclude that:

“...the term multiple chemical sensitivity is misleading...and I do not believe it should be used as a diagnostic label...I prefer...intolerance to smells and fumes.” I think that this is a

³⁷ Fitzgerald, oral evidence, Hansard, p17.

³⁸ [Plastics and Chemicals Industry Association \(PACIA\)](#), written submission, p2.

³⁹ American Academy of Allergy, Asthma and Immunology, Media Resources: Position Statement, www.aaaai.org, p1.

⁴⁰ Donohoe, [Multiple Chemical Sensitivities – State of the Science, \(Paper presented in conjunction with oral evidence\)](#), p2.

⁴¹ [Plastics and Chemicals Industry Association \(PACIA\)](#), written submission, p3.

⁴² [Ibid.](#), p15.

⁴³ [Ibid.](#), p3.

realistic descriptive term which does not seek to assign mechanisms... it is just a description of what people experience.”⁴⁴

Dr Mark Donohoe told the Inquiry that due to the confusion surrounding MCS, there is a need for a standardised clinical definition of MCS. Toward this end, Dr Donohoe informed the Committee he has prepared and submitted an application to modify the Australian version of the International Statistical Classification of Diseases and Related Health Problems (ICD-10-AM) to include a code for MCS. At the time of providing evidence, Dr Donohoe had not been advised of the outcome of his application.⁴⁵

Summary

The Committee recognises that the evidence on MCS is far from conclusive and that this presents difficulties with regard defining MCS and indeed, the appropriate term to describe the condition. The Committee believes it is necessary that a working definition is adopted and applied consistently throughout the medical and scientific community. We acknowledge that further work involving a collaborative approach is necessary to achieve this end. For the purposes of this Inquiry, however, the Committee has elected to use the Multiple Chemical Sensitivity: A 1999 Consensus criteria, as presented in the Archives of Environmental Health, 1999, Vol. 54, No 3, pp. 147-149, as the basis of its understanding of the condition.

B. SYMPTOMS

The Inquiry heard that the presentation of MCS can vary greatly among cases and over time. Some individuals are totally disabled by severe symptoms suffered on a daily basis, while others are disabled only minimally by mild symptoms which they experience occasionally. Many people suffering from MCS have a large number and range of symptoms that they associate with chemical exposures. Research shows that the complaints can be both physical and mental and involve nearly all systems of the body.⁴⁶

It was also suggested in a number of submissions and in the research that the large range of symptoms has meant that some medical practitioners dismiss chemical sensitivity as a real medical condition because it is difficult to diagnose, preferring to suggest immunological or psychological alternatives.⁴⁷

Dr Jim Fitzgerald from the SA Department of Health told the Inquiry that:

“Symptoms appear to occur in multiple organ systems and in response to a wide range of seemingly unrelated chemicals... Symptoms and chemical exposures are often unique and are widely varied between individuals.”⁴⁸

⁴⁴ Loblay, oral evidence, Hansard, [p179](#).

⁴⁵ Donohoe, oral evidence, Hansard, p107.

⁴⁶ Winder, C., Review Article: Mechanisms of Multiple Chemical Sensitivity, School of Safety Science, University of NSW, Toxicology Letters 128, 2002, p89.

⁴⁷ Ibid., p89.

⁴⁸ Fitzgerald, oral evidence, Hansard, [p17](#).

The committee heard that:

“Symptoms reported by sufferers can include headaches, burning eyes, nose or throat, concentration or memory lapses, nausea, stomach problems, muscle pain, dizziness and fever, asthma or other breathing problems, fatigue, depression or mood swings, sleeping problems and eczema.”⁴⁹

Dr Fitzgerald informed the Inquiry of a survey of MCS undertaken by the Department of Health in SA in June 2004. The survey found that the principal symptoms reported by individuals who were sensitive to chemicals were headaches, asthma or other breathing problems, and burning eyes, nose or throat.⁵⁰ About half of the 13 individuals with MCS in this survey reported the same symptoms, as well as concentration or memory problems and nausea/stomach problems. 20-30% of those with MCS also reported muscle pain, dizziness, fever, fatigue, depression and eczema. Half of those with MCS reported that their symptoms were ‘mild’, 2 reported ‘moderate’ symptoms and 5 reported ‘severe’ or ‘somewhat severe’ symptoms. Only one respondent reported having ‘no problem’ at the time of the survey.⁵¹

Dr Bruce Wauchope, a General Practitioner from the Bedford Medical Clinic at Bedford Park, who has had more than 10 years experience in working with Chronic Fatigue Syndrome (CFS) and MCS, told the Inquiry:

“We have a body of patients who are ill and... the common feature is that exposure to chemicals makes them ill...their symptoms are so variable...that it is hard to correlate.”⁵²

Mr Peter Evans, Convenor of the SATFMCS informed the Inquiry that there is a different presentation for each person with MCS. The Committee heard that:

”...some people might be complicated with lots of pain, with fibromyalgia; for other people it is chronic fatigue; for others it might be neurological difficulties...the presentation of this illness is very broad.”⁵³

In their submissions to the Inquiry, many individuals with chemical sensitivities outlined the symptoms they suffer from and the development of their condition over time. Many submissions outlined the poor, and in many instances, declining health they have experienced. A wide range of symptoms were reported in these submissions, reinforcing research findings and the evidence presented by many medical practitioners to the Inquiry. The personal experience described in one submission notes:

“In common with every other sufferer I know personally, or about whom I’ve read, I attribute my illness to exposure to neurotoxins, the most ubiquitous of which are pesticides. Many of the symptoms which caused me to lose my career, and become either fully or partially dependent on social security, were neurological and long term eg...severe migraines, “spaciness” in my general thought processes, difficulty in recalling information and processing new information...difficulty reading...paraesthesia, numbness of extremities,

⁴⁹ Ibid., p17.

⁵⁰ Fitzgerald, J. and Mangas, S., Summary of results of Health Monitor Surveys (September 2002, June 2004) on Multiple Chemical Sensitivity (MCS) for the Social Development Committee, Hazardous Substances Section, Environmental Health Service, Department of Health, September 2004, p2.

⁵¹ Ibid., p2.

⁵² Wauchope, oral evidence, Hansard p14.

⁵³ Evans, oral evidence, Hansard, p82.

muscle cramping, irregular heartbeat, and extremely heightened sense of smell to solvents, petrol, perfumes etc.”⁵⁴

In another submission one woman reported:

*“When I go shopping or into other public places I often use a walking frame as the chemical odours cause me to become extremely dizzy, disoriented and suffer severe muscle, joint and stomach pain. I also have a chronic sore throat and find it hard to breathe when exposed to low levels of chemicals.”*⁵⁵

C. DIAGNOSIS

DIAGNOSING MCS – AN OVERVIEW

It is widely acknowledged that no definitive diagnostic test exists for MCS. This is not surprising given the lack of consensus surrounding the condition.

The Inquiry was informed by Associate Professor John Edwards from the Department of Environmental Health, School of Medicine, Flinders University, that diagnosis is problematic. Dr Edwards argues that:

*“There are no widely accepted defined symptoms or signs which can be used as diagnostic criteria for MCS.”*⁵⁶

Dr Bruce Wauchope, a General Practitioner from the Bedford Medical Clinic told the Inquiry that one of the difficulties in diagnosis is that:

*“...medicine is based on evidence – we are discussing a grey zone... If you came to me and asked, 'Do I have tonsillitis?' I could look at your throat and there is a set diagnostic procedure... If you...asked, 'Do I have leukaemia?' I can do a blood test and, looking at the blood test, I can diagnose leukaemia.”*⁵⁷

Dr Wauchope explained that there are a number of syndromes in medicine in which diagnostic tests are not available.

*“...for instance, there is...multiple sclerosis, which is a neurological condition. We do not have a diagnostic test for multiple sclerosis but after five, maybe 10 or 20 years it becomes apparent that a person has it. So, there...[are] a small number of difficult diseases where we do not have a test. We have the same problem with irritable bowel syndrome. There is no test for it, but we exclude it and assume the person has that condition. When you enter the realm of multiple chemical sensitivity, there is no test; there is no sequence by which you may come to a diagnosis.”*⁵⁸

Dr Jim Fitzgerald advised the Committee that:

⁵⁴ Williams, written submission, p1.

⁵⁵ Trudeau, written submission, p1.

⁵⁶ Edwards, written submission, p2.

⁵⁷ Wauchope oral evidence Hansard p7.

⁵⁸ Wauchope oral evidence, Hansard, p1.

*“No consistent findings or biochemical tests have been found to differentiate MCS individuals from the remainder of the population. However, there is considerable overlap of MCS with chronic fatigue syndrome and fibromyalgia. Researchers appear to have found a unique brain blood flow anatomical aberration in CFS patients. The causes, mechanisms and diagnosis of MCS still remain uncertain and this has resulted in a lack of consensus in Australia as to its aetiology, case definition, diagnosis and treatment of patients.”*⁵⁹

The overlap between MCS and other illnesses such as CFS and the difficulties this presents with regard diagnosis, was also discussed by several other witnesses. The Inquiry heard that as MCS does not have specific diagnostic biomedical changes, it is more difficult for the medical profession to recognise it as a distinct syndrome. Dr Wendy Scheil, Principal Consultant, Acute Care and Clinical Services, at the Department of Health, noted that:

*“...there are other syndromes, for example, Chronic Fatigue Syndrome, which I have worked with previously, which also does not have biochemical changes. However, there is an agreement on the types of criteria you would use to diagnose, and that has improved considerably the recognition of... [CFS] and the treatment modalities that may be suitable for that syndrome.”*⁶⁰

Dr Mark Donohoe, one of the few practitioners in Australia to diagnose MCS, told the Committee:

*“In the early years, chronic fatigue syndrome and multiple chemical sensitivities both had an equal status, that is, disbelief by the medical profession and a tendency to blame sufferers for the illness they experienced. Chronic fatigue syndrome is now relatively well accepted, but chemical sensitivities lags behind. The reason in my opinion is that chronic fatigue ‘has no known cause’, whereas people who are chemically sensitive can often pinpoint the cause and there are commercial interests that would be put at risk if these causes were accepted to be true. Therefore there is a tendency to fight the diagnosis of chemical sensitivities, especially where a person has been exposed to particular types of chemicals.”*⁶¹

The need for clearly defined diagnostic criteria to facilitate diagnosis was raised by several witnesses and in a number of submissions. Practitioners who recognise MCS argue that the 1999 Consensus criteria establish boundaries on the diagnosis and classification of MCS in a similar way to the classification of other disorders such as Chronic Fatigue Syndrome (CFS). The Consensus also outlines clinical protocols to assist physicians who are unfamiliar with evaluating MCS.⁶²

The Inquiry was informed that the 1999 Consensus criteria are the basis of diagnosis for MCS at the Nova Scotia Environmental Health Centre in Canada, a recognised medical treatment and research facility dealing with environmentally triggered illnesses. A detailed assessment, which includes taking a thorough patient history, comprehensive blood tests, a full physical examination, and completion of a symptoms questionnaire by the patient, is made at the Centre upon referral of patients. The Inquiry was informed that a diagnosis is then made based on established criteria set out in the 1999 Consensus.⁶³

⁵⁹ Fitzgerald, oral evidence, Hansard, p17.

⁶⁰ Scheil, oral evidence, Hansard, p53.

⁶¹ Donohoe, oral evidence, Hansard, p99.

⁶² Multiple Chemical Sensitivity: A 1999 Consensus, Archives of Environmental Health (signed by 34 signatories), Vol. 54, No.3 May-June 1999, <http://www.mindfully.org/Health/MCS-1999-Definition.htm>, p 3.

⁶³ Nova Scotia Environmental Health Centre, written submission, p1.

Dr David Gillis, Staff Specialist, in the IMVS Department of Human Immunology, at the Royal Adelaide Hospital (RAH), told the Committee that he believed diagnostic tests were ineffective, and that clinical assessment constituted best practice in diagnosis. He explained that:

*“...frequently there will be an overlap of diagnosis [such as chronic fatigue with features of multiple chemical sensitivity], but it is all clinical assessment. I am not aware—and I know this is controversial—of any test that is good enough to diagnose any of these syndromes.”*⁶⁴

Dr Colin Little, one of a small number of practitioners to diagnose MCS in Australia informed the Inquiry that:

*“...there are no convenient diagnostic tests and this situation has contributed to the controversy regarding MCS. At present the diagnosis of sensitivity to chemicals requires the demonstration of a cause and effect relationship between low level chemical exposures and adverse effects. This connection can be made on the basis of history and ‘challenge’ testing i.e. direct exposure to the chemical.”*⁶⁵

Dr Little explained that in his view:

*“An underrated approach to diagnosis is [taking] a careful history.”*⁶⁶

Diagnosing MCS in SA

In relation to the diagnosis of MCS in South Australia, Mr Peter Evans from the SATFMCS told the Inquiry that:

*“As far as I have been able to work out, we do not [currently] have any doctors in South Australia who diagnose MCS.”*⁶⁷

It was explained to the Inquiry that MCS is, however, diagnosed by a number practitioners interstate such as Dr Colin Little, and Dr Mark Donohoe, who are considered the key proponents of environmental medicine in Australia. Mr Evans informed the Committee that Dr Colin Little practices in Victoria where he conducts clinics for people with environmental illness. Dr Little ran an Environmental Control Unit at Ainslie Private Hospital in Melbourne until the hospital ceased operation in 2003.⁶⁸ Mr Peter Evans told the Committee that:

*“Dr Mark Donohoe is probably one of Australia’s leading authorities on...[MCS]... Dr Donohoe is still involved in providing health care for people with this problem...”*⁶⁹

Dr Mark Donohoe explained to the Committee that he was a member of the now disbanded Australian Society of Environmental Medicine, and that he operated one of only two environmental clinics in Australia as an inpatient hospital unit at Manly Waters Private Hospital in Manly. The aim of the unit was to provide a controlled environment for assessing people who claimed to have chemical sensitivities. The unit operated from 1989 until it closed in 1993.⁷⁰

⁶⁴ Gillis, oral evidence, Hansard, p158.

⁶⁵ Dr Colin Little, written submission, p1.

⁶⁶ Ibid., p1.

⁶⁷ Evans, oral evidence, Hansard, p87.

⁶⁸ Evans, oral evidence, Hansard, p87 & Scheil, oral evidence, p44.

⁶⁹ Evans, oral evidence, Hansard, p78.

⁷⁰ Donohoe, oral evidence, Hansard, pp98&119.

The dilemmas of diagnosis are exacerbated by the different terms used by specialists from various fields in diagnosis. The Inquiry heard that Multiple Chemical Hypersensitivity⁷¹ has been diagnosed in SA. Mr Evans told the Inquiry:

*"I have been diagnosed with multiple chemical hypersensitivity by the immunologist at the Royal Adelaide Hospital..."*⁷²

It was explained that the term "sensitivity" as applied to MCS,

*"...means something different to a clinical ecologist to what it means to an allergist."*⁷³

According to Mr Evans the term hypersensitivity:

*"... is acceptable to an allergist...[and] a conventional allergist might be willing to diagnose multiple chemical hypersensitivity because it fits in more with their terminology."*⁷⁴

Further Issues regarding Diagnosis

It was explained to the Committee that the lack of consensus on diagnostic criteria often results in the symptoms attributed to MCS being attributed to other disorders. The Inquiry heard that the way doctors view the problem contributes to the different diagnostic labels they place on the problem. Dr Robert Loblay told the Committee:

*"Different doctors will focus on different aspects of the clinical problem in the patient, and give it a particular name."*⁷⁵

It is not uncommon, the Inquiry heard, for those with the symptoms associated with MCS to see numerous doctors, and for numerous tests to be conducted. Dr David Gillis, an immunologist who has seen many people with CFS and MCS over the years, commented that it is not uncommon for this patient group to:

*"...go from doctor to doctor having multiple tests, and ...from doctor to doctor having treatment after treatment which is frequently unsuccessful."*⁷⁶

Dr Gillis explained that in his experience, syndromes such as CFS and MCS consume substantial health resources,⁷⁷ and

*"...lead to a lot of health care costs and a lot of inappropriate testing."*⁷⁸

The Committee heard that excessive testing occurs:

*"... because medicos are worried they will miss something; they are worried about the medico-legal aspects of it."*⁷⁹

⁷¹ Hypersensitivity is defined as an excessive sensitivity or allergic reaction to something which would not otherwise cause a reaction in most people.

⁷² Evans, oral evidence, Hansard, p87.

⁷³ Ibid., p88.

⁷⁴ Ibid., p88.

⁷⁵ Loblay, oral evidence, Hansard, pp178-9.

⁷⁶ Gillis, oral evidence, Hansard, p151.

⁷⁷ Ibid., p151.

⁷⁸ Ibid., p150.

Dr Donohoe pointed out to the Committee that in his experience in working with people with chemical sensitivity over many years:

“...there is a typical history of people being exposed to chemicals developing progressive symptoms which are difficult to explain and which doctors initially investigate thoroughly and, finding no disease, eventually pass on to the psychologists and psychiatrists. In our clinic, the average number of practitioners seen by people admitted was approximately eight, that is, eight medical practitioners seen, with no diagnosis and passed from person to person. The majority had seen more than two psychiatrists, without success in treatment, along the way.”⁸⁰

A view often expressed in evidence to the Inquiry was that an understanding of the causal mechanism of MCS was necessary in establishing clear guidelines for diagnosis. It has been proposed that by obtaining more reliable scientific data, the underlying processes which are involved in response to both initiating and triggering stimuli, can be better delineated. This would reduce the reliance placed on definitions of MCS in the diagnosis of individual cases.⁸¹

Mr Peter Evans told the Inquiry that in his view, the lack of standard diagnostic tests:

“...has been a real block for the recognition of MCS... Until the physiological mechanism is better understood and identified you are... going to get...scepticism from elements in the medical community...”⁸²

Link between MCS and other Recognised Illnesses

Evidence presented to the Inquiry suggests that MCS is closely related to a number of other disorders. Dr Jim Fitzgerald from the SA Department of Health informed the Inquiry that:

“... there is considerable overlap of MCS with Chronic Fatigue Syndrome and Fibromyalgia.”⁸³

Evidence presented by a number of medical practitioners supports the view that MCS exists as a condition that overlaps with Fibromyalgia (FM) and Chronic Fatigue Syndrome (CFS), although there are also instances in which it can occur in isolation from other conditions. Dr Bruce Wauchope told the Inquiry that in his view:

“...MCS is not a distinct entity. I would call MCS a symptom: you are exposed to chemicals and you feel ill. That symptom can occur in chronic fatigue and fibromyalgia and it can occur on its own.”⁸⁴

Dr David Gillis pointed out that it is important to look at other syndromes as a significant proportion of people with other syndromes will have multiple chemical hypersensitivity. Dr Gillis told the Inquiry:

⁷⁹ Ibid., p153.

⁸⁰ Donohoe, oral evidence, Hansard, p 101.

⁸¹ Graveling, R.A., Pilkington, A., George, J.P.K., Butler, M.P. and Tannahill, S.N., A Review of Multiple Chemical Sensitivity. Journal of Occupational and Environmental Medicine, 56, 1999, p84.

⁸² Evans, oral evidence, Hansard, pp 81-2.

⁸³ Fitzgerald, oral evidence, Hansard, p17.

⁸⁴ Wauchope, oral evidence, Hansard, p 9.

“...The whole pattern of these syndromes is sensitivity to a range of different stimuli. With MCS you have a range of increased sensitivity to odorants and a number of symptoms relating to odorants. With Fibromyalgia you have an increased sensitivity to pain and this is demonstrated on a scientific basis....So, increased sensitivity is the key to these syndromes and they overlap tremendously.”⁸⁵

The Inquiry heard that there are between 3000-7000 people with Myalgic Encephalopathy/Chronic Fatigue Syndrome (ME/CFS) in SA. A membership survey conducted in 2001 by the ME/CFS Society SA Inc suggests that around 60% of respondent members claim to suffer from chemical sensitivities. Dr Peter Cahalan, President of the ME/CFS Society SA, told the Committee that while not all members experienced “... the critically disabling meltdown type we call multiple chemical sensitivity,...” they did suffer from chemical sensitivity “...at some level.”⁸⁶

Research on the aetiology of MCS also supports the view that there is an overlap between MCS, CFS and FM but indicates that other conditions may also be linked. Research presented as part of a submission from Professor Martin Pall, School of Molecular Biosciences at Washington State University, indicates that MCS is related to three illnesses – CFS, FM, and also Post Traumatic Stress Disorder.⁸⁷

Drawing on international studies, the SATFMCS argues in its submission that in addition to CFS and FM, MCS has been linked to a number of other conditions such as Gulf War Syndrome; Asthma; Attention Deficit Hyperactivity Disorder, and Depression.⁸⁸ In addition to veterans who served in the Persian Gulf, veterans exposed to Agent Orange have also been shown to have links to MCS.⁸⁹

Dr Bruce Wauchope has noted that:

“Veterans of the Persian Gulf War report chemical sensitivities at a three-times higher rate than civilians or veterans who did not participate in the Gulf War. (from 1999 Consensus doc) Persons with Gulf War Illness (GWI) also have a three-fold increased risk of Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) compared to civilians or non-deployed veterans.”⁹⁰

Based on research undertaken by Fielder et al, the SATFMCS submission argues that the Persian Gulf War in 1991 exposed veterans to a range of chemicals including petrochemicals, pesticides, depleted uranium, multiple vaccinations and medication, chemical weapons and drugs to neutralise them, as well as immensely stressful conditions. As a result, large numbers of Gulf War Veterans have reported health problems consistent with CFS, MCS and FM. In a study in which MCS was specifically assessed among randomly selected veterans, investigators found 36% of the 1004 subjects met the common criteria for MCS.⁹¹

⁸⁵ Gillis, oral evidence, Hansard, p151.

⁸⁶ Cahalan, oral evidence, Hansard, p141.

⁸⁷ Pall, M.L., Elevated Nitric Oxide/Peroxynitrite Neurochemical Mechanism of Multiple Chemical Sensitivity - Etiology of Multiple Chemical Sensitivity, research paper accompanying written submission, pp1-3.

⁸⁸ SA Taskforce Multiple Chemical Sensitivity (SATFMCS), written submission, p27.

⁸⁹ Brown, A.E. (Coordinator, Pesticide Education and Assessment Programs), Multiple Chemical Sensitivity (MCS)- An Overview, Maryland Cooperative Extension, University of Maryland, October 1999, p1.

⁹⁰ Wauchope, written submission, p12.

⁹¹ SA Taskforce Multiple Chemical Sensitivity (SATFMCS), written submission, p27.

There is also speculation that people with asthma experience unusual sensitivities to everyday chemicals. Other research suggests that asthma is itself an expression of MCS. Whatever the aetiology, it appears that there is an association between asthma and perceived chemical sensitivity.⁹²

In its submission, the SATFMCS also notes that research indicates that in recent years MCS-like conditions have been named after initiating events including Gulf War Syndrome, Toxic Carpet Syndrome and Darkroom Disease. Prominent symptoms have also been used in diagnostic labelling, for example, Reactive Airways Dysfunction Syndrome (RADS), Chronic Fatigue Syndrome (CFS) and Fibromyalgia (FM). It was suggested that:

“This...approach encourages a belief that these newly named entities are separate conditions and conceals a wider view of a unifying mechanism, where symptoms of illnesses are triggered and perpetuated by common chemical exposures.”⁹³

D. CAUSAL MECHANISMS

Causes and Mechanisms – Introduction

There is considerable speculation about what causes MCS and the mechanism or means by which symptoms are triggered. While the cause of MCS has yet to be identified, research has been and continues to be undertaken to determine the cause(s) and effects on the body. It was explained to the Inquiry by several witnesses that a wide and variable body of evidence points to a complexity of causes.⁹⁴

A number of reviews of the aetiology of MCS, that is, the study of its causes, have been conducted which not only confirm that the causes are at present uncertain but that there are divergent views as to the proven mechanisms.

THEORIES OF CAUSAL MECHANISMS

The causal mechanisms for MCS can essentially be explained by theories of a physiological or psychological nature, and in some cases a combination of both.⁹⁵ Dr Jim Fitzgerald told the Committee that aetiologies suggested include those of a toxicological, physiological, immunological, neurological, psychological, psychiatric and respiratory nature. The Committee heard that violence in childhood, was also reportedly a cause.⁹⁶

Dr Jim Fitzgerald explained to the Inquiry that:

“The fundamental question is whether the cause is primarily a psychogenic or chemical toxicodynamic disorder; that is, where the symptoms are due to an emotional response to perceived chemical exposure or due to a pathological interaction between chemical agents

⁹² Kreutzer, R., Neutra, R.R. and Lashuay, N., Prevalence of People Reporting Sensitivities to Chemicals in a Population-based Survey, American Journal of Epidemiology, Vol 150, No. 1, The John Hopkins University, July 1999, p3.

⁹³ SA Taskforce Multiple Chemical Sensitivity (SATFMCS), written submission, p27.

⁹⁴ Fitzgerald, oral evidence, Hansard, p18.

⁹⁵ Graveling, R.A., Pilkington, A., George, J.P.K., Butler, M.P. and Tannahill, S.N., A Review of Multiple Chemical Sensitivity. Journal of Occupational and Environmental Medicine, 56, 1999, p76.

⁹⁶ Fitzgerald, oral evidence, Hansard, p17.

and organ systems. There is evidence of interplay of both mechanisms in some MCS patients. One theory suggests that MCS is a behaviour-conditioned response to odour. A severe chemical exposure may act as an unconditioned stimulus producing a conditioned psychological response. Some physicians acknowledge MCS as a medical disorder that is triggered by exposures to chemicals in the environment often beginning with a short-term severe exposure like a chemical spill or with longer term small exposures. After the initial exposure, low levels of everyday chemicals such as those found in household products like cleaning agents, pesticides, soaps, cosmetics, newspaper inks, etc. can trigger physical reactions in MCS individuals. However, there is no objective evidence supporting a link to any specific chemical or group of chemicals.”⁹⁷

Dr Fitzgerald further explained to the Committee that:

“Exposure to neurotoxic chemicals via olfactory pathways can elicit a response in the limbic system which includes various brain regions. The levels of chemicals reported to trigger chemical intolerance would normally be considered to be non-toxic or sub-toxic. Heightened susceptibility in this area of the brain in some individuals is hypothesised to contribute to the onset of MCS. A literature review has indicated that MCS individuals do not have lower odour thresholds than healthy individuals although they may respond more markedly once odour is detected. There also appears to be some parallels between MCS and food intolerance; yet, the evidence suggests that MCS is not truly an allergic phenomenon mediated by the immune system.”⁹⁸

A number of reviews of the aetiology of MCS have been conducted. One of the most extensive of these was commissioned by the United Kingdom Health and Safety Executive⁹⁹ and performed by Graveling et al of the Institute of Occupational Medicine in Edinburgh.¹⁰⁰ The review conducted by Graveling et al summarises the key physiological and psychological theories. According to this review the key physiological theories include Immunological Deficits; Respiratory Disorder or Neurogenic Inflammation; Olfactory-limbic system, Kindling and Sensitisation Models; and Porphyrria. The key psychological theories include Conditioned Response; and Psychiatric Disorders.¹⁰¹ In their review of the literature, Graveling et al. noted that the scientific literature on MCS presented a sometimes conflicting and contradictory picture of the mechanisms and causes¹⁰²

A review of the possible mechanisms of MCS has also been conducted by Associate Professor Chris Winder from the School of Safety Science at the University of NSW. As Dr Winder notes:

“The basis of MCS is still to be identified, although a large number of hypersensitivity, immunological, psychological, neurological and toxicological mechanisms have been suggested, including: allergy; autosuggestion; cacosomia; conditioned response; immunological; impairment of biochemical pathways involved in energy production; impairment of neurochemical pathways; illness belief system; limbic kindling; olfactory threshold sensitivity; panic disorder; psychosomatic condition; malingering; neurogenic

⁹⁷ Ibid., p17.

⁹⁸ Ibid., p18.

⁹⁹ [The UK Health and Safety Executive is the Government regulatory body charged with ensuring that risks to people’s health and safety from work activities are properly controlled.](#)

¹⁰⁰ Smith, S (NSW Parliamentary Library Research Service), A Review of Multiple Chemical Sensitivity (Paper prepared for the Hon A Corbett MLC), 23 October 2001, p8.

¹⁰¹ Graveling, R.A., Pilkington, A., George, J.P.K., Butler, M.P. and Tannahill, S.N., A Review of Multiple Chemical Sensitivity. Journal of Occupational and Environmental Medicine, 56, 1999, p76-82.

¹⁰² Smith, S (NSW Parliamentary Library Research Service), A Review of Multiple Chemical Sensitivity (Paper prepared for the Hon A Corbett MLC), 23 October 2001, p12.

inflammation; overload of biotransformation pathways (also linked with free radical production); psychological or psychiatric illness; airway reactivity; sensitisation of the neurological system; time dependent sensitisation, toxicant induced loss of tolerance."¹⁰³

A brief summary of the mechanisms identified in this research is presented in Appendix 1.

The Committee was told that just as there are opposing viewpoints within the body of research literature, there are also opposing viewpoints within the literature reviews. In evidence to the Inquiry Dr Wendy Scheil, Principal Medical Consultant, Acute Care and Clinical Services in the SA Department of Health noted:

*"... the research literature often placed opposing viewpoints ...[and] ...within the review of the literature, there were also opposing viewpoints."*¹⁰⁴

The Inquiry heard that:

*"The literature highlighted that there was a lack of agreement regarding definitional criteria, such that the epidemiological estimates of prevalence and/ or incidence were poor."*¹⁰⁵

Inquiries made by Dr Scheil also show that the lack of medical consensus regarding the aetiology of MCS impact on the treatment and management of MCS, such that there are no evidence-based or consistent treatment or management regimes.¹⁰⁶ In addition, Dr Scheil explained that there is no consistent approach to research. She told the Committee that the focus of American research varies from that placed on MCS by European researchers.¹⁰⁷

Various viewpoints as to the mechanism explaining MCS were put forward by witnesses appearing before the Inquiry, and in the many submissions received. These views are essentially divided into those that ascribe a chemical cause, and those that suggest other causal factors.

Evidence presented by the SATFMCS, Dr Mark Donohoe, Dr Bruce Wauchope, and in many individual submissions, suggests that MCS occurs following a long-term, low-level exposure to a toxin, while others come on acutely after a short, high-level exposure. The body then becomes sensitive to other chemicals, a phenomenon known as 'spreading'.¹⁰⁸

The Committee was informed that a survey of MCS conducted in September 2002 by the Department of Health indicates that 7.1% of the population reported their health to be seriously affected by exposure to perfume; 6.2% by workplace chemicals; 5.9% by traffic pollution; and 5.6% by household chemicals. A further survey undertaken in 2004 shows that the majority of individuals with MCS reported that perfumes and pesticides/herbicides currently trigger their

¹⁰³ Winder, C., Review Article: Mechanisms of Multiple Chemical Sensitivity, School of Safety Science, University of NSW, Toxicology Letters 128, 2002, p85.

¹⁰⁴ Scheil, oral evidence, Hansard, p45.

¹⁰⁵ Ibid., p45-6.

¹⁰⁶ Ibid., p45.

¹⁰⁷ Ibid., p51.

¹⁰⁸ Wauchope, written submission, p12.

symptoms. 30-50% reported symptoms from exposure to building or renovating material, petrochemicals or tobacco smoke.¹⁰⁹

Dr Jim Fitzgerald told the Committee that of the 13 MCS sufferers identified in the 2004 survey of over two thousand adults, 11 identified a chemical exposure as a cause of their MCS, three did not know what caused their MCS, and five stated that they were under considerable stress at the time.¹¹⁰ About two thirds of the individuals with MCS reported that they had first experienced sensitivity to chemicals at between the ages of 21-35.¹¹¹

In other evidence to the Committee Dr Robert Loblay, explained that in his view, the condition is related to rhinitis, an inflammation of nerve endings in the nose.¹¹² Dr Loblay explained that chemical sensitivity is often described as a heightened physical response to chemical odours which can produce symptoms such as headache, nausea, and dizziness. In his view:

“...intolerances to smells and fumes are common in people who suffer chronic rhinitis, whether it be hayfever on an allergic basis or what is called “non-allergic rhinitis”, which has exactly the same symptoms but without an obvious underlying allergy being identified.”¹¹³

According to Dr Loblay, chronic inflammation, in which the sinus membrane lining and the mucous membrane in the nose is thickened and inflamed is a typical finding in people with chronic rhinitis, whatever the cause. Dr Loblay has also observed in his practice that intolerances to smells and fumes are common in people with food intolerances.

“Over 20-odd years we have had a long experience with a whole spectrum of patients who have food intolerances causing a variety of symptoms. Those symptoms can be things like itchy hives, swellings, rhinitis, chronic headaches or migraine, irritable bowel syndrome (often associated with...little ulcerations in the mouth) and, in many people, just a general feeling of being tired, rundown, unwell and nauseated. These are symptoms that can fluctuate from day to day, week to week and month to month. These food intolerances are idiosyncratic which means that they vary from person to person, and their nature and frequency varies. They are triggered off by a variety of food substances, either natural or added.”¹¹⁴

It was pointed out to the Committee by some witnesses and in several submissions that no objective evidence supports the view that MCS can be linked to chemical exposure.¹¹⁵ The issue of chemical causation is discussed further in Section Two, which also includes a discussion of the chemicals attributed to causing MCS and those that subsequently trigger symptoms once the condition is established.¹¹⁶

¹⁰⁹ Fitzgerald, J. and Mangas, S., Summary of results of Health Monitor Surveys (September 2002, June 2004) on Multiple Chemical Sensitivity (MCS) for the Social Development Committee, Hazardous Substances Section, Environmental Health Service, Department of Health, September 2004, p2.

¹¹⁰ Fitzgerald, oral evidence, Hansard, p19.

¹¹¹ Fitzgerald, J. and Mangas, S., Summary of results of Health Monitor Surveys (September 2002, June 2004) on Multiple Chemical Sensitivity (MCS) for the Social Development Committee, Hazardous Substances Section, Environmental Health Service, Department of Health, September 2004, p2.

¹¹² Loblay, oral evidence, Hansard, p187.

¹¹³ Ibid., p172.

¹¹⁴ Ibid., p172.

¹¹⁵ Fitzgerald, oral evidence, Hansard, p17 & Plastics and Chemicals Industry Association (PACIA), written submission, p 15.

¹¹⁶ SA Taskforce Multiple Chemical Sensitivity (SATFMCS), written submission, p17.

AT RISK GROUPS

A review of the literature on exposure to low levels of chemicals in the United States has identified four groups or clusters of people with heightened reactivity to chemical exposures.¹¹⁷ Further to this work, Associate Professor Chris Winder from the University of New South Wales, has observed that while a chemically sensitive individual may arise in any group, there appear to be four main groupings of individuals with a heightened reactivity.¹¹⁸ These groups are:

- Industrial workers who are exposed occupationally to chemicals as part of their daily activities;
- Office workers working in tight¹¹⁹ buildings;
- Individuals who may be located in areas of contamination (such as contaminated sites or close to known sources of pollution); and
- Individuals who, for one reason or another, received an unexpectedly debilitating exposure to a chemical.¹²⁰

A number of submissions from individuals with chemical sensitivities were received by the Inquiry outlining what they believed to be the basis for their condition. Working in tight or “sick” buildings, exposure to a wide range of chemicals, and exposure to chemicals in an occupational setting were the main areas identified as contributing to their condition. Several submissions from pilots, nurses and other health care professionals, among others, were received.

Concerns regarding the issue of contamination to aircraft air supply by oil lubricants and hydraulic fluids, was raised by the Aviation Organophosphate Information Site (AOPIS) – a non profit group run by aircrew. Research presented by the AOPIS in their submission claims that aircrew as well as passengers are being exposed to a mixture of substances in the oils and hydraulic fluids, with short and long term symptoms being shown.¹²¹ This research indicates that aircraft crews are being diagnosed with MCS, and that a causal link between aircraft air supply exposures and symptoms is being made by a growing number of doctors and scientists, among them, Dr Chris Winder from the School of Safety Science, University of NSW. The submission cites an example of one pilot, who after repeated contaminated air exposures, was diagnosed with:

“...autonomic abnormalities...of similar pattern to those we often see in farmers with chronic exposure to organophosphates in sheep dip...”¹²²

In several submissions, nurses and other health care workers identified a number of chemicals as initiating a range of symptoms which were later diagnosed as MCS. Mr Peter Evans, convenor of the SATFMCS, informed the Inquiry that he first developed the symptoms of MCS while working

¹¹⁷ Ashford, N. and Miller, C., Chemical Exposures- Low Levels and High Stakes (2nd edition). Van Nostrand Reinhold, New York, 1998, p3.

¹¹⁸ Winder, C., Review Article: Mechanisms of Multiple Chemical Sensitivity, School of Safety Science, University of NSW, Toxicology Letters 128, 2002, p87.

¹¹⁹ Tight buildings are described by Winder as those that have inadequate ventilation, with off-gassing from construction or refurbishment materials or from office equipment. (Source: Mechanisms of Multiple Chemical Sensitivity, School of Safety Science, University of NSW, Toxicology Letters 128, 2002, p88).

¹²⁰ Winder, C., Review Article: Mechanisms of Multiple Chemical Sensitivity, School of Safety Science, University of NSW, Toxicology Letters 128, 2002, p87.

¹²¹ Aviation Organophosphate Information Site (AOPIS), written submission, p1.

¹²² [Ibid.](#), p4.

with “harsh cleaning agents containing phenol” while employed in a hospital. He explained that some years later:

“My symptoms returned...when I started working with dialysis equipment that had been sterilised with ethylene oxide...This time the symptoms became chronic, with multiple symptoms in multiple organs particularly neurological problems, memory and concentration loss, and visual disturbance...”¹²³

Several submissions from nurses noted the effects of formaldehyde and glutaraldehyde resulting in a range of symptoms, including difficulty breathing, nausea, vomiting, headaches, rash, and burning scalp and skin. In one submission (name withheld), the Inquiry was informed of the uses to which these chemicals were put:

“As a nurse I had come into contact with glutaraldehyde and formaldehyde...Glutaraldehyde was used for cold sterilisation of instruments and was commonly found in sluice rooms. Formaldehyde is and was used for tissue specimens.”¹²⁴

The Inquiry was informed through several submissions of the existence of the Glutaraldehyde Affected Support Persons injured nurses group (GASPing), which has established a register of affected nurses in Victoria.¹²⁵

It was explained in another submission from a Radiographer from New Zealand, that Glutaraldehyde was also used in X-Ray processing chemicals. She states:

“My exposure to this chemical in the course of my work in the X-ray Department of a New Zealand Public Hospital led to the end of a career spanning 20 years. The outcome for me is a life sentence of compromised health, sensitisation to many everyday products and irreversible brain damage.”¹²⁶

The effects of chemical use on a number of workers in other occupational groups was also explained in the submissions. These included a self employed furniture maker, who informed the Inquiry of the effects of his exposed to solvent based lacquers.

“On several occasions I had sprayed pre-catalysed lacquers in an open air environment outside my workshop using a cartridge respirator for personal protection. On these occasions I noticed I developed headaches, felt nauseous and agitated. I subsequently installed a spray booth to improve my...[OHS] and comply with environmental/planning regulations. Following the installation of the spray booth...I experienced extremely debilitating symptoms while spray finishing a job over the course of several days...I was close to collapsing, and experienced the most severe nausea and agitation. I was unable to eat for ...five days and it took over six weeks before I was able to eat normally again.”¹²⁷

“It is difficult for me to communicate at a personal level the devastating health and economic consequences for me as a result of using...solvent based wood finishing products.”¹²⁸

¹²³ Evans, written submission, p1.

¹²⁴ Individual written submission, name withheld, p1.

¹²⁵ Jeffery, written submission, p1.

¹²⁶ O'Connor, written submission, p1.

¹²⁷ Paton, written submission, pp1-2.

¹²⁸ Paton, written submission, p3.

In addition, it is noted in the Report of the Standing Committee on the Environment and Public Affairs in relation to the Alcoa Refinery at Wagerup Inquiry conducted in Western Australia, that a wide range of people in different occupational groups display the symptoms of MCS. Occupational physician and private medical practitioner, Dr Andrew Harper, who presented evidence to the Inquiry, has found in his work that these groups include those who work in the aviation industry, farmers, mechanics, and the workers at Alcoa in Wagerup.¹²⁹

E. PREVALENCE

Introduction

As the medical profession in Australia does not recognise MCS as a disease and as the condition is seldom diagnosed as such, it is difficult to determine accurately how many Australians have MCS and the extent of the impacts associated with the condition. There is a lack of available data establishing the prevalence of MCS in Australia, and it has been suggested, further surveys with larger sample numbers would be required to estimate the national prevalence.¹³⁰

While the prevalence of the condition has not been widely surveyed, the Inquiry heard that several surveys have been conducted in SA and NSW which provide some measure on the number of people who may experience chemical sensitivity generally, and MCS in particular. In addition, anecdotal evidence presented by a number of practitioners who have worked with MCS patients provided some indication of the extent of the condition and factors that have a bearing on determining prevalence.

PREVALENCE OF MCS IN SA

The Inquiry heard that the SA Department of Health has conducted two telephone surveys to assess the prevalence of MCS and general chemical sensitivity in the community. These surveys also sought to examine symptomology and other impact parameters.¹³¹

The Health Monitor Surveys were conducted in September 2002 and June 2004 and randomly surveyed a total of 4009 adults in metropolitan and country areas.¹³² The committee was informed that two individuals with MCS were invited by the DoH to participate in the planning of the most recent survey. Dr Fitzgerald told the Committee that while a significant proportion of the population, (16.4%) experiences some chemical sensitivity, less than one per cent (0.9%) reports an MCS condition.¹³³

Based on the results of the two surveys, a total of 0.9% or 35 people reported that they had been told by a medical doctor that they had MCS. It was noted that there were more females (27) than

¹²⁹ Report of the Standing Committee on the Environment and Public Affairs in relation to the Alcoa Refinery at Wagerup Inquiry, Western Australian Legislative Council, Report 11, October 2004, p55.

¹³⁰ Fitzgerald, oral evidence, Hansard, p20.

¹³¹ Ibid., p19.

¹³² Fitzgerald, J. and Mangas, S., Summary of results of Health Monitor Surveys (September 2002, June 2004) on Multiple Chemical Sensitivity (MCS) for the Social Development Committee, Hazardous Substances Section, Environmental Health Service, Department of Health, September 2004, p1.

¹³³ Fitzgerald, oral evidence, Hansard, p19.

males (8) in this group. The survey results also show that 23 of the 35 MCS sufferers resided in the metropolitan area, with the remaining 12 residing in the country.¹³⁴

The two surveys have also found that 16.4% or 656 individuals reported sensitivity or health effects from exposure to chemicals (separate from the MCS group). More females (402) than males (254) comprised this group. A large number of this group (489) resided in the Adelaide metropolitan area, with a further 167 residing in the country.¹³⁵

The 2004 survey also found that 86% of the population who were not sensitive to chemicals 'strongly agreed' or 'agreed' with the statement 'chemical sensitivity is a valid condition with valid symptoms.' Of this non-chemically sensitive group 6.4% 'disagreed' or 'strongly disagreed' with the statement.¹³⁶

Findings from other Studies

Several witnesses to the Inquiry made reference to the New South Wales Adult Health Survey. In 2002, the NSW Department of Health's Centre for Epidemiology and Research surveyed 12,556 persons aged 16 and over. Questions asked in the survey included: "Have you ever been diagnosed with a chemical sensitivity?" and "Do certain chemical odours or smells regularly make you unwell?"¹³⁷

The survey found that about 25 per cent (24.6%) reported sensitivity to chemical odours with a higher proportion of females (29.9%) more likely to report sensitivity than males (20.1%). 2.9 per cent of respondents reported having been diagnosed with chemical sensitivity with no significant difference between females (3.4%) and males (2.4%).¹³⁸

The survey also found that there was no significant difference in the proportion of people reporting sensitivity to chemical odours between rural areas (23.7%) and urban areas (24.8%). Similarly this trend was evident among respondents who reported having been diagnosed with chemical sensitivity with 2.2% living in rural areas and 3.1% in urban areas.¹³⁹

There was no significant variation in the proportion of those with either diagnosed chemical sensitivity or those reporting sensitivity to chemical odours, based on level of socioeconomic disadvantage.¹⁴⁰

The NSW survey, which based its definition of MCS on the 1999 Consensus diagnostic criteria, sought to establish prevalence on the basis of overseas studies which estimate that between 2-6 per cent of adults have been diagnosed with MCS. On the basis of this data, it was considered reasonable to suggest that the burden of MCS related disease in Australia could be substantial.¹⁴¹

¹³⁴ Fitzgerald, J. and Mangas, S., Summary of results of Health Monitor Surveys (September 2002, June 2004) on Multiple Chemical Sensitivity (MCS) for the Social Development Committee, Hazardous Substances Section, Environmental Health Service, Department of Health, September 2004, p1.

¹³⁵ Ibid., p1.

¹³⁶ Ibid., p3.

¹³⁷ Report of the NSW Health Survey Program, Chemical Sensitivity, 2002, www.health.nsw.gov.au, p1.

¹³⁸ Ibid., p1.

¹³⁹ Ibid., pp1-2.

¹⁴⁰ Ibid., pp1-2.

¹⁴¹ Ibid., pp1-2.

The International perspective

The Inquiry heard that a number of overseas studies of the prevalence of MCS have been conducted, principally in the United States. In his submission, Professor Martin Pall advised the Inquiry that:

*“Epidemiological studies of MCS prevalence in the US have estimated a prevalence of severe MCS of about 3-4% of the population with perhaps another 10-15% or even more being more modestly affected”*¹⁴²

Reference in several submissions was made to the findings of a survey by Kreutzer, et al. Questions about chemical sensitivities were added to the 1995 California Behaviour Risk Factor Survey. The telephone survey of 4046 individuals found that 253 or 6.3% reported doctor diagnosed “environmental illness” or MCS. 643 or 15.9% reported being “allergic or unusually sensitive to everyday chemicals”.¹⁴³

While estimates on the prevalence of the condition vary from survey to survey, international studies have indicated that it is critical that both prevalence and the impact of the condition are measured in some way in order to rationalise the spending of additional resources to better understand MCS, and to enable better diagnosis and treatment of those afflicted.¹⁴⁴

Practitioner Estimates of Prevalence

Individual medical practitioners presenting evidence to the Inquiry have made observations through clinical practice regarding the incidence of MCS. Dr Bruce Wauchope, from the Bedford Medical Clinic in Bedford Park, a practitioner noted for treating a significant number of CF and MCS patients, expressed a view shared by several witnesses:

*“I believe that the societal incidence of MCS is growing but I am unable to comment on that with any data...The trouble is, by what diagnostic measure are you going to collect the data? It is a chicken and egg situation. We have ill people. We cannot classify them correctly, we cannot test correctly and therefore, we cannot help them. It is a very difficult thing.”*¹⁴⁵

Various practitioners provided estimates of the percentage of the population they believed to be suffering from chemical sensitivities generally and from multiple chemical sensitivity in particular.

Dr David Gillis, from the IMVS Department of Human Immunology at the Royal Adelaide Hospital, explained that the overlap of MCS with other syndromes presented difficulties in establishing prevalence of MCS.

*“One of the things about multiple chemical sensitivity is that it is not only multiple chemical sensitivity – these people also have fatigue, they have Fibromyalgia, they have a large range of other symptoms. Many people would call them polysymptomatic syndromes.”*¹⁴⁶

¹⁴² Pall, M.L. op.cit., p2.

¹⁴³ Kreutzer, R., Neutra, R.R. and Lashuay, N., Prevalence of People Reporting Sensitivities to Chemicals in a Population-based Survey, American Journal of Epidemiology, Vol 150, No. 1, The John Hopkins University, July 1999, p1.

¹⁴⁴ Kassirer, J. and Sandiford, K. (Cullbridge Marketing and Communications), Socio-Economic Impacts of Environmental Illness in Canada, 15 November, 2000, p3.

¹⁴⁵ Wauchope, oral evidence, Hansard, p12.

¹⁴⁶ Gillis, oral evidence, Hansard, p154.

Dr Gillis indicated to the Committee that a large percentage of those with CFS and other conditions such as FM also have MCS and that between 10 to 20 percent of the population may be suffering from hypersensitivities.¹⁴⁷

Dr Peter Cahalan, President of the Myalgic Encephalopathy/Chronic Fatigue Syndrome (ME/CFS) Society in SA, informed the committee that there are an estimated 7000 people in SA with ME/CFS. Based on a members poll conducted in 2001, Dr Cahalan estimates that around 3000 people, or 60% of members suffer from chemical sensitivities at some level.¹⁴⁸

The committee also heard that over his professional life, Dr Mark Donohoe has seen thousands of chemically sensitive sufferers.

*“...I have spent about 8 000 to 10 000 hours with people with chemical sensitivities – about 2000 people”.*¹⁴⁹

Dr Donohoe argues that the incidence and prevalence of MCS appears to be increasing.¹⁵⁰ He notes that the NSW population survey indicates that a significant number of the population are affected by chemicals.

*“About 1.8 percent is unable to work or participate in school because of the chemical sensitivity. A significant number – around one in 50 – is disabled sufficiently that they cannot go to work or school. It is not a trivial number That would translate to some tens of thousands of people in New South Wales out of work...and unable to return to work.”*¹⁵¹

It was noted that most surveys undertaken are based on self reporting or self diagnosis largely because MCS is not diagnosed as a specific condition.

On the basis of the survey data available to date, the Inquiry heard that it was not possible to estimate whether MCS was increasing. Dr Fitzgerald explained that he was unable to provide this information and that further research was required to determine whether there had been an increase in MCS in SA over the years.¹⁵²

It was suggested in several submissions to the Inquiry that an agreed upon standardised clinical definition, and classification for MCS under the International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM) was important to determining prevalence. According to Dr Donohoe, this would eliminate the confusion and misclassification resulting from “*a variable, subjectively defined case definition*,” particularly in cases relating to workplace compensation and social security matters.¹⁵³ These issues will be discussed in detail in Section Four of this report.

¹⁴⁷ Ibid., p156.

¹⁴⁸ Cahalan, oral evidence, Hansard, p141.

¹⁴⁹ Donohoe, oral evidence, Hansard, p97.

¹⁵⁰ Donohoe, M. (Dr.) (Fellow of the Australian College of Nutritional and Environmental Medicine), Public Submission Request for Modification to the International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM), 2002, p2.

¹⁵¹ Donohoe, oral evidence, Hansard, p110.

¹⁵² Fitzgerald, oral evidence, Hansard, p26.

¹⁵³ Donohoe, M. (Dr.) (Fellow of the Australian College of Nutritional and Environmental Medicine), Public Submission Request for Modification to the International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM), 2002, p2.

Summary

The Committee notes that the prevalence of MCS has not been widely surveyed and that available data provides, at best, a rough estimate of the numbers of people affected by the condition. Issues such as the reluctance of many medical practitioners to diagnose MCS, and the difficulties presented in diagnosis as a result of the overlap between MCS and a number of other conditions, add to the unreliability of this data. Nonetheless, the Committee acknowledges that the data available from Australian and overseas studies provides some indication of prevalence. These studies suggest that up to 6% of the population may have MCS, and that between 10-25% may have a sensitivity or experience health effects from exposure to chemicals.

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.

F. TREATMENT/ILLNESS MANAGEMENT

TREATING MCS

The Inquiry was advised that the medical profession has, apart from recommending avoidance of contact with all known irritants, not yet been able to identify what types of treatment regimes should be recommended and what types work best.¹⁵⁴ Dr Wendy Scheil told the Committee,

“...people view MCS from a treatment perspective incredibly differently. Some people say calling it a disease and treating it would help. Some people say that it would actually perpetuate the disease. Some people advocate for a multidimensional clinical treatment group, and some people say, 'Well, it's mainly an avoidance strategy.' ...even the research-based treatment regimes for it seem to vary, as well. I think that it still requires quite a bit of research into what works and, surprisingly, to me as an epidemiologist, quite a bit of the research seems to be difficult to implement. Part of that relates to the difficulty in picking your target group because of the lack of definitional criteria, and part to the lack of monitoring of interventions.”¹⁵⁵

The Committee heard that a wide variety of treatments are favoured and recommended for MCS, and that the treatment options prescribed vary from practitioner to practitioner. A range of opinions were put to the Inquiry concerning the effectiveness of treatments, and while some treatments were found to be effective by some practitioners, no conclusive data measuring the effectiveness of available treatment was presented.

Dr Bruce Wauchope informed the Committee that he used a number of treatments, among them Cholestipol, a cholesterol medication, antifungals, a low Glycaemic Index diet, and patient self monitoring.¹⁵⁶

¹⁵⁴ Scheil, oral evidence, Hansard, p52.

¹⁵⁵ Ibid., p51.

¹⁵⁶ Wauchope, oral evidence, Hansard, pp 3 & 10.

Dr David Gillis explained that he believed a multi-disciplinary approach was important in treating patients with MCS. Such an approach involved ensuring odorants were removed, that support was available, and addressing any symptoms the patients may have.¹⁵⁷

With regard the effectiveness of treatments, Dr Mark Donohoe told the Committee:

“...as a doctor who has been treating these people for the last 18 years...I would say that at the moment there is still no treatment.”¹⁵⁸

Dr Donohoe explained that his interest in environmental sensitivities led him to visit laboratories and treatment centres in the United States in 1988 and following his return he opened an environmental clinic, an inpatient unit in the Manly Waters Private Hospital. The clinic, the Committee was told, aimed

“...to provide a controlled environment for assessing people who claimed to have chemical sensitivities and to advise them on the kind of agents to which they were sickened or exposed.”¹⁵⁹

An audit of the unit was conducted after three and a half years to assess the benefits patients had experienced. It found patients attributed the majority of benefits they experienced to education and family support. Dr Donohoe told the committee:

“One of the reasons for closing down the unit was that the medical approaches of treatment – the drug therapies, the psychological and dietary counselling and the dietary advice – had not been effective in modifying their illness or, in any large way, reducing their disability...the net outcome was that they were better but not for the reasons we thought. We thought we were treating them with clever medical approaches; but, taking the best medical advice we had, the medical approaches did not work. However, the education, support and acknowledgement of the illness did make a significant difference to the majority of people who entered our clinic.”¹⁶⁰

The Committee heard that Dr Robert Loblay, another practitioner with considerable experience in working with patients with chemical sensitivities, believes:

“...there is no single treatment that has reproducibly been found to be helpful for that cluster of symptoms...Many claims have been made. However, I have been looking at this for over 20 years and, when someone comes up to me with a wonderful new magic treatment, I list off...all the wonderful new treatments I have heard over 20 years and that all of them have eventually fallen by the wayside when they were properly tested.”¹⁶¹

He explained that in his view there are:

“...natural fluctuations in illness and disease severity...”[and]... in many cases,...improvement would have happened anyway...”¹⁶²

¹⁵⁷ Gillis, oral evidence, Hansard, p157.

¹⁵⁸ Donohoe, oral evidence, Hansard, p104.

¹⁵⁹ Ibid., p98.

¹⁶⁰ Ibid., p98.

¹⁶¹ Loblay, oral evidence, Hansard, p190.

¹⁶² Ibid., p190.

Avoidance of chemicals, foods and medications that are known to trigger symptoms, was also acknowledged by the SATMCS as the most effective treatment for MCS. The SATFMCS submission notes that while common MCS treatment regimes have not been fully evaluated, clinical observations of the effectiveness of various treatments can provide sufferers with some guidance. They cite common recommendations as including Vitamin B12, glutathione, DHEA amino acids, and various anti-oxidant vitamins minerals and other nutritional supplements.¹⁶³

ILLNESS MANAGEMENT

Dr Jim Fitzgerald from the Department of Health told the Committee:

“As the cause of MCS remains obscure and diagnosis problematic, treatment strategies can only be based on understanding and supportive care.”¹⁶⁴

Research conducted by Dr Mark Cullen, Professor of Medicine and Public Health at the School of Medicine, Yale University, who first coined the term MCS, proposes that while there are no established specific therapies for the treatment of MCS, a number of factors are necessary in the treatment of “almost every patient”. He identifies education, support, environmental modification and economic support as the essential factors in illness management.¹⁶⁵ Each of these is explained thus:

Education:

A careful explanation of MCS, including what is and is not known about its cause and natural history, is required for the patient, their family, and often, the employer. It is crucial that the patient understand that the disorder is neither lethal nor curable;

Support:

This may include self-help groups, counsellors, social workers, or more formal clinical care to manage the inevitable psychologic and social issues that the patient with MCS will have to confront. The goal should be return to the highest level of social, personal and occupational function of which the patient is capable;

Environmental modification:

Although removing the patient from all contact with modern life is both highly counterproductive and unlikely to succeed, some changes are important, especially a removal or reduction in the heaviest exposures that are associated with the onset of illness. Often, this entails a work modification and changes in the home environment to make it comfortable and safe;

Economic support:

If MCS results in profound levels of disability or a marked reduction in income because of job modification, it is necessary to use available entitlement and benefit programs to guarantee that severe hardship does not undermine treatment and rehabilitation. Rehabilitation to promote new occupational possibilities within limitations is highly desirable.”

¹⁶³ SA Taskforce Multiple Chemical Sensitivity (SATFMCS), written submission, p33.

¹⁶⁴ Fitzgerald, oral evidence, Hansard, p21.

¹⁶⁵ Report of the Standing Committee on the Environment and Public Affairs in relation to the Alcoa Refinery at Wagerup Inquiry, Western Australian Legislative Council, Report 11, October 2004, p61

Dr Cullen has noted that beyond these measures, little else has been shown to be helpful. Radical therapies, including isolation from all chemicals, megavitamins, antioxidants, desensitization regimes and fat purification, he claims are “expensive and of unproved value”. The benefits of behavioural therapy and psychiatric treatment, including pharmacologic and/or psychotherapeutic modalities, he reports, also remain unproven.¹⁶⁶

Other research provided in a submission to the Inquiry outlines the findings of a three year study¹⁶⁷ which investigated the management of chronic illnesses such as ME/CFS. In this study a clear distinction is made between treatment and illness management, which refers to measures that can be taken to “...make a difference to the way that people live their day to day lives when they have a chronic illness.”¹⁶⁸ Key findings of the study suggest that individuals with chronic illnesses require a framework for understanding their illness and support from others in assisting with illness management. It is proposed that:

“Doctors, health professionals and family can make the difference between whether a person is able to manage or not...one of the most important contributions...a doctor can offer is a considered diagnosis, followed with information (sometimes written) and support.”¹⁶⁹

An adjustment of hopes and expectations around work, study, family and other interests is often also required.

These findings are reflected in many personal accounts presented in submissions to the Inquiry. Many submissions voiced their frustration at the way they had been treated by the medical profession. Issues of concern identified by people with MCS at a public workshop¹⁷⁰ held in Adelaide in September 2004, also reflect the belief that doctors generally did not acknowledge the views of people with MCS regarding their own illness. Women in particular, it was proposed, “were often dismissed as hysterical.”¹⁷¹

Other issues identified included a general lack of access to informed medical and GP services; and absence of a network of supportive professional medical practitioners.¹⁷²

Summary

It is clear from the information provided to the Inquiry through submissions and in evidence, that MCS is a highly controversial condition which raises many issues. Evidence indicates that there is not only a lack of consensus on an appropriate term and case definition for the condition but that diagnosis is problematic.

The Committee notes that the debate surrounding MCS is characterised by a plethora of different views and approaches. While some progress has been made in research to establish whether MCS

¹⁶⁶ [ibid.](#), p61.

¹⁶⁷ The study was undertaken as part of a Doctor of Philosophy thesis at the ANU by Roslyn Valerie Woodward in 1993.

¹⁶⁸ Woodward, written submission, p1.

¹⁶⁹ [Ibid.](#), p4.

¹⁷⁰ The workshop was co-sponsored by the SATFMCS and the ME/CFS Society in SA.

¹⁷¹ SATFMCS and the ME/CFS Society SA, [MCS Workshop Report, 2004](#), p1.

¹⁷² [ibid.](#), pp1-2.

exists as a disease entity, what causes it, and consequently how best to treat the condition, these issues cannot be reconciled at this point in time as there is no objective evidence supporting the different theories and viewpoints that have been put forward.

The Committee acknowledges that the lack of a consistent approach has made treatment of MCS difficult for many practitioners and sufferers. The Committee notes that there are a range of opinions on how best to treat MCS. In the absence of evidence which measures the effectiveness of available treatments, the Committee has had to rely on the anecdotal evidence presented.

While no one treatment offers hope for all sufferers, there is evidence that the condition can be managed if sufferers receive empathy, information about their condition and how to manage it, and support from medical practitioners, family and friends and more broadly in the workplace and community.

The Committee has made a number of recommendations to ensure that MCS sufferers receive compassionate and informed treatment and care until such time as developments in the medical and scientific community are able to further clarify this complex area.

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 TWO: CHEMICALS AND MCS

A. THE CHEMICAL CAUSATION DEBATE

As indicated earlier in this report, the cause of MCS remains uncertain. Arguments and evidence presented to the Inquiry show that the medical and scientific community is divided on the fundamental issue of whether chemicals are indeed the cause of MCS.

The Inquiry heard that while some research supports the view that chemicals are implicated either as causal agents or in triggering the symptoms of MCS, others argue that there is no objective evidence supporting a link to any specific chemical or group of chemicals as the cause of MCS.

THE ARGUMENTS FOR AND AGAINST

Arguments Against Chemical Association

The Inquiry was informed that the issue of chemical causation of MCS is open to serious question, indeed, that chemicals are not the cause of the condition.¹⁷³ The Plastics and Chemicals Industries Association (PACIA), Australia's peak industry body representing the plastics and chemicals sector, points to research undertaken by Australian toxicologist Dr Roger Drew, for its submission. This research argues that:

*"There are no tests that can be applied to chemicals to predict a potential association with IEL."*¹⁷⁴

The PACIA submission refers to a number of reviews which support the view that a direct link between MCS and chemicals as causative agents is unfounded. The findings of an interagency workshop on MCS conducted by several US Federal health agencies in 1998, indicate that:

*"...The scientific evidence is currently inadequate to enable determination of the associations between human exposure(s) to chemicals in the environment and the development or exacerbation of MCS."*¹⁷⁵

Further a review of some 200 publications on MCS in the biomedical literature undertaken by the Health Council of the Netherlands in 1999 concluded that:

*"...the relationship between exposure to chemical substances and reported non-specific health disorders is at best associative."*¹⁷⁶

PACIA put forward the view that due to the lack of tests and objective evidence for a causative association with environmental chemicals, regulatory intervention that imposes further management control of industrial, consumer, agricultural or pharmaceutical chemicals in Australia, would be inappropriate.¹⁷⁷

¹⁷³ Plastics and Chemical Industries Association (PACIA), written submission, p15.

¹⁷⁴ The PACIA have indicated in their written submission that they favour the use of the term Idiopathic Environmental Intolerance, rather than MCS.

¹⁷⁵ Plastics and Chemical Industries Association (PACIA), written submission, p11.

¹⁷⁶ Ibid., p11.

¹⁷⁷ Ibid., p3.

The argument advanced by PACIA aligns with proponents of the view that there is a psychogenic/psychological explanation for the onset of MCS. In their submission PACIA refers to studies of the literature which argue that:

*“...the most compelling evidence suggests that one or more psychological disorders best account for the various symptom pictures reported by individuals with a diagnosis of MCS.”*¹⁷⁸

It further argues that there is very little evidence to support a toxicogenic theory and that psychogenic/psychosomatic theories are supported by a growing body of evidence that fulfils *“...all the criteria used in science and medicine for evaluating cause and effect relationships.”*¹⁷⁹

Associate Professor John Edwards from the Department of Environmental Health, School of Medicine, Flinders University, explained to the Inquiry that many studies support a psychogenic or belief based origin of MCS.¹⁸⁰ Psychogenic theory suggests that the lack of a definite cause of symptoms experienced by MCS patients, and the inability of doctors to define the cause, leads to further anxiety and symptoms. In his submission, Dr Edwards explains that attribution of cause to some physical or chemical factor may alleviate this anxiety and reinforce the belief in MCS.¹⁸¹

Arguments for Chemical Association

Practitioners who recognise MCS argue that research has established a strong association between chemical exposure and onset of the condition, and that the association is either chemical causation or significant exacerbation of an underlying (presumably partly genetic) predisposition.

In relation to arguments that purport a psychological or psychogenic link, practitioners such as Dr Mark Donohoe, point to sources such as Harrison's Principles of Internal Medicine, which propose that *“evidence does not support MCS as a purely psychogenic illness.”*¹⁸²

Literature reviews have noted that as MCS does not fit established knowledge regarding disease processes, the conclusion is reached that MCS must be psychological in origin.¹⁸³ The review of scientific literature undertaken in Britain by Graveling et al in 1998 notes that while:

*“...some authors have chosen to categorise MCS as a belief fostered by those providing the treatment, others have reviewed such theories and concluded that although tenable in some individual cases, it is highly unlikely that such a mechanism can account for most cases.”*¹⁸⁴

Indeed, PACIA acknowledges in its submission that it is important not to prematurely conclude that because an organic cause has yet to be determined, MCS must be considered a psychological disorder.¹⁸⁵

¹⁷⁸ Ibid., p14.

¹⁷⁹ Ibid., p11.

¹⁸⁰ Dr John Edwards, written submission, p3.

¹⁸¹ Ibid., p4.

¹⁸² Donohoe, M. (Dr.) (Fellow of the Australian College of Nutritional and Environmental Medicine), Public Submission Request for Modification to the International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM), 2002, p2.

¹⁸³ Graveling, R.A., Pilkington, A., George, J.P.K., Butler, M.P. and Tannahill, S.N., A Review of Multiple Chemical Sensitivity. Journal of Occupational and Environmental Medicine, 56, 1999, p84.

¹⁸⁴ Ibid., p82.

The lack of consistent findings emerging from a number of reviews of the scientific literature on MCS makes it apparent that both psychological and some biologically based theories have attracted support despite conflicting evidence.

The Unknown Implications of Chemical Use

While the link between chemical causation and MCS may not be objectively established, the Committee was advised by Mr. John Kassebaum, Manager of the Rural Chemical Program in the Department of Primary Industries and Resources (PIRSA) SA, that in Australia there are between 6000-8000 approved chemical products containing 400 different active agents, and that approximately 6000 of these products are in significant use.¹⁸⁶

Several submissions to the Inquiry presented arguments that the effects on human subjects of this wide range of chemicals are largely unknown. The world renowned scientist, Dr David Suzuki, in correspondence to the Hon Sandra Kanck, during the formative stages of instigating this Inquiry pointed out that:

“We live in a world in which tens of thousands of completely novel chemicals now assault us through the air, water and food. Almost none has been tested even in the most primitive way for their toxicity to humans. And when it comes to synergistic interactions between two or more compounds there is no way that science can possibly address the possibility because the number of combinations and permutations of concentration, conditions etc, becomes so enormous, even if we had the facility to do testing, the cost would be prohibitive.”¹⁸⁷

Given the inconclusive evidence on the effects of chemicals generally and the role and effects of chemicals in relation to MCS in particular, the Committee heard that a precautionary approach is needed in considering the implications of chemical use.

CHEMICAL CAUSES AND TRIGGERS

While the link between chemicals as the causative agents in MCS has not been proven, research has established an association between chemicals that may either initiate or trigger MCS symptoms.

The committee heard that it was important to distinguish between chemicals that initiate or cause MCS and those that subsequently trigger symptoms once the condition is established. The SATFMCS informed the Inquiry that MCS initiation can occur due to a single, high dose chemical exposure or by repeated low dose exposures over time. Following initiation, chemical sensitivities broaden so that multiple environmental incitants, often unrelated to the initial exposure, begin triggering symptoms.¹⁸⁸

Research also suggests that the inducing chemical or substance may or may not be the same as the substances that thereafter provoke or “trigger” responses.¹⁸⁹

¹⁸⁵ Plastics and Chemical Industries Association (PACIA), written submission, p14.

¹⁸⁶ Kassebaum, oral evidence, Hansard, p131.

¹⁸⁷ Legislative Council Hansard, 14 May 2003.

¹⁸⁸ SA Taskforce Multiple Chemical Sensitivity (SATFMCS), written submission, p17.

¹⁸⁹ Ashford, N. and Miller, C., Chemical Exposures- Low Levels and High Stakes (2nd edition). Van Nostrand Reinhold, New York, 1998, p7.

Chemicals Linked to MCS Initiation

Professor Martin Pall, from the School of Molecular Biosciences at Washington State University, submitted a number of his research papers to the Inquiry in which he argues that the chemicals involved in initiation of MCS most often fall into two classes: organophosphate/carbamate pesticides and volatile organic solvents. Professor Pall suggests that MCS cases are thought to have become substantially more prevalent following moves in the 1970s to lessen air flow in buildings as an energy conservation measure. He argues that many cases of MCS are often reported to be initiated by so-called “sick building syndrome” situations. According to Professor Pall:

“Remodelling of buildings is reported to often produce a series of cases of MCS presumably due to the outgassing of volatile organic solvents from the new materials and glues being used.”¹⁹⁰

International research which shows that exposure to pesticides, volatile organic compounds, solvents and petrochemicals can initiate MCS, was also presented by the SATFMCS in its submission to the Inquiry. These studies have identified a range of other products associated with MCS initiation. These include surgical anaesthesia, hair dyes, pentachlorophenol-based wood preservatives, adhesives, propane gas, inorganic chlorine compounds, pharmaceutical drugs, film developing and fixing chemicals, formaldehyde, glutaraldehyde, new carpets, silicone breast implants, new paints, and toluene disocyanate.¹⁹¹

The SATFMCS submission also cites a US population study undertaken in 2003 which found that exposure to pesticides, new building products, harsh cleaning agents, solvents and petrochemicals were the most frequently cited causes of MCS initiation.¹⁹²

The claim that a large number of chemicals have been shown to initiate MCS and elicit MCS reactions following sensitisation is also supported by the Australian Chemical Trauma Alliance Inc. (ACTA) In its submission, the ACTA lists the following chemicals as those predominantly associated with initiating MCS: Organophosphate insecticides; other pesticides including organochlorins¹⁹³; herbicides including 2,4-D and Glyphosate; solvents; sterilants, including formaldehyde and Glutar Aldehyde; and cleaning products particularly those based on Glycol Ethers.¹⁹⁴

Chemicals Implicated in Triggering MCS Symptoms

The SATFMCS also drew on the findings of the US population study conducted in 2003 in identifying a range of agents frequently cited as triggering symptoms of MCS. They include perfume, cigarette smoke, pesticides, cleaning products and vehicle exhaust.¹⁹⁵

¹⁹⁰ Pall, M.L. op.cit., p2.

¹⁹¹ SA Taskforce Multiple Chemical Sensitivity (SATFMCS), written submission, p17.

¹⁹² Ibid., p17.

¹⁹³ The committee was advised by Dr Jim Fitzgerald from the DoH that organochlorines such as 2,4-D are known to be toxic and persistent in the environment and that as most have been banned, they no longer present reason for concern. Dr Fitzgerald acknowledged, however, that he was unable to say whether these chemicals presented a concern to those with MCS during the time in which they were used. (Source: Fitzgerald, oral evidence, Hansard, p29.)

¹⁹⁴ Australian Chemical Trauma Alliance Inc. (ACTA), written submission, p1.

¹⁹⁵ SA Taskforce Multiple Chemical Sensitivity (SATFMCS), written submission, p17.

An extensive list of chemicals seen as eliciting MCS reactions were submitted by the ACTA. They include:

Pesticides; fragranced products such as perfumes, aftershave, deodorants; virtually all volatile organic compounds, including paint, carpeting, printing ink, soft plastics, synthetic fabrics, cigarette smoke, cleaning products, chlorinated and fluorinated water; pharmaceutical drugs and anaesthetics; electromagnetic radiation (EMR), encompassing in extreme cases, sensitivity to light; common incidents of EMR reactions including computers, televisions, vehicles and other appliances with motors, photocopiers, mobile and landline phones and other microwave transmitters and high tension power lines.¹⁹⁶

SA Department of Health records show that of a range of chemicals that sufferers most commonly identify as problematic, pesticides, and Glyphosate in particular, are frequently cited as chemicals that can trigger MCS. The Department's principal toxicologist, Dr Jim Fitzgerald, informed the committee that:

*"...MCS sufferers often mention pesticides-and one in particular, glyphosate, which is very common."*¹⁹⁷

Dr Fitzgerald pointed out that Glyphosate is more commonly known as Roundup, a very common weed killer which can be bought off the shelf, and which does not require a licence to use.¹⁹⁸

Numerous individual submissions to the Inquiry indicated that the use of chemicals for weed control by local Councils are particularly pernicious for those with MCS. Many of these submissions note that the wide use of Glyphosate-based herbicides such as Roundup, are of particular concern.

A number of witnesses to the Inquiry also identified traffic pollution, which is recognised as "*a very complex mixture of chemicals*", as a major concern to those with MCS.¹⁹⁹ Dr Bruce Wauchope, a General Practitioner with over 10 years of experience in working with Chronic Fatigue sufferers in SA, gave evidence that while household chemicals, food and smells all have variable effects, diesel fumes are almost a universal common trigger of MCS.²⁰⁰

Dr Wauchope acknowledged that while there is no known trigger link:

*"Cigarette smoke, paint, gasoline, new carpet and furniture, household cleaners, perfume, newspapers, pesticides, alcohol, caffeine, and food additives are some of the chemical exposures commonly cited as producing the symptoms of MCS."*²⁰¹

International studies have also shown that a range of chemicals have also been shown to bring about reactions in the general population. A telephone survey conducted in 1995 as part of the California Behaviour Risk Factor Survey, indicates that a wide range of everyday chemicals can trigger reactions within the wider community. Survey respondents identified a range of everyday

¹⁹⁶ Australian Chemical Trauma Alliance Inc. (ACTA), written submission, p1.

¹⁹⁷ Fitzgerald, oral evidence, Hansard, p26.

¹⁹⁸ [Ibid.](#), pp26-7.

¹⁹⁹ [Fitzgerald, oral evidence, Hansard, p28.](#)

²⁰⁰ [Wauchope, oral evidence, Hansard, pp12-13.](#)

²⁰¹ [Ibid.](#), p11.

chemicals such as environmental and tobacco smoke, cologne, aftershave or perfumes as chemicals which made them sick.²⁰²

In addition, the survey on MCS undertaken by the DoH in SA in 2004 established that cosmetics were among the chemicals respondents identified as reacting to. The survey shows that an estimated 10 % of women respondents claimed to be sensitive to some cosmetics.²⁰³

Summary

The Committee notes that the cause of MCS is uncertain. Evidence presented suggests that while there is no objective evidence to show a causal link between MCS and chemicals, research has been able to establish an association.

The Committee also notes that establishing the cause of MCS is central to clarifying the status of the condition.

While it is not the role of this Committee to assess the validity of the scientific data available in the body of evidence on MCS, it believes that until clear evidence is presented indicating that chemicals play no role in initiating or triggering the symptoms of the condition, a cautionary approach in considering the implications of chemical use is required. Such an approach is a necessary cornerstone of sound public health policy.

For the purposes of this Inquiry the Committee has elected to base its understanding of MCS on the 1999 Consensus criteria of the condition. While this position assumes an association between chemicals and MCS, it does not dismiss evidence which suggests other causes.

B: CHEMICAL USE AND THE REGULATION OF CHEMICALS – AN OVERVIEW OF THE REGULATORY ENVIRONMENT

THE COMPLEXITIES OF CHEMICAL REGULATION AND MCS

It was acknowledged in a large number of submissions to the Inquiry that responsible management and use of chemicals is critical to ensuring that the potential harmful effects of chemicals are minimised.

The Inquiry was informed that the Australian chemical industry is comprehensively regulated to ensure that appropriate controls are in place for the protection of people, property and the environment. A number of regulations and authorities are involved in managing a range of chemicals at the Federal, State, and Local Government level. The Inquiry heard that chemicals are assessed and registered under separate schemes according to their end use – industrial, agricultural/veterinary, therapeutic, and food related. A wide range of Commonwealth, State and

²⁰² Kreutzer, R., Neutra, R.R. and Lashuay, N., Prevalence of People Reporting Sensitivities to Chemicals in a Population-based Survey, *American Journal of Epidemiology*, Vol 150, No. 1, The John Hopkins University, July 1999, p3.

²⁰³ Fitzgerald, oral evidence, Hansard, p24.

Territory legislation covers the management of chemicals in the environment, community, and in relation to worker health and safety.²⁰⁴

On the basis of evidence presented, a brief overview of the current regulatory environment at the Federal, State and Local government levels has been prepared for this report. Key chemicals that research has established are associated with MCS are identified and considered as part of a broader discussion of measures that need to be taken to minimise the impact of chemicals in the environment, workplace and community at large. The large number of chemicals associated with MCS, present in a range of environments, has necessitated such an approach.

FEDERAL REGULATORY RESPONSIBILITIES

The Inquiry was informed that the Commonwealth is responsible for the assessment of chemicals and the coordination of national chemicals management, with the States and territories managing the control of chemicals use.²⁰⁵

Regulation of chemicals occurs primarily through four national chemicals assessment and registration schemes which cover food (Food Standards Australia New Zealand - FSANZ); industrial chemicals (National Industrial Chemicals Notification & Assessment Scheme – NICNAS); pharmaceuticals (Therapeutic Goods Administration –TGA), and agricultural and veterinary chemicals (Australian Pesticides and Veterinary Medicines Authority – APVMA). The scope of each of the schemes is defined by legislation which also specifies what chemicals or chemical products are to be covered by each scheme, as well as the requirements for the manufacture and/or importation of chemicals.²⁰⁶

Key Federal Agencies

In relation to chemicals that present a risk for those with MCS, two agencies in particular play a central role in chemical regulation – the Australian Pesticides and Veterinary Medicines Authority (APVMA), and the National Industrial Chemical Notification and Assessment Scheme (NICNAS).

Mr John Kassebaum from PIRSA told the Inquiry that the APVMA is the Australian Government statutory authority responsible for the assessment and registration of pesticides and veterinary medicines prior to sale, and their regulation up to and including the point of retail sale.²⁰⁷

In a submission received from the APVMA it was explained that pesticides include agricultural and many household chemicals such as insecticides, herbicides and fungicides; swimming pool products and products for treating mould and for preventing rot and infestation in marine structures. Veterinary medicines, the Inquiry was informed, include veterinary chemical products such as vaccines, antibiotics, worming treatments, flea and tick washes and other parasiticides for both domestic and production animals.²⁰⁸

²⁰⁴ Plastics and Chemical Industries Association (PACIA), written submission, p2.

²⁰⁵ Commonwealth Department of Environment and Heritage, National Profile of Chemicals Management Infrastructure in Australia, Environment Australia, November 1998, p2.

²⁰⁶ Commonwealth Department of Health and Ageing, Office of Chemical Safety written submission, p1 and National Industrial Chemicals Notification & Assessment Scheme website: <http://www.nicnas.gov.au/ACA.asp>.

²⁰⁷ Kassebaum, oral evidence, Hansard, p125 & Australian Pesticides and Veterinary Medicines Authority, written submission, p1.

²⁰⁸ Australian Pesticides and Veterinary Medicines Authority, written submission, p1.

The Inquiry was informed that APVMA operates in accordance with its governing legislation, the Agricultural Chemicals (Administration) Act 1992 and the Agricultural and Veterinary Chemicals Code Act 1994.²⁰⁹

The Inquiry was advised that before a pesticide or veterinary medicine can enter the Australian market it must undergo a rigorous assessment process to ensure that it meets high standards of safety and effectiveness. Under this process data for each product is extensively evaluated to establish that it is safe to animals and people using and exposed to it, and that it will not damage the environment, among other factors. Assessments are then expressed on the labels for products.²¹⁰

Mr Kassebaum told the Committee that the APVMA also relies on expert advice from a number of Federal Government agencies on issues such as health effects (Therapeutic Goods Administration), environmental effects (Environment Australia) and on occupational health and safety matters (various specialist agencies).²¹¹ In addition the APVMA receives advice, where appropriate, from relevant State and Territory authorities.²¹² The Inquiry heard that State and Federal agencies work closely with each other in arriving at national decisions.²¹³

*“In the process of coming to a national decision...we talk to each other and discuss things with each other; and also we work with the national bodies to get national decisions where we can.”*²¹⁴

With regard international best practice, the APVMA informed the Inquiry that their requirements and processes meet the highest standards of international best practice.²¹⁵

The committee heard the APVMA has the capacity to request or instruct manufacturers to recall or ban products.²¹⁶ Under the APVMA’s Chemical Review Program reviews of registered pesticides and veterinary medicines are conducted to ensure that they meet current standards of registration, and do not pose unacceptable risks to people, the environment or trade. The reviews also enable new information or issues that emerge to be assessed and for appropriate corrective action to be taken.²¹⁷

A further safeguard is achieved through the APVMA’s Pesticide and Veterinary Products Adverse Experience Reporting Programs (AERP) which seeks to ensure that:

*“... registered products remain safe, effective, ...of acceptable quality, and are used in the best possible way..and that instructions and warnings on labels are appropriate.”*²¹⁸

²⁰⁹ Ibid., p1.

²¹⁰ Ibid., p1.

²¹¹ [Kassebaum, oral evidence, Hansard, p131.](#)

²¹² Australian Pesticides and Veterinary Medicines Authority, written submission, p1.

²¹³ [Kassebaum, oral evidence, Hansard, p133.](#)

²¹⁴ Ibid., p133.

²¹⁵ Australian Pesticides and Veterinary Medicines Authority, written submission, p1.

²¹⁶ [Kassebaum, oral evidence, Hansard., p131.](#)

²¹⁷ Australian Pesticides and Veterinary Medicines Authority, written submission, p1.

²¹⁸ Ibid., p2.

It was explained in the APVMA submission that while the veterinary AERP has been operating since 1995, the pesticides AERP was only introduced in December 2003. The AERP receives adverse experience reports from the general public, veterinarians, farmers, agronomists, health workers, state departments and product registrants. All reports are maintained on an internal database and investigated to determine whether there is a link between the use of or exposure to the product and the adverse experience reported. (APVMA p2) While a trend analysis has yet to reveal any emerging issues, it was acknowledged in the submission that this may be due to the relatively low total number of reports received to date for the pesticides program.²¹⁹

In relation to MCS specifically, the Inquiry was informed that:

“The APVMA has received and continues to receive reports of suspected ‘multiple chemical sensitivity’ to pesticides, (and to veterinary medicines to a very limited extent.)”²²⁰

The submission notes the “considerable challenge” posed to regulatory authorities such as the APVMA by reports from people with MCS. It was explained that in some reports of suspected MCS, the causative agent, that is the registered pesticide product, is not clearly identified, while other reports do not contain supporting medical evidence to indicate that the clinical symptoms reported are related to chemical exposure.²²¹ The submission emphasised that the APVMA must rely on valid scientific and medical information when determining causality and subsequent regulatory actions. It was noted that:

“The APVMA may not be able to establish a causal link between the chemical exposure and the reported symptoms or take regulatory action as a result of reports.”²²²

As a consequence, it was explained, individuals reporting adverse experiences can become frustrated if no immediate regulatory action is taken on the basis of their report. The Inquiry was informed that while individual reports of MCS have not as yet resulted in regulatory action, the APVMA will continue to work closely with other government departments and the medical profession to better understand MCS and its causes.²²³

Advice on matters relating to human health, the submission informed the Inquiry, will be sought through an advisory committee, including an independent clinical medical expert, which the APVMA is establishing.²²⁴

Assessing Industrial Chemicals

A submission received from the Office of Chemical Safety (OCS) explained to the Inquiry that the National Industrial Chemical Notification and Assessment Scheme (NICNAS) is the Australian Government’s regulatory body for industrial chemicals. NICNAS is located within the OCS as part of the Therapeutic Goods Administration (TGA) group of regulators in the Australian Department of Health and Ageing.²²⁵

²¹⁹ Ibid., p3.

²²⁰ Ibid., p3.

²²¹ Ibid., p3.

²²² Ibid., p3.

²²³ Ibid. p3.

²²⁴ Ibid. p2.

²²⁵ Commonwealth Department of Health and Ageing, National Industrial Chemicals Notification & Assessment Scheme, written submission, p1.

Under the Industrial Chemicals (Notification and Assessment) Act 1989, an industrial chemical is described as any chemical that has an industrial use. Industrial chemicals include dyes, solvents, adhesives, plastics, photographic materials, as well as chemicals used in the home such as paints, cleaning agents and cosmetics and toiletries. (NICNAS website) They also include laboratory chemicals, chemicals used in mineral and petroleum processing, refrigeration, printing and photocopying.²²⁶

NICNAS was established to protect workers, the public, and the environment from the harmful effects of industrial chemicals, and aims to ensure the safe use of industrial chemicals by making risk assessment and safety information on chemicals and their potential risks widely available.²²⁷

The submission outlines the range of assessment activities NICNAS performs under its governing Act. These include assessing industrial chemicals that are new to Australia for their health and environmental effects before they are used and/or released.²²⁸ Chemicals already in use, known as existing chemicals on a priority basis (PECs), are also assessed in response to specific concerns about potential health and/or environmental effects.²²⁹

Declaration of a chemical as a PEC ensures that a closer examination and detailed assessment of chemicals that are seen to pose a potential risk to human health and/or the environment are made, enabling recommendations to be made regarding their control and risk reduction.²³⁰ The Inquiry was informed that any interested person can nominate a chemical of potential concern for declaration as a PEC.²³¹ The Inquiry was also informed that most of the 38,000 existing chemicals in Australia have never had an independent assessment of their potential risks.²³²

It was explained that assessments of new or existing chemicals are conducted on a case-by-case basis and are based on a weight of evidence approach, taking into account scientific judgement, knowledge of the mechanism of action of effects and recognition of the inherent uncertainty in extrapolating animal data to humans.²³³

NICNAS acknowledges that following initial assessments, changes in circumstances may occur which require a reassessment, or secondary notification and assessment, of a chemical. Tailored or focussed assessments are also undertaken addressing specific aspects of an existing chemical, such as its use or intrinsic adverse effects.²³⁴

As well as ensuring industrial chemicals are assessed, NICNAS disseminates information about industrial chemicals and its activities through the release of public assessment reports and the

²²⁶ Ibid., p2.

²²⁷ Ibid., pp1-2.

²²⁸ Ibid., pp2-3.

²²⁹ Ibid., p1.

²³⁰ Ibid., p3.

²³¹ Ibid., p4.

²³² Ibid., p3.

²³³ Commonwealth Department of Health and Ageing, National Industrial Chemicals Notification & Assessment Scheme, written submission, Attachment 1, p1.

²³⁴ Commonwealth Department of Health and Ageing, National Industrial Chemicals Notification & Assessment Scheme, written submission, p4.

Chemical Gazette.²³⁵ A range of other information on chemicals of concern and matters of interest, is also produced, and includes Chemical and Safety Information Sheets; Alerts; and Existing Chemicals Information Sheets.²³⁶

The Inquiry was advised that a register of all importers and manufacturers of industrial chemicals in Australia is maintained and compliance with the Act is sought through the development of partnerships with industry. Instances of non-compliance are minimised through education and awareness raising activities and outreach services to new registrants. In cases where compliance is not achieved, penalties can be applied under the Act.²³⁷

In addition, an Australian Inventory of Chemical Substances (AICS) is maintained, listing all industrial chemicals in use in Australia. It was noted in the submission that chemical identity data only is listed, and that the AICS does not provide information on toxicity.²³⁸

According to NICNAS, the scientific program for assessing industrial chemicals in Australia that it has established meets international best practice standards.²³⁹

Australia's International Obligations

The Inquiry was informed that NICNAS also ensures that Australia meets International Treaty Obligations, particularly in relation to two significant treaties – the Rotterdam and Stockholm Conventions.²⁴⁰

It was explained that the Rotterdam Convention on the Prior Informed Consent (PIC) Procedure for Certain Hazardous Chemicals and Pesticides in International Trade Treaty (Rotterdam Convention) and the Stockholm Convention on Persistent Organic Pollutants (POPs) Treaty, aim to improve access to chemical safety information.²⁴¹

The Rotterdam Convention was ratified in Australia in May 2004 and came into force in August 2004. Enabling legislation - the Industrial Chemicals (Notification and Assessment) Amendment (Rotterdam Convention) Bill 2004 was passed in the Senate in March 2004.²⁴² The Convention aims to promote shared responsibility and cooperation among parties in the international trade of certain hazardous pesticides and industrial chemicals to protect human health and the environment from potential harm and contribute to their environmentally sound use, by facilitating information exchange about their characteristics.²⁴³

The Stockholm Convention which was also ratified in May 2004 and which came into effect in August 2004, requires all parties to phase out the use and manufacture of what are considered to be some of the most toxic chemicals on earth. The Inquiry learnt that:

²³⁵ Ibid., p1.

²³⁶ Ibid., p4.

²³⁷ Ibid., p5.

²³⁸ Ibid., p5.

²³⁹ Ibid., p1.

²⁴⁰ Ibid., pp5-6.

²⁴¹ Ibid., p5.

²⁴² Ibid., pp 5-6.

²⁴³ Ibid., p6.

“The ratification of the...Convention is consistent with the evolution and maintenance of a regulatory system that promotes the sustainable use of chemicals.”²⁴⁴

Persistent Organic Pollutants (POPs) which fall under this convention are characterised by persistence, bioaccumulation, potential for long-range environmental transport and adverse effects on human health and the environment. It was explained that the Convention will initially:

“...cover control measures on 12 POPs, including the industrial chemicals polychlorinated biphenyls (PCBs), hexachlorobenzene and the by-product dioxins and furans.”²⁴⁵

The Inquiry was informed that parties to the convention are required to take into account the characteristics of POPs when conducting assessments on new and existing chemicals.²⁴⁶

Industry and the Regulators – Co-operative relations

As indicated in the NICNAS submission, regulatory bodies in Australia work closely with industry to ensure compliance with their governing Acts. Industry groups such as the National Association for Crop Production and Animal Health (Avcare) informed the Inquiry that they work in partnership with the APVMA and Government to:

“...ensure that the regulatory requirements in Australia are of the highest and most appropriate standard, reflecting international best practice.”²⁴⁷

Avcare, the Inquiry learnt, represents the large majority of all manufacturers, registrants, and marketers of agricultural and veterinary (agvet) chemicals in Australia. The Avcare submission points out that Avcare has encouraged the APVMA in developing and implementing the AERP as a quality assurance component of the National Registration Scheme. Avcare notes that:

“We see such post registration activities by the regulator are paramount to instil public confidence in responsible use of registered agvet chemicals in Australia.”²⁴⁸

CHEMICAL MANAGEMENT AND THE EFFECTIVENESS OF THE REGULATORY STRUCTURE

Evidence presented to the Inquiry identified issues that impact on the management of chemicals nationally. In 1998, a National Profile was prepared by Environment Australia to assess Australia's national infrastructure for the management of chemicals. It found that Australia's chemical management infrastructure has undergone considerable change and innovation over the past decade. Such changes have included enactment of many of the key laws for administering chemicals.²⁴⁹

The Committee was informed that Legislation governing the use of chemicals varies from state to state, is overseen by a mix of different agencies and implemented through varying methods of delivery. There are some 144 separate pieces of Commonwealth, State and Territory legislation

²⁴⁴ Ibid., p6.

²⁴⁵ Ibid., p6.

²⁴⁶ Ibid., p6.

²⁴⁷ National Association for Crop Production and Animal Health (Avcare), written submission, p1.

²⁴⁸ Ibid., p1.

²⁴⁹ Commonwealth Department of Environment and Heritage, National Profile of Chemicals Management Infrastructure in Australia, Environment Australia, November 1998, p1.

covering the management of chemicals for the environment, community and worker health and safety.²⁵⁰ Mr John Kassebaum, Manager of the Rural Chemicals Program in the Department of Primary Industries and Resources (PIRSA), SA, told the Inquiry that the legislation “...*is not as uniform as it could be.*”²⁵¹

The National Profile also found that due to the complexities imposed by the three levels of government, separate assessment regimes for different chemicals, and the overall level of reform and change in chemicals management infrastructure, coordination among the various regulatory agencies has emerged as an important aspect in maintaining effective chemicals management in Australia. It was noted that coordination is currently addressed through the development of new agreements on chemicals management between the Commonwealth and State and Territory levels of government, consultation with the community (including industry) on chemicals infrastructure, and coordination and consultation within and between the various schemes of national chemical assessment. The report concludes that the degree to which chemicals management infrastructure is coordinated to the satisfaction of all stakeholders remains an area of debate and review.²⁵²

In addition, the Profile identified definite limits to access to information on chemicals use or emissions.²⁵³ It found that information on the use of chemicals (and their generation as emissions or waste) is currently fragmented in Australia. However, it was noted that this was an area where cooperative effort and greater consistency of approach is beginning to occur.²⁵⁴ It was also considered that the introduction of a National Pollutant Inventory indicates that this is a recognised problem, with reform and debate on access to and the gathering of data, an expanding area. The implementation of ‘Chemwatch’, which includes the establishment of a database on agricultural and veterinary chemical use, was cited in the report as further evidence of moves to correct this issue.²⁵⁵

The Inquiry also learnt that in May 2002 the Environment Protection and Heritage Council established the National Chemicals Taskforce to scope issues associated with the need for a national approach to ecologically sustainable management and regulation in Australia. Its report – Towards Ecologically Sustainable Management of Chemicals in Australia – concluded that while Australia has made significant progress toward ecologically sustainable chemical management, more work is needed. The EPHC has established a working group to develop a proposal for a national environmental risk management.²⁵⁶

Other Issues of Concern

A number of submissions to the Inquiry pointed to a range of issues of concern regarding the current regulatory system. Organisations such as ECO-Buy, the Victorian Local Government environmental purchasing program, noted that in its work to support councils in making environmentally preferable purchasing choices, which includes recommending products with

²⁵⁰ Plastics and Chemical Industries Association (PACIA), written submission, p2.

²⁵¹ Kassebaum, oral evidence, Hansard, p133.

²⁵² Commonwealth Department of Environment and Heritage, National Profile of Chemicals Management Infrastructure in Australia, Environment Australia, November 1998, p3.

²⁵³ Ibid., p4.

²⁵⁴ Ibid., p2.

²⁵⁵ Ibid., p4.

²⁵⁶ Environment Protection and Heritage Council (EPHC). Working Group on the Environmental Risk Management of Chemicals- Report to Stakeholders, April 2004 (www.ephc.gov.au/ephc/chemicals_mgt.html).

lower than usual toxicity, Australian sources are “very deficient in information”. ECO-Buy, the Inquiry was informed is based in the Municipal Association of Victoria, the peak body for local government in that State.²⁵⁷

The ECO-Buy submission argues that product Material Safety Data Sheets (MSDC) are difficult to interpret and often do not give warnings about potential health effects or the effects of combining a substance with other commonly used chemicals. Material Safety Data Sheets (MSDS), the Inquiry was informed in other evidence, are fact sheets which provide information about hazardous chemical ingredients in commercial products. The manufacturer is required to provide the MSDS for the product on request. It is argued that while detailed information on each chemical, including human health hazard data, effects of long-term exposure, safe handling and storage guidelines and first aid procedures is provided in MSDS sheets from Canada and the US, such information is not available in Australia.²⁵⁸

In its submission, ECO-Buy also notes that the National Occupational Health and Safety Commission’s Designated Hazardous Substances List identifies a very large number of substances but provides no overview or summary of the most dangerous substances. Further, a complete listing cannot be obtained and substances can only be searched for under specific names. The submission claims:

“... this compares poorly with the American Environmental Protection Authority (EPA)...[which]... has comprehensive and decisive research and recommendations on the avoidance of a range of hazardous substances.”²⁵⁹

It is pointed out that on the basis of guidance available at the Federal level, a number of States across the US have been able to develop lists of prohibited chemicals, and this in turn has given clarity to specifications used in weed and pest management and cleaning contracts for example, as it is a requirement that successful applicants not use chemicals from the prohibited list. The ECO-Buy submission concludes that more information and legislation restricting the use of hazardous chemicals is required in Australia both at a Federal and State level.²⁶⁰

The Inquiry was informed of several international reviews of pesticide and herbicide use which have resulted in precautionary reforms in Europe, Canada, the USA and New Zealand.²⁶¹ While some of these reviews did not specifically focus on MCS, they did consider key chemicals associated with the condition. One such review undertaken by the City of Auckland, New Zealand in developing its current Weed Management Policy, while exploring the issue of the health effects of chemicals generally, specifically considered MCS. A particular focus was on Glyphosate, the active ingredient in Roundup, as, it was explained:

²⁵⁷ ECO-Buy, written submission, p1.

²⁵⁸ Chemical Awareness in Schools website: <http://www.netspeed.com.au/rdi/cas/toxschool.htm>.

²⁵⁹ ECO-Buy, written submission, p1.

²⁶⁰ Ibid., p1.

²⁶¹ Peter Evans, written submission, 22 February 2005, p4.

“... it accounts for the vast majority of herbicide use... and hence is the herbicide to which the public is most likely to be exposed.”²⁶²

The review was premised on the understanding that while it is difficult to prove or disprove a causal link between exposure to herbicides and pesticides and occurrences of ill health, this should not be taken to suggest that adverse health effects do not occur. The study cites an extensive review of the effects of pesticides conducted by the British Medical Association in 1992 which concluded that:

“until we have a more complete understanding of pesticide toxicity, the benefit of the doubt should be awarded to protecting the environment, the worker and the consumer....This precautionary approach is necessary because the data on risks to human health from exposure to pesticides are incomplete.”²⁶³

The Inquiry was advised by Mr Peter Evans from the SATFMCS that since 1993 the City of Auckland has been actively reducing its use of chemical herbicides. Auckland City’s current policy requires that:

“Herbicides ...only be used where there is no practicable alternative control measure”.²⁶⁴

The Inquiry was also informed that restrictions on the use of Glyphosates were imposed in Denmark in 2003 following publication of data which showed the chemical’s presence in groundwater, the main source of Denmark’s drinking water.²⁶⁵

The Inquiry learnt that sustainable pesticide use throughout Europe is currently under consideration by the European Commission, where a proposal for a thematic strategy on the sustainable use of pesticides is being finalised. Under the proposal, all European countries are expected to adopt National Pesticide Action Plans to reduce the use risk and dependence on chemical pesticides. The final strategy is scheduled for adoption in September 2005.²⁶⁶

In Canada, a review of the evidence on pesticides and human health effects requested by the Ontario College of Family Physicians in 1997 concluded that there is a “serious problem” with the amounts of pesticide to which the population, and particularly the paediatric population is exposed.²⁶⁷

The review found a lack of cooperation or collaboration between government agencies, lack of adequate public access to pesticide related information, lack of effective monitoring of the environmental fate and the health effects of pesticides, and inconsistent procedures for applying risk assessment and risk management. It recommended the need for clearly defined risk assessment processes, risk assessment based on human risk, risk of pesticides to be based on a more complete picture of experience of exposure, re-evaluation programs for products, post-

²⁶² Auckland City Weed Management Policy: Health Effects of Herbicides in <http://www.aucklandcity.govt.nz/council/documents/resources/weed/section8-3.asp>, as cited in Peter Evans, written submission,, 22 February 2005, p2.

²⁶³ Ibid., p1.

²⁶⁴ Peter Evans, written submission, 22 February 2005, p4.

²⁶⁵ Third World Network Biosafety Information Service, Danish Water Contaminated by Roundup - Ban Imposed, <http://www.twinside.org.sg/title/service76.htm>, p1, as cited in Tanya Lockett, written submission, p2.

²⁶⁶ Tanya Lockett, written submission, p2, and Europa, European Union website, Sustainable Use of Pesticides (<http://europa.eu.int/comm/environment/ppps/home.htm>).

²⁶⁷ Martin, K, M.D. Why Canadian Physicians are Concerned about the Policies Regulating Pesticide Use. Presentation to the Standing Committee on the Environment, Canadian Association of Physicians for the Environment (<http://www.cape.ca/>), p1.

regulation monitoring, a precautionary approach and the need for alternatives to pesticides to be investigated.²⁶⁸

Numerous submissions to the Inquiry noted their concerns regarding the regulation of pesticides and herbicides in particular. In relation to MCS the SATFMCS has pointed out that:

“In setting national safety standards for human pesticide exposure the Australian Pesticides and Veterinary Medicines Authority relies on technical data provided by the Office of Chemical Safety (OCS) within the Commonwealth Department of Health and Ageing (DoHA). Neither OCS nor APVMA have any agreed mechanism by which a pesticide or combination of pesticides can be assessed for their potential to initiate or exacerbate symptoms of MCS.”²⁶⁹

They further note that while the Adverse Experience Reporting Scheme for Agricultural Chemicals:

“...is a step forward, it is not an adequate tool to respond to MCS. People reporting MCS initiation to AERP...are not clinically investigated under the scheme and there appears to be no mechanism within any of the associated federal agencies to initiate such investigations.”²⁷⁰

Summary

The Committee acknowledges that a wide range of chemicals are implicated in MCS and that these are regulated by a diverse mix of authorities at the Federal level. It further notes the large number of separate pieces of legislation that cover chemical management at all tiers of Government.

The Committee also acknowledges that the lack of consensus on the cause of MCS presents difficulties with regard the regulatory action that can be taken by Federal authorities.

The Committee notes the concerns raised as to the effectiveness of the current regulatory system and its mechanisms. It is clear from the evidence presented that there are a number of issues regarding chemical management that need to be addressed. The Committee considers that further precautionary measures in particular would ensure greater safety in chemical use.

Evidence presented leads the Committee to the view that an extensive review of the regulatory environment would be necessary to determine the adequacy and effectiveness of these structures in relation to MCS.

STATE RESPONSIBILITIES

The Inquiry heard that after sale, responsibilities relating to chemical use become a State issue. Mr John Kassebaum, Manager, Rural Chemicals Program, PIRSA, told the Committee that a comprehensive system is in place in South Australia to minimise risks to humans from pesticides

²⁶⁸ Ibid., pp5-8.

²⁶⁹ SA Taskforce Multiple Chemical Sensitivity (SATFMCS), written submission, p41.

²⁷⁰ Ibid., p42.

and other chemicals. He explained that a number of State Government Departments and agencies are involved in assessing and addressing the risks presented by chemicals.²⁷¹

The Role of PIRSA and Chemical Trespass

The Inquiry was informed that PIRSA plays a central role in investigating reported incidents of chemical trespass or spray drift²⁷² that is, situations in which chemicals are perceived to affect another party. PIRSA through the Rural Chemicals Program, acts as the gateway for complaints and reports concerning all chemical trespass incidents. All reports are recorded and assessed by PIRSA's Chemical Trespass Coordinator. In addition, PIRSA coordinates responses and provides education to minimise future incidents.²⁷³

Investigations of incidents of Chemical Trespass are carried out under the Agricultural and Veterinary Products (Control of Use) Act. It was explained to the Committee that the Act and its regulations define in a legal context, a general duty of care in relation to the use of pesticides, and that specific sections and regulations in the Control of Use Act relate to pesticide use.²⁷⁴

In recording incidents of chemical trespass PIRSA maintains a database of its investigations which record the people, situations and chemicals involved. The Inquiry heard that in the 2003-4 period there was a significant increase in the number of reports received compared with the two previous years. This increase was attributed to a major incident of spray drift in the Riverland in which over twenty vineyards were affected by a chemical drift event. Mr Kassebaum noted that the increase in the number of complaints received did not signal an escalating problem, and that the increase could also be related to:

*"...an increasing awareness of...[the Chemical Trespass] program, and...a tapping into some existing concerns which are just coming to the surface."*²⁷⁵

The Inquiry was advised that in the 2003-4 reporting period, PIRSA did not receive any drift reports in which MCS was specifically mentioned. Two calls from people with MCS voicing their concerns about the use of Glyphosate but not reporting a specific trespass event, were received in 2002. In addition, one query from a MCS sufferer concerning PIRSA's Chemical Trespass Program was received in 2005.²⁷⁶

Health issues for this period represented approximately half of all reports received. It is noted that while this was the case, health effects are described in general terms as PIRSA does not have a specific code for MCS. It was explained to the Inquiry that MCS would be identified in the incident notification details of a report.²⁷⁷

Classifications recorded by PIRSA include 'health effects perceived' and 'health effects reported.' Mr Kassebaum explained that:

²⁷¹ Kassebaum, oral evidence, Hansard, p126.

²⁷² [Ibid.](#), p130.

²⁷³ Department of Primary Industries and Resources (PIRSA), Fact Sheet: Guidelines for Reporting Chemical Trespass Incidents, 2002, p2.

²⁷⁴ [Kassebaum, oral evidence, Hansard, p126.](#)

²⁷⁵ [Ibid.](#), p128.

²⁷⁶ Correspondence received from John Kassebaum, Manager, Rural Chemicals Policy, PIRSA via email 23 June 2005.

²⁷⁷ [Ibid.](#), 23 June 2005.

*'Health effects perceived' means that someone rang up with a general concern about spraying in general...The 'health effects reported' group means 'I am feeling sick', or 'I have some perception of actual exposure'.*²⁷⁸

It was also noted that a number of cases of chemical trespass during 2003-4 involved licensed pest control operators. The Committee heard that to address this issue PIRSA contacted licensed operators and worked with the the DoH as the licensing body,

*"... "to re-emphasise the need for best practice in chemical application."*²⁷⁹

The Inquiry heard that while legislation enables the Department to place site specific compliance orders on chemical use practices, informal resolutions are sought from investigations where possible.²⁸⁰ Mr Kassebaum told the Committee that in situations in which it has been claimed that chemicals have affected another party, opportunities exist to negotiate voluntary agreements which allows coexistence and recognition of a *"sensitive situation over the fence."*²⁸¹

The Inquiry heard that a number of voluntary written agreements with regard chemical use are in existence. In such agreements it was explained, the parties involved agree to adhere to certain conditions, such that, for example,

*"...the sprayer undertakes to do certain things or not do others."*²⁸²

Other Departmental and Agency Responses to Chemical Trespass

Evidence presented to the Inquiry shows that there is an overlap between a number of government departments and agencies in addressing a range of public health issues, including those that impact on people with MCS.

While PIRSA is the first port of call in relation to reports of chemical trespass and provides advice to relevant Departments and agencies of all incidents that come under their jurisdiction,²⁸³ Chemical Trespass or Spray Drift is addressed by various agencies. Mr John Kassebaum explained to the Committee that issues concerning the environment are referred to the Environmental Protection Agency (EPA), the Department of Environment and Heritage and the Department of Water, Land and Biodiversity Conservation.²⁸⁴ The Inquiry was informed that the Department of Health, Workplace Services and Local Government authorities are also responsible for using their legislated powers to deal with the effects of chemical trespass incidents.²⁸⁵

²⁷⁸ Kassebaum, oral evidence, Hansard, p128.

²⁷⁹ [Ibid., p129.](#)

²⁸⁰ [Ibid., p128.](#)

²⁸¹ [Ibid., p127.](#)

²⁸² [Ibid., p127.](#)

²⁸³ Department of Primary Industries and Resources (PIRSA), Fact Sheet: Guidelines for Reporting Chemical Trespass Incidents , 2002, p2.

²⁸⁴ [Kassebaum, oral evidence, Hansard, p126.](#)

²⁸⁵ Department of Primary Industries and Resources (PIRSA), Fact Sheet: Guidelines for Reporting Chemical Trespass Incidents , 2002, p2.

More broadly, risks related to health, including issues of chemical residues in food, are addressed by the Department of Health and Workplace Services, in the Department of Administrative and Information Services.²⁸⁶

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.

Chemicals and the Environment

Submissions to the inquiry noted that traffic pollution and environmental pollutants, particularly those from contaminated industrial sites, were of particular concern to people with MCS. Indeed, the SATFMCS has called for:

“Reforms in industrial emission standards that recognise MCS, particularly in respect to volatile organic compounds, and the clean-up of contaminated sites.”²⁸⁷

In its submission, the Environmental Protection Authority (EPA), informed the Inquiry that as part of the State’s Environment and Conservation portfolio, it is the sole agency in South Australia with the responsibility for controlling and managing the regulation of polluting activities. It was explained that the EPA performs a range of tasks, including providing environmental authorisations allowing activities that have the potential to pollute the environment. Such authorisations can occur in areas such as major industry and agriculture. Pollution avoidance and monitoring and evaluation of the local and state environment, mainly in relation to air and water quality are also undertaken.²⁸⁸

The work undertaken by the EPA includes preparation of:

- Guidelines for air quality impact assessment using ground level pollution concentrations (DGLC’s) to minimise the effects of chemical discharges from facilities in the local community;
- Information for Household Hazardous Waste Management and Control;
- A strategy for the management of hazardous waste within SA. Action plans to enact the strategy are currently being put in place;
- Guidelines for Odour Assessment using odour source measurement to ensure that negligible odours are emitted from facilities that operate in close proximity to nearby residents.

In addition, the EPA operates a Household Hazardous Waste Collection depot where householders and farmers can deliver hazardous waste free of charge for disposal.

²⁸⁶ Kassebaum, oral evidence, Hansard, p126.

²⁸⁷ Evans, oral evidence, Hansard, p74.

²⁸⁸ Environmental Protection Agency (South Australia), written submission, p1.

It was explained to the Inquiry that the EPA's role in chemical management is primarily through setting in place a range of policy instruments, including both regulatory and non-regulatory guidelines and controls for the management of chemical waste and emissions from industrial premises. The EPA cooperates with all Federal Government initiatives in relation to chemical management and is a partner on a number of national committees working on standards for monitoring and managing chemicals in the environment.²⁸⁹

On the national level, the EPA has been a party to the development of the Federal Government plan for enacting Australia's responsibilities under the Stockholm Convention, and the National Environment Protection (Air Toxics) Measure.²⁹⁰ The Inquiry was informed that the EPA is currently preparing the Managing the Health Impacts of Pollution guidelines, which recognise that some people suffer from adverse health effects when they are exposed to pollutants at levels lower than thresholds determined by expert bodies such as the World Health Organisation (WHO). The Guidelines note that health risk or health impact assessments can be used to set standards for pollution exposure to protect the community in general. It was noted in the EPA submission to the Inquiry that such assessments consider likely impacts from polluting or potentially polluting activities on most people but are unable to address issues arising for conditions that have no known cause, such as MCS. Similarly, it was noted, standards for air quality, noise, water quality, and food for example:

*"...cannot protect all the people all the time; when unusual sensitivities arise, they will need to be addressed on a case-by-case basis".*²⁹¹

The EPA advised the Inquiry that a mixture of legislation, such as the Environment Protection Act 1993 and the Public and Environment Health Act 1987, regulation, policy, community and industry behavioural change programs, and cooperation and collaboration are used to manage the adverse effects of human activities on public health.²⁹²

It was noted that the EPA has worked closely with Local Government on programs including the 'Sharing Responsibilities with Local Government' pilot program, which has led to proposed changes to the Environment Protection Act. The EPA and DoH have also worked closely in a number of areas. These include developing a coordinated and integrated approach to identifying and dealing with high priority risks to health arising from industrial activity.²⁹³

To protect against the risks presented by hazardous waste, the Inquiry was advised that in addition to the EPA's Household Hazardous Waste Collection depot, Zero Waste SA also operates such a program in conjunction with a number of local councils. Zero Waste SA's submission explained that it is the State Government Department responsible for assisting South Australian's to reduce waste and use resources in a sustainable manner.

The primary objective of Zero Waste SA is to promote waste management practices that as far as possible eliminate waste or its consignment to landfill and to advance the development of resource recovery and recycling. The Household Hazardous Waste program aims to reduce in particular, the

²⁸⁹ Ibid., p1.

²⁹⁰ Ibid., p2.

²⁹¹ Environmental Protection Agency (South Australia), written submission Attachment: Managing the Health Impacts of Pollution Draft Guidelines, p1.

²⁹² Ibid., p1.

²⁹³ Ibid., p2.

amount of hazardous materials being stored on properties or being inappropriately disposed of. The program commenced in March 2004 and aims to incorporate 51 councils by the end of the 2005-2006 financial year. To date collections have occurred in 10 council areas.²⁹⁴

The Role of the Department of Health

The Inquiry heard that the impact of chemicals in the environment and community at large is diverse, and that the Department of Health (DoH) plays a key role in providing information and advice on a range of public health issues.

Evidence presented to the Inquiry suggests that a wide range of chemicals used in a variety of environments have been shown to affect people with MCS. It has been observed that cases of MCS are reportedly initiated by “sick building syndrome” situations.²⁹⁵ Dr Jim Fitzgerald from the DoH told the Inquiry that while there may be some link between MCS and chemicals emitted within buildings and MCS, it is difficult to control all chemical emissions. As this is the case, Dr Fitzgerald informed the Committee that OHS workplace policies include management approaches to reduce exposures to indoor building chemicals.²⁹⁶

The Inquiry was also informed of a wide range of chemicals used in hospital environments, that present difficulties for those with MCS. Dr Wendy Scheil, principal consultant to the Acute Care and Clinical Services unit in the DoH, informed the committee that hospitals regularly use chemicals for infection control and processing tests:

“...such that the avoidance of these processes for people with MCS could be difficult.”²⁹⁷

Dr Scheil explained that the use of chemicals in hospitals is regulated by Workplace Services under the Occupational Health Safety and Welfare Act. She further informed the Committee that the DoH Acute Care and Clinical Services Division is reviewing available interstate and overseas policies relevant to the safe access of MCS sufferers to health centres, including public hospitals.

While specific policies addressing MCS have not been established in SA, the Inquiry heard that, if it can be shown that chemicals are the cause of MCS, any legislation that limits chemical exposure of any sort is likely to have a positive impact on people with MCS.²⁹⁸

In relation to traffic pollution, a known irritant to MCS sufferers, the Committee was advised that the DoH has had input into legislation which is being drafted to improve the quality of motor vehicle fuels to reduce air pollution. It was noted that changes such as this, while slow to occur, will benefit people with MCS as well as the wider population.²⁹⁹

Other legislation of a general nature that would assist those with MCS to which the DoH has made a contribution, includes the Agricultural and Veterinary Products (Control of Use) Bill 2001, which was introduced through PIRSA to reduce the occurrence of spray drift and environmental pollution from the use of agricultural and veterinary chemicals. The Committee also heard that the

²⁹⁴ Zero Waste SA, written submission, p1.

²⁹⁵ Pall, M.L., op.cit., p2.

²⁹⁶ Fitzgerald, oral evidence, Hansard, p19.

²⁹⁷ Scheil, oral evidence, Hansard, p45.

²⁹⁸ Fitzgerald, oral evidence, Hansard, p28.

²⁹⁹ Ibid., p28.

DoH is up-dating the Controlled Substances (Pesticides) Regulations 1988, and the training, supervision, and surveillance of pest control operators with the view to optimising compliance with operational standards. In this way, it was explained, inadvertent chemical exposures in this industry are being minimised.³⁰⁰

Mr Fitzgerald told the Inquiry that the DoH has also worked with local Councils in relation to issues arising from MCS. This has involved liaising with local Councils with regard establishing a communication process to notify MCS sufferers of when pesticides are sprayed so that residents can take adequate precautions.³⁰¹

To assist in controlling chemicals in the environment more generally, the Committee was advised of the stipulation for adequate notification to be provided to the public before, during, and after a pesticide is applied in or near public buildings to allow MCS sufferers and the concerned public to make informed choices about entering such areas. Dr Fitzgerald explained that this requirement is outlined in the SA Health Commission Termiticides (Safe Use) Code of Practice, and exemplified in the National Environmental Health Forum Monograph "Pesticide Use in schools and school grounds".³⁰²

Chemicals in the Workplace

The Committee was informed through a number of submissions and in evidence that exposure to a wide range of chemicals in the workplace causes or exacerbates the symptoms of MCS.

The submission received from Workplace Services, a directorate of the Department of Administrative and Information Services (DAIS), notified the Inquiry that it is the regulatory authority for Occupational Health and Safety in SA. The Occupational Health Safety and Welfare Act 1986 (the OHS&W Act), and associated regulations and Codes of Practice, is the governing legislation which applies to OHS issues in the workplace.³⁰³

The Workplace Services submission explains that under OHS legislation, employers have a general duty of care, as far as is reasonably practicable, to provide a safe working environment, safe systems of work, and plant and substances in a safe condition. Employees have responsibilities to take reasonable care for their own health and safety and to avoid adversely affecting others. The Inquiry was advised that this approach is known as performance based legislation, requiring employers to systematically identify hazards arising out of work, and assess risks in consultation with employees, on an ongoing basis to achieve a safe workplace.³⁰⁴

In relation to the management of chemicals in the workplace, the OHS legislation prescribes specific requirements. The Inquiry was informed that the Hazardous Substances Regulations and associated approved codes of practice reflect requirements developed nationally by the National Occupational Health and Safety Commission and that these regulations have been adopted around the country. These Regulations are also based on a risk management approach, which forms the basis of how employers must control exposure to chemicals in the workplace. The Inquiry learnt

³⁰⁰ Fitzgerald, written submission, p5.

³⁰¹ Fitzgerald, oral evidence, Hansard, p19.

³⁰² Fitzgerald, written submission, p5.

³⁰³ Workplace Services, Department of Administrative and Information Services (DAIS), written submission, p1.

³⁰⁴ Ibid., p1.

that once a chemical is identified, the employer must ensure exposure is minimised to a level that is as low as reasonably practicable. The regulations provide detailed minimum requirements which are nationally consistent, regularly reviewed at a national level and updated where appropriate.³⁰⁵

The Workplace Services submission to the Inquiry notes that there have been few prosecutions involving exposure to hazardous substances, as many of the consequences of unsafe levels of exposure manifesting as illness or disease may take years to become apparent. The Inquiry was informed that this situation was addressed in the Occupational Health, Safety and Welfare (SafeWork SA) Amendment Bill 2004.

A key issue in relation to MCS raised in the submission was whether the condition arises from the work environment or the environment generally. The Inquiry was informed that while many hazards in the workplace are well known, others are less well understood. It was noted that in such cases, the issue of appropriate and reasonable prevention measures can be more complex.³⁰⁶ While employers are encouraged to undertake a number of precautionary steps to prevent illness or disease arising out of exposure to hazardous substances in the workplace, even with these precautions, it was noted, a chemically sensitive individual may be affected. It was explained that should chemical sensitivity occur, the employer must ensure that the worker is no longer exposed to the identified sensitiser.³⁰⁷

The employer's duty is to assess the employee's work to establish the likelihood of aggravating the employee's condition and to take appropriate action to prevent the potential for exposure. It was acknowledged that where an individual develops MCS, difficulties for the employer may arise in finding suitable work in an environment where none of the potential sensitisers are present. The issue of what constitutes suitable work would, it was explained, need to be evaluated by the employer's medical practitioner.³⁰⁸

The Inquiry was informed that in SA the employer's obligations in relation to provision of alternative duties for injured employees are provided under workers compensation legislation administered by the WorkCover Corporation.³⁰⁹ Issues relating to WorkCover practices will be discussed in Section 4.

MCS Symptoms and EMR in the Workplace

As previously indicated, Electromagnetic Radiation (EMR), generated by a number of devices commonly found in workplaces such as computers, photocopiers and mobile and landline phones, has been attributed to triggering MCS symptoms. The Inquiry was informed that Workplace Services has had only one case of EMR related illness on record. Specific codes for EMR or MCS, however, are not kept by Workplace Services.³¹⁰

³⁰⁵ Ibid., p2.

³⁰⁶ Ibid., pp2-3.

³⁰⁷ Ibid., p3.

³⁰⁸ Ibid., p4.

³⁰⁹ Ibid., p4.

³¹⁰ Correspondence received from Tony MacHarper, Policy & Strategy Group, Workplace Services, DAIS, 23 May 2005 notes that this case was recorded in the 2002-3 period.

WorkCover informed the Inquiry that 21 cases in which an employee has attributed their illness or symptoms to EMR exposure have been recorded since May 1991. Of these, nine had no time lost from work. Two cases of exposure to EMR from aircraft radar resulted in significant time off work. The other cases recorded resulted from exposure to computers, lights, and mobile phones, among other equipment. While a specific code for exposure to EMR is not used by WorkCover, it does record exposure to non-ionising and ionising radiation. WorkCover advised that the National Occupational Health and Safety Commission (NOHSC) and the National Health and Medical Research Council (NHMRC) have issued a joint National standard for limiting occupational exposure to ionising radiation. The NHMRC also has a number of Codes of Practice on radiation. A number of standards set by the Australian Standards Association also apply to ionising and non-ionising radiation safety in a number of work environments including laboratories, and in relation to personal protective equipment and laser safety. WorkCover noted that EMR is an emerging OH&S issue but that as it is seen as a low risk to the scheme, they have not undertaken any specific programs in relation to the issue. They point out that many individual employers and workers have taken action to reduce EMR exposure, however, including locating photocopiers in separate rooms and putting in place policies that describe correct operating procedures.³¹¹

The Inquiry was also notified by the EPA that while it did not keep records of EMR related incidents, the EPA was involved in developing a new national standard for EMR through the participation of a Radiation Protection Division officer on a national Working Group.³¹²

CHEMICAL USE AND LOCAL GOVERNMENT

While a wide range of chemicals are used by local Councils, the Inquiry heard that herbicides such as those used for weed control are primarily identified as problematic by those with MCS. The Inquiry heard that the care, control and management of extensive areas of crown lands, parks, reserves and public spaces is a key responsibility of local Councils, as defined under the Local Government Act. Mr Chris Russell, Director of Policy and Public Affairs, Local Government Association (LGA), told the Committee that Local Government is required to control weeds on roadsides and footpaths, in parks, gardens, sporting and recreation areas, and that the most cost effective way of doing so is by spraying with herbicides.³¹³ Mr Russell advised the Committee that:

“To stop using chemicals to deal with weeds would have very substantial ramifications for ratepayers.”³¹⁴

In relation to the use of herbicides and registered chemicals, the committee was advised that the Local Government Association (LGA) ensures that Councils are aware of standards and procedures to protect workers and the public, and that regular audits are conducted into the storage, record keeping and management of chemicals.³¹⁵

Mr Russell pointed out that legislation requires that chemical registers and safety data sheets are kept by local councils and while all chemical spraying is carried out by contractors and not council

³¹¹ Ibid., p1.

³¹² Ibid., p1.

³¹³ Russell, oral evidence, Hansard, p55.

³¹⁴ Ibid., p65.

³¹⁵ Ibid., pp55-6.

staff, high environmental standards and safe work systems need to be demonstrated to secure contracts.³¹⁶

The Inquiry was informed that Glyphosate, a chemical identified as causing and triggering the symptoms associated with MCS, is widely used domestically as well as by Local Government for weed control. Information requested by the Committee from local councils identified Glyphosate (Roundup); Simazine; Driftex; Biactive; and Garlon; as chemicals used by contractors employed by Councils in SA.

Local Government and MCS

Information on Council practices with regard MCS was sought from all 68 Councils in SA. The Inquiry received responses from 21 Councils.

Responses received indicate the lack of a consistent approach within local government to identifying MCS sufferers, maintaining a Register of those with the condition through which no spray zones can be established, or in advising sufferers of spraying times.

Mr Russell told the Inquiry that some Councils over the years have responded to concerns about herbicide sprays in particular by establishing informal Registers.³¹⁷ The Inquiry has established that several Councils undertook to protect residents with MCS and others with a preference for chemicals not to be used in the vicinity of their properties, by providing Voluntary Registers or through negotiated agreements with residents.

Of the Councils that responded to the Inquiry's request for information, it appears, however, that many Councils do not operate a Register or list of any kind. Several Councils surveyed were not aware of whether residents in their locality had MCS and therefore did not make any provisions in relation to their spraying practices.

While several councils informed the Inquiry that they were aware of residents with MCS in their municipality, only one Council indicated that they offered contractors guidelines on Chemical Sensitivity. The Holdfast Bay Council in their Contract Special Conditions Site Control and Contractors Submission to Council, states that in:

*"...areas where there exists a known sensitivity toward herbicides (in fact any chemical) additional care and emphasis on reducing any residents concern is to receive our attention."*³¹⁸

Another Council, Victor Harbor, indicated that staff and contractors receive regular instruction with regard honouring weed spray free zones, with contractors facing loss of future contracts for non-compliance.

It appears from the responses received by the Inquiry that very few Councils undertook to monitor contractors to ensure that exclusion zones around the homes of those with MCS or those who had indicated their objections to spraying in the vicinity of their properties, were honoured. Responses

³¹⁶ Ibid., pp60-1.

³¹⁷ Russell, oral evidence, Hansard, p56.

³¹⁸ Holdfast Bay Council, written submission, p1.

received indicate that many Councils rely on complaints and self regulation of contractors to ensure that no-spray zones are honoured.

Holdfast Bay Council advised the Inquiry that it had been informed of concerns about spraying in parks and gardens with playgrounds. Parents concerned about the effects of chemicals on their children suggested that signage be provided by Councils indicating when an area was last sprayed. While the need for signage such as this was recognised by this Council, the issue of costs were raised.

As indicated by Mr Russell, some Council's have investigated alternatives to herbicides and found them to be ineffective in controlling weeds and not cost effective. Some Councils indicated, however, that they would continue to review their policies on weed spraying and were monitoring the availability of more environmentally friendly products for weed control. In addition, of those that did not currently operate a Register, several Councils indicated that they would be willing to develop a Register or consider advice from Councils where one was in place.

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.

C. MINIMISING THE IMPACT OF CHEMICALS

GUIDELINES FOR BEST PRACTICE

Evidence provided to the Inquiry indicated that several factors need to be considered in developing guidelines for best practice in chemical use.

Access to information was identified as a key factor in ensuring that chemical use is conducted safely and with minimal impact on residents and the environment. Mr John Kassebaum told the Inquiry that:

*"...a key factor in getting people to do the right thing is to make it easier for them to find out what the right thing to do is."*³¹⁹

The Inquiry heard that this understanding was a key driver in the provision of the chemical information service operated by PIRSA.

The Inquiry was informed that PIRSA has world-class practice with regard spray drift management, and that the need for best practice in agriculture is well acknowledged. Mr Kassebaum informed the Committee that in 2002 the Primary Industries Standing Committee released the publication, 'Spray Drift Management Principle Strategies and Supporting

³¹⁹ Kassebaum, oral evidence, Hansard, p131.

Information,’ which is seen by PIRSA as the template for defining best practice. This publication, it was noted, sets the benchmark in terms of factors which establish quality chemical application and management.³²⁰

To assist chemical users and/or individual primary industry sectors to develop spray drift management strategies relevant to their particular circumstances, the publication provides information on practices for working safely with chemicals, as well as information on alternative methods which do not only rely solely on the use of chemicals.³²¹

Legislation and Best Practice

Despite the lack of provision for MCS specifically in existing legislation, the Inquiry was informed that an adequate legal framework is in place to support the responsible use of chemicals, thereby minimising risks to human beings.³²² It was explained that Chemical use is subject to the Agriculture and Veterinary Products (Controls of Use) Act 2002, which sets out mandatory instructions that must be followed as law. General duty in the legislation sets out in legal terms, factors that should be considered in determining best practice. Mr Kassebaum told the Inquiry that general duty requires that:

*“...one...take all reasonable and practical measures to prevent or minimise actual or potential harm to the health and safety of human beings”.*³²³

Mr Kassebaum informed the Committee that there are also equivalent obligations in relation to:

*“...contamination of product and contamination of the environment. These apply to all users – there are no exemptions.”*³²⁴

With regard best practice in legislation, the SATFMCS informed the Inquiry that a number of States in the US have pesticide legislation which is sensitive to the issue of MCS. Mr Peter Evans from the SATFMCS told the Committee that Florida for example :

*“...has had pesticide sensitivity legislation since...1989. Under their legislation, if you have MCS and you can get a doctor to confirm it, then you can put yourself on a register, and the company that sprays the pesticide in your area is required under the law to give you prior notification. So, basically, pesticide legislation in the USA often has provisions for prior notification for people who are on a register.”*³²⁵

With regard preventive strategies in relation to MCS, the SATFMCS informed the Committee that there was a need for:

*“Pesticide trespass legislation, including a state register for mandatory prior notice of pesticide applications, coupled with a statewide strategy to reduce human exposure to pesticides.”*³²⁶

³²⁰ Ibid., pp129-130.

³²¹ Ibid., p129.

³²² Ibid., p130.

³²³ Ibid., p129.

³²⁴ Ibid., p129.

³²⁵ Evans, oral evidence, Hansard, p77.

³²⁶ SATFMCS, written submission, p74.

The Inquiry heard that such legislation should include provisions that make it unlawful for spray to drift from one property to another.³²⁷

Best Practice and Community Involvement

The Inquiry was informed that best practice is context specific and that community involvement was important to ensuring that residents have a significant say in processes that affected them, and particularly in determining best practice in their own environment. Mr Kassebaum told the Committee that the specifics of what constitutes best practice were best devised by industries and the people in local communities. In this way:

“...the law can be supported by voluntary codes of practice which deliver use of chemicals in a way that the community is comfortable with.”³²⁸

Whilst it was acknowledged by PIRSA that legislation was an important element in a regulatory environment, awareness of minimal impact practices and behaviour change were vital to ensuring that best practice was implemented. According to Mr Kassebaum,

“One can put laws in place, but the key thing is the behaviour and awareness of the views to put in place good practice.”³²⁹

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.

Summary

The Committee notes that, as on the Federal level, a diverse range of authorities operating under various pieces of governing legislation regulate chemical use at the State and Local Government levels. Similarly, the wide range of chemicals implicated in MCS and the lack of consensus regarding causation presents difficulties in relation to regulation and how best to respond to the risks presented to people with chemical sensitivities.

³²⁷ Evans, oral evidence, Hansard, p77.

³²⁸ Kassebaum, oral evidence, Hansard, p130.

³²⁹ Ibid., p130.

The Committee acknowledges that some steps have been made to address issues relating to the effects of chemicals on members of the community with MCS. It is further noted that a cooperative working relationship currently exists between a number of Government Departments and agencies and between State government departments and some local Councils.

From the evidence provided, the Committee believes that further work is required to more effectively address issues of chemical use and its impact on those with MCS, particularly at the Local Government level.

SECTION THREE: THE COMPARATIVE STATUS OF MCS

A. THE CURRENT STATUS OF MCS

MCS is not recognised as a defined medical condition in Australia. In evidence presented by a number of witnesses and in several submissions, the Committee was informed that Germany is the only country to have formally recognised the condition.

The Inquiry heard, however, that MCS is considered a serious debilitating condition. Despite the lack of formal recognition, MCS is widely recognised by Federal, State and local authorities in a number of overseas countries but predominantly in Canada and the USA.

A growing number of hospitals and health care facilities have recognised MCS by adopting protocols and policies for the care of patients with the condition. A wide range of authorities have also adopted scent free guidelines and policies which recognise the health problems experienced by MCS sufferers from exposure to fragrances.

The Inquiry heard that MCS is also recognised as a legitimate disability in Australia as well as overseas. Several states in the US and Canada in particular have developed disability access provisions for people with MCS.

Despite the recognition of the condition reflected in the many policies that have been adopted, MCS it is still considered by many professional bodies that MCS is not a scientifically valid diagnosis and this is also reflected in a range of position statements.

CURRENT STATUS IN AUSTRALIA

With regard the current status of MCS in Australia, Dr Mark Donohoe explained to the Committee that:

“...the question often raised is: is multiple chemical sensitivity a disease...in Australia at this point in time the answer is no.”³³⁰

While it is not considered a disease, the Inquiry heard that it is nonetheless a serious illness. Many submissions to the Inquiry reinforced Dr Donohoe’s view that people with the condition experience considerable suffering and disability. According to Dr Donohoe:

“The illness of chemical sensitivities is real and, I think, very few people doubt that it is an illness. In the studies done to date, the suffering of chemical sensitivities is rated as approximately on a par with multiple sclerosis and epilepsy in terms of disability.

In terms of suffering and disability, we have a serious condition that is not a disease, and medicine struggles with this; we have struggled with it through history. In the past, we called multiple sclerosis 'hysterical paralysis'. Any time medicine does not have a good theory to understand what is presented to us as doctors, a division—a kind of schizophrenic approach—happens within medicine. The clinicians see the cases and document them; the

³³⁰ Donohoe, oral evidence, Hansard, p99.

text books say it cannot be true. On the whole, we believe our text books until such time as the theory can match the observations. It has happened with epilepsy and migraines.”³³¹

The Committee heard that Dr Donohoe, as a Fellow of the Australian College of Nutritional & Environmental Medicine (FACNEM), was instrumental in attempting to gain recognition for MCS as a disease in Australia. To enable the condition to be classified and consequently coded, ensuring that sufferers receive support and practical recognition of their condition, a submission was made to the National Centre for Classification in Health³³² for inclusion of a new code to index MCS in the International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification³³³ (ICD-10-AM)³³⁴ This submission was prepared by Dr Donohoe and Ms Jo Immig, Legislative Advisor to the Hon. Alan Corbett,³³⁵ and submitted on behalf of the Honourable member. The submission acknowledges the uncertainty and divergent views surrounding MCS but argues that:

*“...the dominant view, with the widest support, is that the illness or disease is an idiosyncratic adverse neurological response to exposure to either a single or repeated exposure to one or more chemicals.”*³³⁶

It puts forward the view that:

*“The widely agreed differences between multiple chemical sensitivities and allergy, on the one hand, and toxic injury on the other, is a strong argument for a separate and new classification category of a novel illness or disease. No current category allows for accurate classification, and this results in confusion and misclassification on the part of clinicians.”*³³⁷

The submission further argues that the incidence and prevalence of MCS appears to be increasing, and that the lack of an ICD category has hampered research into, and management of MCS. Classification would enable epidemiological data to be collected, focusing research and addressing inequities in the provision of medical and social services for sufferers.³³⁸ The Submission points out that:

*“Agencies such as WorkCover NSW have expressed a need for appropriate classification to aid rehabilitation and early intervention to prevent further economic loss and to reduce disability on the part of those suffering multiple chemical sensitivities.”*³³⁹

³³¹ Donohoe, oral evidence, Hansard, p99.

³³² The National Centre for Classification in Health, Sydney is situated at the University of Sydney and was formerly known as the National Coding Centre. The Centre was formed as a result of a joint venture agreement on January 1 1997 with the National Reference Centre for Classification in Health situated at Queensland University of Technology.

³³³ The ICD-10-AM is the latest in a series that was formalized in 1893 as the Bertillon Classification or International List of Causes of Death. While the title has been amended to make clearer the content and purpose and to reflect the progressive extension of the scope of the classification beyond diseases and injuries, the familiar abbreviation ‘ICD’ has been retained. (Source: Report of the Standing Committee on the Environment and Public Affairs in relation to the Alcoa Refinery at Wagerup Inquiry, Western Australian Legislative Council, Report 11, October 2004, pp 68-71).

³³⁴ Donohoe, oral evidence, Hansard, p107.

³³⁵ Alan Corbett MLC was a member of the Legislative Council of the NSW Parliament until February 28 2003.

³³⁶ Donohoe, M. (Dr.) (Fellow of the Australian College of Nutritional and Environmental Medicine), Public Submission Request for Modification to the International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM), 2002, p2.

³³⁷ Ibid., p2.

³³⁸ Ibid., p3.

³³⁹ Ibid., p2.

In evidence to the Committee Dr Donohoe explained that it had been a year and a half since the submission had been made.

“It takes a very long time for each disease code to change and we are yet to find out whether there was any success on this occasion.”³⁴⁰

Further to this evidence the Inquiry has established that the National Centre for Classification in Health (NCCH) has rejected the proposal to assign a unique code to MCS in ICD- 10-AM. The NCCH concluded that, although it is acknowledged by a number of national and international clinical specialists and committees that the set of symptoms of MCS represents an important clinical problem, the proposal was rejected because:

- *“There is no clinical or laboratory evidence of an underlying pathological (disease) process in patients who have acquired this descriptive label, despite many attempts to identify one over the past 20 years.*
- *There is a wide spectrum of intolerance/irritation from smells and fumes in the general population, and it is not possible to draw any clear dividing line to delineate patients who might fall into the category of the proposed classification.*
- *There is no internationally accepted diagnostic criteria, nor validated diagnostic tests.*
- *There are a number of syndromes (ie symptom complexes) that appear to overlap with the clinical features proposed for the category of MCS, such as chronic fatigue syndrome and fibromyalgia. The relationship between these entities and MCS syndrome is unclear at present and this creates difficulty with diagnostic categorisation.”³⁴¹*

Emerging Issues Regarding the Classification of MCS in Australia

The Committee learnt that a classification is a system of categories to which morbid entities are assigned according to established criteria. Health classifications consist of hierarchical systems of codes for diseases, injuries and interventions as documented in health care services. It was further established that coding is the translation of clinical data such as diseases, injuries and interventions from a patient record into an agreed coded format. Currently in Australia, diagnoses and procedures are assigned a series of numerical and /or alphanumerical codes using the ICD-10-AM. This allows the comparison, analysis and interpretation of collected morbidity data.³⁴²

While medical practitioners code to ICD codes, the Inquiry was informed that WorkCover uses the national Occupational Health and Safety codes in its claims coding process.³⁴³ Ms Dianna Alder, Manager, Self Insured Operations and Systems WorkCover, told the Committee that WorkCover coding classifications:

“...are determined from the National Occupational Health and Safety Commission's classifications for the nature of injury, the body location, the mechanism, and the agency.”³⁴⁴

³⁴⁰ Donohoe, oral evidence, Hansard, p114.

³⁴¹ South Australian Task Force on Multiple Chemical Sensitivity (SATFMCS), written submission, p40.

³⁴² Report of the Standing Committee on the Environment and Public Affairs in relation to the Alcoa Refinery at Wagerup Inquiry, Western Australian Legislative Council, Report 11, October 2004, pp 68-71)

³⁴³ Alder, oral evidence, Hansard, pp203 & 207.

³⁴⁴ Ibid., p214.

The Committee heard that while cases of MCS have been attributed to exposure to a range of chemicals in a variety of workplaces, WorkCover in SA does not recognise MCS in its coding of claims.³⁴⁵ With regard its coding practices, Ms Leeanne Kearney, Supervisor of Coding at WorkCover, told the Inquiry:

“There is nothing in our reference material for MCS.”³⁴⁶

The lack of medical consensus on the existence of MCS was cited as one of the main reasons WorkCover did not classify MCS in its coding, and consequently why they were unable to identify the number of claims that may have been made by people with MCS. Ms Alder explained to the Committee that:

“I suspect that...the main reason why we have not got it in our statistics, [is] because it has not been classified. When I spoke to our medical practitioners about whether they have been involved in any cases, they said they were still waiting to get more information from the medical area on this disease and its classifications. They were still looking for the medical field to set a classification around it.”³⁴⁷

The Inquiry was informed through many submissions of the difficulties presented to people with MCS as a result of the lack of recognition of the condition. The implications of the lack of coding for MCS, particularly in relation to workers compensation will be considered further in Section 4.

CURRENT STATUS OVERSEAS

Evidence presented to the Inquiry from a range of sources has shown that Germany was one of the first countries to put forward an application to the ICD for a classification of MCS. In November 2000 Germany became the only country to list and recognise MCS as a disease, when the condition was coded in the ICD German update (ICD-10-SGBV, version 3.1) as “Multiple-chemical-sensitivity-syndrome” in the main alphabetical index, and under syndromes and “Chemical-Sensitivity-Syndrome, Multiple.”³⁴⁸

Dr Jim Fitzgerald from the SA DoH told the Committee that health authorities in Germany,

“...assigned an international classification of diseases code for MCS under a pre-existing code for 'allergy not otherwise specified'.”³⁴⁹

Indeed, it is noted in the Australian submission to the ICD that while Germany is to be commended for achieving a designated code for MCS, its introduction raises concerns due to its listing as an allergy. The submission notes that:

“...there is significant concern amongst environmental medicine specialists that its listing as an allergy (albeit in the section on poisonings) is misleading when it has been clear from the

³⁴⁵ Ibid., p207.

³⁴⁶ Kearney, oral evidence, Hansard, p213.

³⁴⁷ Alder, oral evidence, Hansard, p213-21.

³⁴⁸ Donohoe, M. (Dr.) (Fellow of the Australian College of Nutritional and Environmental Medicine), Public Submission Request for Modification to the International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM), 2002, p5.

³⁴⁹ Fitzgerald, oral evidence, Hansard, p18.

medical literature for over a decade that MCS reactions are not IgE mediated and thus are distinct from 'allergy'."³⁵⁰

B. POLICIES, PROTOCOLS AND POSITION STATEMENTS ON MCS

The Inquiry was informed that while MCS is not recognised as a disease, it is nonetheless recognised in a wide range of guidelines, policies, and protocols by a number of Federal, State and local authorities, predominantly in Canada, and the USA, but also to a limited extent in Australia. Policies, protocols, and guidelines on MCS have been adopted in relation to health care, education, employment and housing.³⁵¹ The status of MCS is reflected further in an array of position statements produced by government agencies, medical and professional bodies.

MCS HOSPITAL POLICIES AND PROTOCOLS IN AUSTRALIA

The Inquiry was informed that hospitals are chemically rich environments that contain a wide variety of chemicals that have been reported to initiate symptoms of MCS. The situation is exacerbated further as hospitals are:

*"...tightly sealed, poorly ventilated air conditioned buildings that frequently undergo renovations and rebuilding...using toxic products."*³⁵²

In its submission to the Inquiry the SATFMCS put forward the case that the combination of these factors makes it impossible for people with MCS to access hospital services without experiencing chemical sensitivity reactions.³⁵³ The introduction of protocols for MCS patients, were one of a number of recommendations made by the SATFMCS and in a number of other submissions, that would address the issue of safe access to general health care.

Dr Jim Fitzgerald from the DoH told the Committee that the Department's Acute Care and Clinical Services Division was reviewing available interstate and overseas policies relevant to the safe access of MCS sufferers to health centres, including public hospitals.³⁵⁴

Dr Wendy Scheil from Acute Care and Clinical Services explained that she became involved in investigating the issue of MCS hospital policies following a request in August 2002 from the Director of the Environmental Health Branch of the SA DoH to the Director of the Acute Care and Clinical Services Division. The request sought information on whether SA hospitals or the DoH had any specific policies in place for accommodating and/or treating people with MCS.

The Inquiry heard that Dr Scheil had previously worked with the Primary and Community Care Branch in response to various approaches it had had from the Myalgic Encephalitis/Chronic Fatigue (ME/CFS) Society with regard treatment and diagnostic considerations in South Australia. She explained to the Committee that:

³⁵⁰ Donohoe, M. (Dr.) (Fellow of the Australian College of Nutritional and Environmental Medicine), Public Submission Request for Modification to the International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM), 2002, p5.

³⁵¹ South Australian Task Force on Multiple Chemical Sensitivity (SATFMCS), written submission, p34.

³⁵² Ibid., pp53-4.

³⁵³ Ibid., p54.

³⁵⁴ Fitzgerald, oral evidence, Hansard, p19.

*“The Medical Journal of Australia had published the Royal Australian College of Physicians (RACP) Clinical Practice Guidelines for chronic fatigue syndrome in May 2002. However, the SA [ME/CFS] society felt that it did not address diagnosis and management in the community or primary care setting and that we should put forward an alternate guideline, for which I acted as an observer.”*³⁵⁵

Dr Scheil explained that although the RACP guidelines recognised MCS as a potentially co-existing condition with CFS, both these groups considered that MCS was outside the scope of that particular guideline development.³⁵⁶ Regarding hospital policies for MCS Dr Scheil told the Committee that following a review of the DoH’s administrative circulars and approaches to individual hospitals:

*“It became apparent that there was no policy in place that specifically dealt with the environmental requirements of people with MCS entering hospitals. At that time I also consulted individual clinicians who specialised in the care of people with MCS, and they confirmed...that there was no generic MCS hospital policy in South Australia.”*³⁵⁷

Dr Scheil told the Committee she attended an environmental health special interest group meeting in Adelaide in September 2002, at which issues relating to CFS and MCS were discussed. These inquiries revealed that:

*“...no public hospital in Australia at the time had a policy regarding management of the hospital environment for people with MCS.”*³⁵⁸

Dr Scheil’s investigations, the Inquiry heard, led her to conclude that:

*“...there were no evidence based guidelines that could be used to inform a hospital management policy to provide a suitable hospital environment for people with MCS.”*³⁵⁹

Royal Brisbane Hospital Draft Protocols for MCS

Several submissions and evidence presented to the Inquiry made reference to the draft policy guidelines that have been developed by the Royal Brisbane Hospital & Royal Women’s Hospital and Health Service Districts. The draft policy outlines processes for the treatment of MCS patients demonstrating a commitment:

*“...to providing an environment that reduces exposure to incitants, for those patients who identify themselves as suffering...MCS/IEI...”*³⁶⁰

According to the SATFMCS, the draft policy was developed by the Royal Brisbane Hospital following a complaint lodged with the Human Rights and Equal Opportunity Commission.³⁶¹ In its submission to the Inquiry, the Allergy and Environmental Sensitivity Support and Research

³⁵⁵ Scheil, oral evidence, Hansard, p44.

³⁵⁶ Ibid., p44.

³⁵⁷ Ibid., p44.

³⁵⁸ Ibid., p44.

³⁵⁹ Ibid., pp44-5.

³⁶⁰ Royal Brisbane Hospital (RBH) & Royal Women’s Hospital and Health Service Districts, Policy 80503/ALL: Multiple Chemical Sensitivity (MCS) Patients, Processes For, Queensland Government/ Queensland Health, p1.

³⁶¹ South Australian Task Force on Multiple Chemical Sensitivity (SATFMCS), written submission, p55.

Association (ASEHA) Queensland Inc, noted that the draft protocols had "...not moved past draft status."³⁶²

The Royal Brisbane Hospital & Royal Women's Hospital and Health Service Districts draft policy on MCS is presented in Appendix 2.

MCS Related Policies and the SA Health Sector

The SATFMCS informed the Inquiry that there was an increase in awareness of the public health problems associated with personal fragrances in SA and that this had resulted in the introduction of a number of fragrance control policies. The Southern Fleurieu Health Service was reported to operate a fragrance control procedure among staff³⁶³, and it was noted, the South Coast District Hospital at Victor Harbor was considering adopting a similar approach.³⁶⁴ A number of other groups and organizations were cited as having implemented fragrance free codes. They include the AIDS Council of SA, and the Disability Information Resource Centre, which have fragrance free codes for staff and visitors, and the Asthma Foundation of SA which has included personal fragrance control clauses in staff contracts.³⁶⁵

While access to hospital services for MCS patients is a key focus for the SATFMCS, they have also identified a need for:

*"...the development of MCS management protocols in relation to...GP clinics, nursing homes, domiciliary care and community services...to provide patients with MCS with access to chemical-free spaces and staff who are trained in the management of MCS."*³⁶⁶

MCS PROTOCOLS IN HOSPITALS AND HEALTH SERVICES OVERSEAS

A growing number of hospitals and health care facilities have recognised MCS by adopting protocols and policies for the care of patients with the condition. The SATFMCS informed the Inquiry that the Louisville Jewish Hospital, Kentucky, and the Mercy Medical Centre, California are among the hospitals in the US to have adopted MCS/Environmental Illness protocols. Specific environmental health care clinics such as the Environmental Health Centre in Nova Scotia, Canada, were also reported to have best practice MCS protocols.³⁶⁷

In addition to policies relating to the general health care of patients with MCS a number of hospitals have also adopted Scent-Free or fragrance control policies. According to the SATFMCS, many commercial fragrances contain industrial solvents and petrochemicals, which have been identified as initiators of MCS symptoms.³⁶⁸ The Task Forces submission notes that research has established that perfume in particular is one of the most frequently reported products triggering

³⁶² Allergy, Sensitivity & Environmental Health Association (ASEHA), Queensland, written submission, p3.

³⁶³ Further information on this procedure is provided in Section 4 of this report, as part of the discussion on increasing access for MCS sufferers through the introduction of policies and protocols for safe access to health services.

³⁶⁴ South Australian Task Force on Multiple Chemical Sensitivity (SATFMCS), written submission, p49.

³⁶⁵ Ibid., p49.

³⁶⁶ Evans, oral evidence, Hansard, p72.

³⁶⁷ SATFMCS, written submission, p35.

³⁶⁸ Ibid., p21.

symptoms of the condition.³⁶⁹ Hospitals that have adopted Scent-Free policies include the Grace Health Centre, Halifax, Nova Scotia,³⁷⁰ Carleton Hospital, Queensway, Canada³⁷¹ Uppsala University Hospital, Sweden³⁷² and the Brigham and Women's Hospital, Boston.³⁷³

BROADER APPLICATIONS OF MCS RELATED POLICIES IN AUSTRALIA AND OVERSEAS

Scent-Free guidelines and policies which acknowledge the health problems experienced by MCS sufferers, have been implemented beyond hospitals and health services. A wide range of authorities in Canada, the US and SA have introduced Scent-Free policies in workplaces, and a range of public buildings and facilities.

In Halifax, Nova Scotia, Canada, wide ranging Scent-Free policies have reportedly been introduced in a range of municipal buildings including schools, libraries, courts, workplaces, theatres and shops.³⁷⁴ Scent Free policies were also reported enforced on buses in the Canadian capital Ottawa, and at the YMCA in Toronto, Ontario, as well as in other Canadian provinces and cities.³⁷⁵

The Inquiry found that guidelines for the implementation of Scent-Free policies in workplaces have been prepared by the Canadian Centre for Occupational Health and Safety (CCOHS), (see Appendix 3) and the Workers Health and Safety Centre, Ontario. In addition, the University of Minnesota has adopted voluntary guidelines on chemical sensitivity which outline the responsibilities of its Department of Environmental Health and Safety and Disability Services.³⁷⁶

The Inquiry was also informed by the SATFMCS, that in South Australia, workplaces such as the TAB Call Centre have introduced voluntary staff codes for fragrance control, as have the Australian Greens at their Adelaide office.³⁷⁷

In Australia, the Committee heard, attempts to formulate policies for MCS had not been successful to date. The first and only National Workshop on CFS/MCS in Australia was hosted by the SA DoH Environmental Health Branch in 2002. It was held in collaboration with the Public Health Association of Australia, the ME/CFS Society of SA, and the Therapeutic Goods Administration (TGA), a unit of the Commonwealth Department of Health and Ageing. The Inquiry was informed that the recommendations arising from the workshop have not given rise to policies on MCS at either a state or national level.³⁷⁸

³⁶⁹ Ibid., p17.

³⁷⁰ McLaren, L. Halifax Hysteria: Non-scents in Nova Scotia. The Globe and Mail, 29 April, 2000, p1.

³⁷¹ Fumento, M. Scents and Senselessness. The American Spectator, April 2000, p2.

³⁷² Uppsala University Hospital, Sweden, Akademiska Sjukhuset - Perfume-free hospital (http://www.uas.se/templates/page__10961.aspx).

³⁷³ Brigham and Women's Hospital, Boston, USA, Brigham and Women's Hospital Personnel Policy Manual – Fragrance Controlled Workplace, (<http://healthgate.partners.org/browsing/browseContent.asp?fileName=13512.xml&titl...>)

³⁷⁴ McLaren, L. Halifax Hysteria: Non-scents in Nova Scotia. The Globe and Mail, 29 April, 2000, p1.

³⁷⁵ Fumento, M. Scents and Senselessness. The American Spectator, April 2000, p2.

³⁷⁶ University of Minnesota, USA, Environmental Health and Safety Office, Guideline on Chemical Sensitivity (www.dehs.umn.edu/iaq/chemical.html).

³⁷⁷ South Australian Task Force on Multiple Chemical Sensitivity (SATFMCS), written submission, p49.

³⁷⁸ Ibid., p38.

Government agencies such as WorkCover in SA pointed to the lack of prominence of the condition to explain why WorkCover did not have a specific policy with regard to “multiple chemical sensitivity disorder”. Ms Dianna Alder told the Committee that:

“We don't have policies for every type of condition that a worker may present with, and as this has not been an injury that has been prominent or has not been of great cost or concern to the WorkCover scheme, it is not something that we have gone about producing a policy about...it has not been raised as an issue.”³⁷⁹

RECOGNITION OF MCS AS A DISABILITY

The Disability Status of MCS in Australia

The Inquiry heard that MCS is recognised as a legitimate disability. Mr Peter Evans, Convenor of the SATFMCS told the Committee that:

“...there seems to be confusion amongst some people as to whether MCS is classified as a disability. We would like to assure this committee that the Equal Opportunity Commission and the Human Rights and Equal Opportunity Commission consider MCS to be a legitimate disability under the Disability Discrimination Act, and will act on legitimate claims of discrimination from people with MCS. In relation to MCS disability access, it is very clear that we need a broad access strategy for all areas of public life, such as public buildings, public spaces, public transport, schools, supermarkets and other basic services.”³⁸⁰

A submission presented on behalf of the Central Community Legal Service (CCLS) by John Steele, a disability discrimination lawyer, notes that:

“...I have encountered a number of problems where people with MCS have experienced difficulty accessing spaces and facilities which are open to the public...”³⁸¹

Mr Steele confirms that:

“...Complaints about the inaccessibility of both indoor and outdoor places due to contamination can be lodged under the Disability Discrimination Act (1992)...MCS is recognised as falling within the definition of “disability” in section 4 of this Act, and “premises” includes outdoor spaces...use of toxic substances in a publicly accessible space arguably amounts to the imposition of a condition on which persons are allowed access.”³⁸²

The Inquiry was advised that the SA Equal Opportunity Commission had taken up a complaint of discrimination against a person with MCS by the Royal Adelaide Hospital on the basis of disability access.³⁸³ While details of this case were not provided to the Inquiry, it was established that this complaint has now been settled by conciliation between the parties involved.³⁸⁴

³⁷⁹ Alder, oral evidence, Hansard, p207.

³⁸⁰ Evans, oral evidence, Hansard, pp72-73.

³⁸¹ Central Community Legal Service (CCLS), written submission, p1.

³⁸² Ibid., p1.

³⁸³ South Australian Task Force on Multiple Chemical Sensitivity (SATFMCS), written submission, p55.

³⁸⁴ Correspondence received from Michael Guarna, Principal Policy Adviser, Equal Opportunity Commission, via email on 8 June 2005.

Evidence presented notes that the Disability Discrimination Act 1992 (DDA) covers discrimination against people with disabilities in areas which include employment, education, accommodation, and provision of services (including health and public transport). Disability for the purposes of the DDA is defined as including ‘total or partial loss of the person’s bodily...functions, or ‘malfunction...of part of the person’s body.’³⁸⁵

In a letter to the ASEHA Queensland, the Disability Discrimination Commissioner, Dr Sev Ozdowski, points out that:

*“A person who could show that he or she in fact had the reactions to commonly used chemicals...would meet this definition.”*³⁸⁶

The Committee heard that the SATFMCS has been working with several non-government agencies to establish MCS disability access policies, and that policies are now in place at the Disability Information Resource Centre, Gilles Street, Adelaide, and the AIDS Council of South Australia.³⁸⁷

The Inquiry was also informed that people who have been medically diagnosed with MCS are eligible to receive Disability Support Pension payments from the Commonwealth Department of Family and Community Services. Eligibility is assessed on a case by case basis, and on the level of disability.³⁸⁸

It was also established that the Adelaide City Council (ACC) was embarking on a review of its Disability Action Plan (DAP). While the current plan does not cover issues relating to MCS, the ACC has indicated that the review will take note of this Inquiry’s research and recommendations to accommodate people with MCS.³⁸⁹

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.

MCS Disability Status Overseas

The Inquiry was informed that US jurisdictions at a state and city level have developed guidelines for MCS in accordance with the Americans with Disabilities Act. The City and County of San Francisco updated its Disability Action Plan in 1991 to accommodate MCS sufferers; the State of Washington, produced the Reasonable Accommodation Guide for Employers, Businesses and Persons with Disabilities; and in 1996 the State of New Mexico directed the Governor’s

³⁸⁵ SATFMCS, written submission, p41.

³⁸⁶ Ibid., p41.

³⁸⁷ Evans, oral evidence, Hansard, pp72-73.

³⁸⁸ SATFMCS, written submission, p40.

³⁸⁹ Correspondence received from Andrea Sargent, Team Leader Social Planning, Social Development Unit, Adelaide City Council, via email, 21 May 2005.

Committee on the Concerns of the Handicapped to study issues related to MCS, resulting in the adoption of MCS specific legislation.³⁹⁰ Disability access provisions for people with MCS also exist in community based services and private organizations in Canada and the US.³⁹¹

The Inquiry heard that California is one of the most progressive jurisdictions in the world with regard MCS disability access. In addition to the provisions made in the San Francisco Disability Action Plan, California's clean air policy also offers guidelines on MCS disability access in public buildings.³⁹²

The ME/CFS Society SA also advised the Inquiry that environmental illness legislation (Bill C-416) was introduced in Canada in 2000 to protect the needs of people with MCS, CFS and FM.³⁹³

POSITION STATEMENTS ON MCS

Submissions presented to the Inquiry show that a large number of statements recognising or disputing MCS as a valid diagnosis are produced by a range of Government agencies, medical and professional bodies in Australia and overseas. It was explained to the Inquiry that the Commonwealth Department of Health and Ageing (DoHA) Position Statement describes the term MCS as:

“...a questionable designation that incorrectly implies that a linkage between chemical exposure and the immune system has been established.”³⁹⁴

DoHA asserts that:

“...there is insufficient evidence upon which to base a strategy for MCS that would be cost and resource effective, acceptable to the Australian community, and unlikely to cause unintended consequences.”³⁹⁵

In a submission from the Royal Australasian College of Physicians (RACP), the Inquiry was informed that without thorough analysis of the evidence on MCS the RACP would not make a definitive statement on the condition. It was explained that the College had undertaken a substantial evidence based review in the preparation of the Chronic Fatigue Syndrome Guidelines and believed a similar review, which gathered and analysed the MCS evidence base, was required. It was pointed out to the Committee that the CFS review was:

“...a very expensive and time consuming process that was funded by the Commonwealth Department of Health and Ageing.”³⁹⁶

The Inquiry noted that a question without notice relating to chemical-free hospital facilities was raised by the Hon. A. G. Corbett in the NSW Parliament on 29 November 2000. The response from the Minister for Health notes that:

³⁹⁰ Myalgic Encephalopathy/Chronic Fatigue Syndrome (ME/CFS) Society SA, written submission , p2.

³⁹¹ South Australian Task Force on Multiple Chemical Sensitivity (SATFMCS), written submission, p35.

³⁹² Evans , oral evidence, Hansard, pp72-73.

³⁹³ [ME/CFS Society SA, written submission, p2.](#)

³⁹⁴ South Australian Task Force on Multiple Chemical Sensitivity (SATFMCS), written submission, p38.

³⁹⁵ Ibid., pp38-9.

³⁹⁶ The Royal Australasian College of Physicians (RACP), written submission, p1.

*“The condition referred to as multiple chemical sensitivity has been debated in professional circles for many years, without consensus. Given the lack of consensus, the New South Wales Department of Health considers providing special facilities to be inappropriate at this time.”*³⁹⁷

A NSW Parliamentary Library Review of MCS was subsequently initiated. The review concludes that:

*“Whatever the aetiology, it is important that patients are treated with compassion and care.”*³⁹⁸

The report cites the findings of a US Interagency Work Group finding that:

*“It is appropriate for public health leadership to work to mitigate illness in persons with disorders that are not fully explainable. In so doing, it must be recognised that chemical agents found to be noxious by a significant portion of the population may, and often do, present public health hazards that lead to health concerns such as MCS.”*³⁹⁹

Institutional Positions on MCS in the US

The institutional response to MCS has been mixed and reflects the difference in opinion that exists in the scientific and medical community with regard the aetiology of MCS. It is noted that in the US MCS has achieved credibility in workers' compensation claims, liability case law and in the interpretation of regulations by various US Government Departments.⁴⁰⁰

Medical and professional bodies such as the American Medical Association, American Medical Council on Scientific Affairs, American College of Physicians, American College of Occupational and Environmental Medicine and the American Academy of Allergy, Asthma and Immunology, have rejected MCS as a legitimate organic disease.⁴⁰¹

Other organizations such as the International Labor Organisation (Geneva), Association of Occupational and Environmental Clinics in Washington DC, American Academy of Environmental Medicine in Denver, Colorado, and the California Medical Association, are reported to recognise MCS.⁴⁰²

It was noted that MCS has increasingly been the focus of scrutiny in the US, Canada and Europe. According to the SATFMCS, growing public concern and litigation has led to numerous studies, workshops, investigations and reports on MCS.⁴⁰³ A 1998 draft report on MCS prepared by the US Department of Health and Human Services Interagency Working Group found the condition lacked an accepted case definition, that limitations are found in the design of many published studies, and that no widely accepted protocols are proven to be effective in addressing MCS

³⁹⁷ Smith, S (NSW Parliamentary Library Research Service), A Review of Multiple Chemical Sensitivity (Paper prepared for the Hon A Corbett MLC), 23 October 2001, p19.

³⁹⁸ [Ibid., p19.](#)

³⁹⁹ [Ibid., p19.](#)

⁴⁰⁰ [Ibid., p14.](#)

⁴⁰¹ Fumento, M. Scents and Senselessness. The American Spectator, April 2000, p6.

⁴⁰² Myalgic Encephalopathy/Chronic Fatigue Syndrome (ME/CFS) Society SA, written submission , pp1-2.

⁴⁰³ South Australian Task Force on Multiple Chemical Sensitivity (SATFMCS), written submission, p33.

symptomatology.⁴⁰⁴ Agencies involved in the Work Group such as the Department of Defence, National Institute of Environmental Health Sciences and the Agency for Toxic Substances and Disease Registry, have all recognised the need for scientific research to enable a better understanding of MCS, and have provided funds to ensure that this occurs.⁴⁰⁵

A Report released in Denmark in March 2005 based on a study of the scientific literature on MCS, referred to as Odour and Chemical Hypersensitivity, found that MCS is a real condition. The Report, prepared by the Danish Environmental Protection Agency, concludes that:

“MCS differs from the common scientific understanding of illness because the condition is always manifested by multiple non-specific symptoms from different organs at the same time and because these symptoms may occur after exposure to chemicals at very low concentrations.”⁴⁰⁶

Other studies such as the Socio-Economic Impacts of Environmental Illness in Canada report points to research that suggests that different standards of proof are required by conventional science and for the formulation of public or corporate policy. It notes that:

“...science demands strict standards – the amount and type of evidence required to support a hypothesis. The response to uncertainty is further data collection. But these standards may not be appropriate in the realm of policy making (though appeals to scientific rigour have been used to block policy changes). The issues are different and the need to act is greater because the costs of not correcting a problem may be high; lives may be lost or the quality of life impaired...with respect to environmental hazards and other causes of ill health where the evidence is relatively persuasive.”⁴⁰⁷

Summary

The Committee acknowledges that while MCS is only formally recognised by the ICD as a medical condition in Germany, it has gained recognition and credibility in a number of countries overseas, particularly in some Canadian provinces and US states. The Committee recognises that differing views exist and that this is not surprising considering the lack of agreement in the scientific and medical community on the aetiology of MCS. This translates into a diverse range of policies and position statements.

It is evident that the lack of a classification code for MCS raises several issues such as an inability to quantify and monitor the number of cases that arise in the workplace. It also raises concerns regarding equitable access to health care and social services, and to public institutions and facilities more broadly.

The Committee believes that further research is required to enable a better understanding of MCS. This would ensure that measures developed to address the needs of people with MCS were

⁴⁰⁴ Smith, S (NSW Parliamentary Library Research Service), A Review of Multiple Chemical Sensitivity (Paper prepared for the Hon A Corbett MLC), 23 October 2001, p13.

⁴⁰⁵ Ibid., pp15-17.

⁴⁰⁶ Danish Environmental Protection Agency, Multiple Chemical Sensitivity, MCS, Environmental Project no. 988, 2005, http://www.mst.dk/udgiv/publications/2005/87-7614-548-4/html/default_eng.htm

⁴⁰⁷ Kassirer, J. and Sandiford, K. (Cullbridge Marketing and Communications), Socio-Economic Impacts of Environmental Illness in Canada, 15 November, 2000, p5.

founded on a strong evidence base. It is clear, however, that several measures could be introduced in the interim to assist members of the community with MCS to gain greater quality of life.

SECTION FOUR: THE IMPACT AND IMPLICATIONS OF MCS

A. THE IMPACT OF MCS

MCS significantly impacts the lives of many sufferers. The lives of some individuals are severely restricted by debilitating symptoms which are thought to be triggered by contact with a wide range of chemicals that do not appear to affect the majority of people in their daily lives. Sufferers experience ill health, disability, loss of income, and the ability to contribute as productive members of society on many other levels. Many sufferers are forced to stop work and limit their social contact and involvement in a range of activities and environments in order to manage their condition. Many rely on the care they receive from partners and family members, and this often has a significant impact on these relationships. In addition to the immeasurable personal costs, MCS sufferers also incur significant expenses in relation to health care and maintaining a chemical free lifestyle.

The condition also appears to have broader social and economic impact, particularly in relation to the costs associated with the dependence of many sufferers on the health and welfare system. Quantifying these costs, however, is difficult as there is a dearth of data relating to MCS. Studies on the prevalence of the condition are limited, as are studies that establish the incidence of MCS in the work environment. There is nonetheless some suggestion that the costs associated with diagnosing and treating MCS, often resulting in hospitalisation, lost productivity, loss of career for sufferers, partners who assume carers responsibilities and families, could be considerable.

THE IMPACT OF MCS ON THE HEALTH OF SUFFERERS

A great number of submissions from individuals with MCS received by the Inquiry outlined the many ways in which MCS has impacted on their lives, and on those close to them. The primary impact of MCS is unquestionably on the health of sufferers. As previously established in this report, many sufferers experience a wide range of symptoms which can either be initiated or triggered by exposure to any number of every day chemicals. People with MCS can be totally disabled by severe symptoms which they experience on a daily basis, or disabled to a lesser degree by milder symptoms which they experience occasionally. Research indicates that MCS can become progressively debilitating, and that until more conclusive evidence becomes available on treatment strategies, avoiding contact with substances that can induce symptoms remains the most effective way of managing the condition.

The adverse impact of MCS symptoms on the health and well being of sufferers is acknowledged by some medical practitioners and professional bodies. In the absence of objective evidence that establishes the legitimacy of the condition, there remains, however, scepticism at large in the medical profession. Many submissions from sufferers explain that they are often tagged as malingerers or in need of psychiatric help when doctors fail to readily identify their condition as MCS. Many of the submissions received welcomed the opportunity to recount their experience of living with MCS on their own lives and those close to them.

The Committee heard that certain chemicals generated severe suffering in people with MCS, such that it left them unable to leave their homes. Dr Mark Donohoe told the Inquiry that the majority of sufferers:

“... were confined, unable to work and suffered a disability that was exceptional – to me, much greater than the disability of diabetes or multiple sclerosis, when people are usually not in pain and are able to work until late in the disease.”⁴⁰⁸

The impact of MCS on sufferers’ ability to contribute fully in society is recognised in the American College of Occupational and Environmental Medicine (ACOEM) 1999 position statement which points out that:

“Irrespective of scientific uncertainties regarding the diagnosis, aetiology and management of MCS, the impact of these symptoms on the well-being, productivity and lifestyle of those affected can be dramatic. It is neither helpful nor appropriate to address the problem solely by the hypotheses that emphasise malingering or desire for compensation. Controversies about specific theories of MCS, diagnostic approaches or treatment modalities should not preclude the compassionate care of patients presenting with complaints consistent with MCS.”⁴⁰⁹

The Inquiry was informed in a number of submissions that people with MCS can experience increasing levels of disability, and that they may go on to develop other illnesses and a worsening of chemical sensitivities over time. A 2002 study conducted in the Southern and Hills districts in Adelaide by the Bridges and Pathways Institute on the service needs, priorities, and self-management issues for those with complex illnesses with which MCS is associated, found that 80% of respondents were housebound due to their disability.⁴¹⁰

Many individual submissions noted that their health had deteriorated and their condition had worsened over time. One sufferer explained that:

“At age 55, I have suffered with Multiple Chemical Sensitivity to a greater or lesser degree for around two decades...Each year has brought an increase in symptoms and consequently a decrease in lifestyle. The words “Pain”; “Distress”; “Isolation”; “Ridicule”; “Abandonment” well describe my life.”⁴¹¹

Another sufferer described the devastating effects on her life in the following way:

“...my illness is hideous and life altering. We have gone from a double income professional family, happy and healthy with goals and dreams to devastation in every aspect of life, in the space of three years.”⁴¹²

Other sufferers described the widely variable and unpredictable health effects that they experienced, noting that their ability to avoid contact with incitant chemicals, once their condition had been identified, was their best chance in maintaining some quality of life. One 27 year old sufferer described the rapid change that occurred in his health and lifestyle within months. In the early stages he experienced a “mild allergic reaction”, minor cognitive effects and speech difficulties which, he explains:

“...were quite manageable...I was able to continue working and studying without too many adjustments to my very active lifestyle...inexplicably I became sensitive to all foods...I would

⁴⁰⁸ Donohoe, oral evidence Hansard, p101.

⁴⁰⁹ Ibid., p100.

⁴¹⁰ Bridges and Pathways Institute, written submission, [p2](#).

⁴¹¹ Crossett, written submission, p1.

⁴¹² Lillis, written submission, p4.

become disoriented and dizzy, and I would have difficulty articulating words. Because I could not function properly, after ingesting even the smallest amounts of food, over the next four to six weeks I lost around 12 to 15 kilos in weight, which is obviously quite frightening for someone who had generally been healthy up until that point in time."⁴¹³

Fluctuations in the health of many sufferers, often brought about by inexplicable reactions to a wide range of substances, can be summed up by the conclusion drawn by this sufferer:

*"MCS does not seem particularly logical. I am a fairly scientific, rational type. I would love to be able to say that something affects me or does not: but, because it changes so often, it is really difficult to deal with."*⁴¹⁴

The Inquiry heard that for seriously impaired sufferers, seeking treatment in hospitals, surgeries and health centres was a hazardous experience, due to the large number of chemicals in the hospital environment which are thought to trigger MCS symptoms.⁴¹⁵ It was brought to the attention of the Inquiry that many MCS sufferers also suffer from a range of other severe ailments and conditions which require hospitalisation. As one elderly sufferer with a heart condition commented:

*"...I was put in the Heart ward...for three day (sic), no one cared wether (sic) I was chemically sensitive or not, the place was a nightmare for me, with them spraying all the beds around me, mopping floors, the worse part was nurses wearing perfume...If they could have put me in a single room, & not mopped the floors and asked the nurse not to wear perfume I would not be as sick as I am...now..."*⁴¹⁶

A 2004 Workshop on MCS jointly sponsored by the SATFMCS and the ME/CFS Society in SA found that there was "deep dissatisfaction" among many sufferers with the medical profession, and a perceived misunderstanding and misdiagnosis of MCS.⁴¹⁷ Many submissions also described the poor treatment they had received in medical institutions, predominantly due to a lack of awareness and recognition of MCS. Many sufferers face accusations of malingering and, when diagnostic tests fail to identify the cause of their illness, many are often diagnosed with a psychological illness. A sufferer described the treatment she received after being taken to hospital by ambulance. She explained that she collapsed shortly on arrival and:

*"Whilst I was still on the floor in a gown, the intern rolled me over with his foot and yelled at me to get up. He then accused me of pretending to faint."*⁴¹⁸

Another sufferer explained that:

*"The attitude that people 'imagine' illness, represents one of the greatest cruelties of all time to suffering people."*⁴¹⁹

Attributing MCS symptoms to a psychiatric cause was seen by many to have considerable impact on their condition. One woman described how:

⁴¹³ Nicholls, oral evidence, Hansard, pp161-2.

⁴¹⁴ Ibid., pp161-2.

⁴¹⁵ Myalgic Encephalopathy/Chronic Fatigue Syndrome Society SA, written submission, p8.

⁴¹⁶ Guthrie, written submission, p1.

⁴¹⁷ MCS Workshop Report, p1, submitted as part of evidence presented by the SATFMCS, 20 September, 2004.

⁴¹⁸ Heinrich, written submission, p3.

⁴¹⁹ Jeffreys, written submission, p4.

“Three times during the course of my illness, the only practical help available to me was being admitted to a Psychiatric Unit...due to the failure of the ...health workers to recognise the legitimacy of my health condition, my physical symptoms worsened, as did my feelings of helplessness and alienation.”⁴²⁰

Many other sufferers also indicated that the stress they experienced due to the lack of understanding and recognition of their condition from medical practitioners and health care workers led to a worsening of their symptoms. On the basis of the treatment experienced by one young woman, she concluded that:

“...I never imagined that South Australian health institutions could be capable of such humiliation, disempowerment and neglect. In numerous state medical institutions I experienced treatment that I would consider physically abusive and psychologically degrading.”⁴²¹

The Impact on the Health System

As indicated in Section One of this report, people with MCS are thought to consume substantial health resources as a result of what has been described as excessive and inappropriate testing in the diagnosis of the condition. Dr David Gillis told the Inquiry that the cost of such testing is a considerable cost burden to the health system.⁴²² The Inquiry learnt that research has not been undertaken to establish the impact of MCS on the health sector, either at the national level or in SA.

THE IMPACT OF CHEMICALS ASSOCIATED WITH MCS ON HUMAN FERTILITY

The Inquiry heard that fertility rates in chemically sensitive people have not been measured or monitored.⁴²³ According to Dr Mark Donohoe, while there may be changes in the fertility of people with MCS, limited research funds have been directed into other areas. He explained that:

“...since infertility is not their complaint, clinicians see them for neurological or immunological measurements or some other type of measurement. They are not turning up to specialists [for issues of] fertility ...and that is why fertility does not get looked at.”⁴²⁴

While it appears that research investigating the effects of chemicals on the fertility of people with MCS has yet to be conducted, international research has established that chemicals implicated in MCS, such as pesticides and organic solvents, are responsible for reducing fertility in men and women. This is seen to manifest as a decline in sperm counts, genetic damage in sperm, spontaneous abortion, low birth weight, and foetal abnormalities.⁴²⁵

In relation to women's fertility, Dr Fiona Young, Lecturer in Biotechnology, Department of Medical Biotechnology, School of Medicine, Flinders University, informed the committee that while an association between chemicals and miscarriage in women can be made, it has yet to be

⁴²⁰ Villis, written submission, p3.

⁴²¹ Ibid., p3.

⁴²² Gillis, oral evidence, Hansard, p151.

⁴²³ Donohoe, oral evidence, Hansard, p118.

⁴²⁴ Ibid., p119.

⁴²⁵ South Australian Task Force on Multiple Chemical Sensitivity (SATFMCS), written submission, p73.

proven. The Committee was told that approximately 25 percent of all pregnancies end in miscarriage, with the rate of miscarriage increasing as women get older. Dr Young explained that it is reasonable to attribute a percentage of the miscarriage rate to chemical exposure, with research indicating that approximately 70% of aborted embryos display genetic damage from exposure to chemicals.⁴²⁶

Dr Young provided a brief background on reproductive physiology, explaining that the effects of chemicals on women's fertility can occur over the entire reproductive lifespan. Each egg in a woman's ovaries is surrounded by cells which are protected by the basement membrane, which forms a barrier. The cells inside the membrane surrounding the egg are known as the granulosa cells. The egg surrounded by the granulosa cells and the basement membrane is known as a follicle.⁴²⁷ Chemicals, it was noted, were able to cross the membrane barrier, and in many circumstances, miscarriage occurs because chemicals have crossed the protective basement membrane barrier, entered the egg through the cells surrounding it, affecting chromosomes and causing genetic damage. When the egg is fertilised and the embryo starts to develop, the genetic damage interferes with and prevents further development, which results in miscarriage.⁴²⁸

In relation to male fertility, research has established that exposed to a toxic substance may result in aberrant sperm or a decrease in the sperm count during each 90-day cycle in which sperm is produced. Dr Young explained to the Committee that the effect can vary according to the severity of the exposure. It was noted that in addition to environmental chemicals, a range of other factors, such as alcohol intake and smoking, can also impact on human fertility and must be taken into account.⁴²⁹

The Committee was informed that Dr Young is currently engaged in research into reproductive toxicology which uses human cell life to test the effect of chemicals on the granulosa cells in vitro, and on toxicants in sperm.⁴³⁰ A particular focus of this research is the investigation of the chemical Amitraz, commonly used to control ticks and mites in agriculture and animal husbandry. Amitraz, a known reproductive toxicant, is also widely used to control fleas on dogs, and exposure can occur when people pat their dogs.⁴³¹ Dr Young told the Committee she has observed that differing doses of the chemical have a significant impact on a woman's ability to become pregnant and maintain a pregnancy. Her research shows that concentrated doses of the chemical killed the granulosa cells, indicating that if a woman was exposed to such a dose, and if that concentration entered the granulosa cells:

*"...it would kill...[those] cells, those cells will not make oestrogen...the egg will not develop, and she will not get pregnant."*⁴³²

A more diluted dose stopped progesterone production, suggesting that while a woman might become pregnant, she would not maintain the pregnancy. Dr Young conceded that while these

⁴²⁶ Young, oral evidence, Hansard, pp120-221.

⁴²⁷ Ibid., p221.

⁴²⁸ Ibid., pp120-221.

⁴²⁹ Ibid., pp120-222.

⁴³⁰ Ibid., pp222-3.

⁴³¹ Ibid., p224.

⁴³² Ibid., p227.

tests do not indicate the exact effects of Amatriz on human subjects, they are significant in that they are the first tests of their kind to be carried out on human tissue.⁴³³

The Committee heard that while evidence of the harmful effects of Amitraz is accumulating, it is not at present sufficient to warrant a warning being placed on products containing the chemical. The lack of research on the affects of chemicals on fertility results in the lack of detailed information displayed on products. Dr Young noted:

“If it is indicated that it is perilous or it is going to cause a problem, they just put it off label for pregnant women. They say, ‘Don’t take this if you are pregnant.’ Even Panadol.”⁴³⁴

International Studies on Chemical Impacts and Fertility

The Committee was informed of a number of studies which have established links between chemicals associated with MCS and human infertility. These include research conducted by the Centre for the Evaluation of Risks to Human Reproduction on the effects of propylene glycol (ethylene glycol) (PEG), methanol, bromopropenes, phthalates, and some organophosphates. According to Dr Young, studies on the effects on human fertility of environmental oestrogens, which are present in many pesticides, provide:

“...quite convincing evidence that their effects are very cumulative.”⁴³⁵

The Committee learnt that while DDT, a “...classic environmental oestrogen” is no longer in use, many pesticides still have oestrogen activity, and that this activity is being investigated by Dr Young.⁴³⁶ According to Dr Young:

“It is fair to say that chemicals are affecting human fertility but we do not know how much. It is happening but we do not know the details...there is evidence that there are chemical residues in reproductive tissues in people today...We do not know whether that is on the increase, decrease or otherwise – we need more work.”⁴³⁷

Other studies have shown that exposure to Glyphosate, a chemical frequently cited as initiating and triggering the symptoms of MCS, has also been linked to reproductive problems in humans. A study of fathers in farming families in Ontario, Canada, found that use of Glyphosate was associated with an increase in miscarriages and premature births.⁴³⁸

MCS and Women’s Fertility

While specific research on the effects of chemical exposure on women with MCS have yet to be undertaken, evidence suggests that MCS is a condition that affects more women than men. Surveys such as those undertaken by the SA DoH have indicated that the ratio of women to men with the condition is 3:1.⁴³⁹

⁴³³ Ibid., pp227-228.

⁴³⁴ Ibid., p224.

⁴³⁵ Ibid., p230.

⁴³⁶ Ibid., p225.

⁴³⁷ Ibid., pp230-1.

⁴³⁸ Cox, C., (ed) *Journal of Pesticide Reform* v.108, n.3 Fall98 rev.Oct00, P7, Glyphosate Fact Sheet (<http://www.mindfully.org/Pesticide/Roundup-Glyphosate-Factsheet-Cox.htm>).

⁴³⁹ Fitzgerald, written submission, p1.

Research has found that women are disproportionately affected by environmental contamination due to female body composition. A report released by the Women's Foundation of California in 2003 found that women on average have a two to 10 percent higher proportion of body fat and naturally store more fat-soluble toxic materials, even when exposed to the same amount as men. The report also found that:

*"Women of reproductive age transfer a lifetime of accumulated toxins to their fetuses in utero and to their new-borns through breast milk. During pregnancy, chemicals cross the placenta and may disrupt foetal development, resulting in serious health affects that may not be evident until a child reaches puberty or adulthood."*⁴⁴⁰

Women employed in low paid jobs as domestic help, commercial cleaners, and in some areas of manufacturing, were seen as particularly vulnerable due to high incidences of chemical exposures in these occupations. Women comprised 70% of the semiconductor manufacturing workforce in California, and their illness rate is three times that of workers in other manufacturing industries. The children of these workers were found to have a 40% higher rate of birth defects. It also found that 20% of California's 700,000 farm-workers are women and that their risks for stillbirth and miscarriage are four times greater than found in other women. In response to this study it was noted that:

*"Viewed from an economic perspective, and in terms of treatment, care, and lost productivity, the cost of chronic diseases possibly caused by exposure to contaminants is staggering."*⁴⁴¹

A Table listing the effects of a wide range of chemicals on women's fertility is attached in Appendix...

Chemicals in the Work Place and Human Fertility

The Inquiry heard that a wide range of chemicals commonly found in many workplaces are associated with either initiating or triggering MCS symptoms.

A study conducted by the National Institute for Occupational Safety and Health (NIOSH) in the US found that while it has been estimated that 1000 workplace chemicals have shown reproductive effects on animals, most have not been studied to ascertain their effects on humans. More than 4 million other chemical mixtures in commercial use are also untested, and physical and biological agents in the workplace that may affect fertility and pregnancy are essentially unstudied. The report notes that the contribution that may be made by occupational factors on human fertility is largely unexplored as the reproductive health of workers has only recently emerged as a serious focus of scientific investigation. (National Institute for Occupational Safety and Health (NIOSH) is the Federal US agency responsible for conducting research and making recommendations for the prevention of work related injury and illness.⁴⁴²

Although numerous occupational exposures, such as some pesticides and solvents, have been shown to impair fertility, the overall contribution of occupational exposures to male and female infertility is unknown. It is noted that observed global trends in men's decreasing sperm counts

⁴⁴⁰ Eshaghpour, T. (The Women's Foundation of California) , Confronting Toxic Contamination in Our Communities: Women's Health and California's Future, 2003 (http://www.womensfoundca.org/fullreport10_7.pdf).

⁴⁴¹ Ibid., p9.

⁴⁴² National Institute for Occupational Safety and Health, Fertility and Pregnancy Abnormalities, p1, <http://www.cdc.gov/niosh/nrpreg.html>.

have elevated concerns about the role of chemicals encountered at work and in the environment at large.⁴⁴³ While some specific reproductive hazards such as solvents and ionizing radiation have been identified in humans, data on the overall contribution of workplace exposures to reproductive disorders and congenital abnormalities is also unavailable.

The Report concludes that substantial research is required to achieve a broad understanding of the most significant hazards, their impacts and preventative strategies.⁴⁴⁴ Such studies would play an important role in identifying preventable effects in workers and/or their offspring, such as field studies that have detected reduced semen quality in men occupationally exposed to glycol ethers, or increased spontaneous abortions in semiconductor workers.⁴⁴⁵

THE SOCIAL IMPACT OF MCS

For many sufferers, social isolation is consistently an outcome of MCS. This arises largely due to the reactions that MCS sufferers experience from exposure to a wide range of chemicals commonly used in indoor and outdoor environments. The Committee heard that some sufferers may take extreme measures to avoid exposure to chemicals that they associate with triggering their symptoms. Other sufferers limit their contact with environments known to contain chemicals that they may react adversely to. For many, social isolation becomes a necessary protective measure and a form of illness management.

Dr Robert Loblay told the Committee that he believed the term MCS can lead to isolation and disability due to the social withdrawal that it generates. The term, he explained:

*“...frightens patients, and they experience their symptoms as more distressing and disabling...The people who get frightened by what they have been told or the circumstances in which they have been exposed or become ill often develop what I have called... 'chemophobia'... They become frightened of all exposure including the things that they have become reactive to.”*⁴⁴⁶

Dr Loblay noted the extreme case of:

*“...a family who moved to Kangaroo Island about 25 years ago and lived a Stone Age lifestyle to get away from their exposures,...at that time this was commonly referred to as “allergy to the 20th century”.”*⁴⁴⁷

Many sufferers consider their self imposed social isolation to be a necessary protective measure. One sufferer explained that following her diagnosis with MCS she was unable to participate in many social activities due to her sensitivity to chemicals present in many personal fragranced products:

“I increasingly retreated to the lonely life which most MCS sufferers experience. Many lose friendships and relationships, because we can’t go out or join in unless it is a smoke free,

⁴⁴³ Ibid., p1.

⁴⁴⁴ Ibid., pp2-3.

⁴⁴⁵ Ibid., p3.

⁴⁴⁶ Loblay, oral evidence, Hansard, pp179- 180.

⁴⁴⁷ Ibid., p176.

*perfume free event...Because of perfumed products, there are few places where MCS sufferers can go.*⁴⁴⁸

Many sufferers withdraw from everyday social activities and find any contact with the world outside of their specially modified homes difficult. Another sufferer drew attention to the wide range of activities she was unable to participate in when she noted:

*"Imagine not being able to sit in a public park, read a newspaper, go to a library, visit the doctor, go out for coffee, without being made sick."*⁴⁴⁹

Routine activities such as supermarket shopping was frequently cited as problematic for those with MCS, particularly for women who assume the primary caring and domestic role and responsibilities in a family. One 44 year old MCS sufferer and mother of a disabled child, noted:

*"One of the most difficult tasks for me was shopping in the supermarket. The moment I set foot in the door my eyes began to weep and my sinuses would close up in response to the strong smells emanating from the "cleaning aisle".*⁴⁵⁰

While some sufferers can continue to undertake many basic functions, the impact of the condition is so severe for others that they require full time care. In such cases their capacities are considerably diminished. The severity of the circumstances some find themselves in is summed up by one woman who explains:

*"...I can no longer work and my husband is now my fulltime carer as I can no longer care for myself. I can no longer shop, use public libraries, walk in parks, or visit friends because of the effect the chemicals they use have on me. I am too ill to drive, write or even hold a book and my daughter is typing this for me as I am unable to."*⁴⁵¹

The Impact of MCS on Education and Housing

The Inquiry heard that the disabling symptoms experienced by MCS sufferers from exposure to chemicals also impacts on the ability of individuals to access educational institutions and housing.

Submissions received pointed to the difficulties experienced by MCS sufferers in attending schools and tertiary institutions. While anecdotal evidence indicates that this is an issue of some concern, the extent of this problem is unknown due to a lack of research and data. Chemicals present in the school environment and a lack of awareness of MCS among teachers were among the issues of concern identified in submissions. One parent explained the difficulties her daughter experienced and the struggle she had in informing teachers of her daughter's needs.

*"...I ...remember having to enlighten a PE teacher who ridiculed her and made her social isolation the subject of class amusement...this style of leadership was very damaging to my child's self esteem, because she had already been socially different for many years and this only highlighted her feeling of being different."*⁴⁵²

⁴⁴⁸ Individual written submission, name withheld, p3.

⁴⁴⁹ [McCraig, written submission, p4.](#)

⁴⁵⁰ Reen, written submission, p2.

⁴⁵¹ Hoge, written submission, p1.

⁴⁵² Sanzaro, written submission, pp 1-2.

Another parent noted that her daughter was so ill as a young child she was finally became unable to attend school. She explained that chemicals in the environment made her daughter ill and that:

*“Her MCS was not recognised by her primary school, despite my efforts to educate them. That attitude made her continuation of school attendance impossible...for Lori, the most basic of a child’s needs to gain an education proved to be extremely harmful to her health.”*⁴⁵³

In its submission, the Allergy and Environmental Sensitivity Support and Research Association Inc. (AESSRA) notes that children with chemical sensitivities require:

*“...an environment free of the chemicals that adversely affect their health and/or ability to learn. No Australian school does this.”*⁴⁵⁴

The ME/CFS SA has noted that chemically sensitive people who wish to attend schools or tertiary institutions are often not accommodated and their needs for a safe environment are not taken seriously.⁴⁵⁵

In relation to housing, the Inquiry was informed that access to safe and affordable housing was an issue of considerable concern to many sufferers, particularly those who were reliant on public housing. In its submission, the SATFMCS explained that in order to maintain their health and quality of life:

*“...it is essential that people with MCS have access to a chemical-free living environment and stable accommodation.”*⁴⁵⁶

Unless individuals with MCS own their own homes they are reliant on public housing to meet their need for a chemical free environment. Anecdotal evidence was presented indicating that the public housing needs of some sufferers had not been met. One MCS sufferer who lives in a Department of Housing unit in North-West Sydney, advised the Inquiry that despite being aware of his chemical sensitivity, the DOH has repeatedly sprayed toxic chemicals around his home. He notes that:

*“95 percent...of all my communications with the DOH have been soundly ignored.”*⁴⁵⁷

The difficulties of finding suitable housing were outlined in a number of submissions. One woman explained that it became:

*“...too much for me to physically/financially maintain so I sold [my home] intending to move into a much smaller house with less garden. Despite...searching I have found nothing suitable to my requirements...Finding a place to rent is even more difficult, indeed, impossible. Even if a “friendly” house were found there would be no security of longterm occupancy nor control over what chemical treatments the owner might wish to make.”*⁴⁵⁸

⁴⁵³ Matthews, written submission, p1.

⁴⁵⁴ Allergy and Environmental Sensitivity Support and Research Association (AESSRA), written submission, p19.

⁴⁵⁵ ME/CFS SA, written submission, p9.

⁴⁵⁶ Evans, oral evidence, Hansard, p73.

⁴⁵⁷ Thompson, written submission, p1.

⁴⁵⁸ Cherry, written submission, p 3.

Impact on partners and families

In evidence to the Committee, Dr Mark Donohoe pointed out that the stresses of caring for someone with MCS often leads to relationship breakdown. According to Dr Donohoe:

*“...the majority of marriages and relationships break up. The stresses of being sick with this means that the support person—husband, wife, spouse or children—find it intolerable to look after a person who is this disabled and bound to home all the time.”*⁴⁵⁹

Dr Donohoe estimated that tens of thousands of people with MCS in Sydney are left to cope alone, in many cases without even the support of their families.⁴⁶⁰

Other sufferers reported that following a relationship breakdown, and despite their illness, they were left to assume primary care for their children. One 58 year old women, reported that she was a:

*“...mother of three children, deserted by my husband due to the restricted lifestyle of MCS, now desperately attempting to stay alive in suburbia.”*⁴⁶¹

Caring for a child with MCS often means that the whole family is affected. As one mother pointed out:

*“It is not only my daughter who has MCS – our family has MCS. We have had to totally change our way of living to accommodate our daughter’s affliction.”*⁴⁶²

Many elderly people also found themselves as carers for partners or children with the condition. A 38 year old woman described the impact on her mother’s life of assuming full time care for her for over 10 years.

*“She has lost many friends...[and] most other family members have totally deserted us because they find complying with the no chemical policy we have too ridged (sic).”*⁴⁶³

THE ECONOMIC IMPACT OF MCS

The Costs of a Chemical Free Lifestyle

The Committee was informed that those with chemical sensitivities often incurred considerable health care costs and other costs associated with maintaining a chemical free diet and lifestyle. This was often achieved on a very limited income, as many were unable to work, and their partners had often forgone full time work to care for them. A pensioner with MCS explained to the Inquiry that he and his wife, who also had the condition:

*“...have to purchase expensive organic food on a pensioners budget because you cannot eat the other kind without being very ill and in a great deal of pain...The only safe food for us is organic food, and it is very expensive to have an all organic diet.”*⁴⁶⁴

⁴⁵⁹ Donohoe, oral evidence, Hansard, p111.

⁴⁶⁰ Ibid., pp110-111.

⁴⁶¹ Prideaux, written submission, p1.

⁴⁶² Lee, written submission, p6.

⁴⁶³ Tosch, written submission, p4.

Another sufferer described the financial pressures that arise from managing his condition.

*“...on top of the incredible number of problems with which MCS sufferers have to deal – is financial stress...much of my income (limited at present though it is) goes on medical expenses. My base income is \$355.00 per week and thus, I am not entitled to a health care card...I am not...sure how I am going to make ends meet in the future, should my illness get worse...”*⁴⁶⁵

Once productive members of society, many people with MCS can no longer support themselves financially or contribute more fully to society. It was pointed out that some sufferers were unable to continue working, often in careers that they had enjoyed for many years. As one sufferer pointed out that:

*“Like most people in society, people with MCS want to contribute...We want to work when and if we can and in the ways that we can, and many of us have a great deal to offer. I believe that I certainly do; we just need some help in certain areas and some understanding.”*⁴⁶⁶

For some, relinquishing their jobs became inevitable following long absences due to their illness. One woman explained:

*“I used to work full time as a youth worker, however, I missed so much work due to my illness that I eventually had to resign.”*⁴⁶⁷

For others the impact of losing their careers was considerable. One man noted:

*“...I was given a Compensation payout...while I was horizontal on a sick bed. The effect of losing a 30 year career was devastating.”*⁴⁶⁸

Issues Regarding Income Support

It was noted that while some sufferers were able to receive Commonwealth Government income support payments, largely on the basis of having their condition recognised as a disability, others were not. Dr Donohoe explained to the Committee that while many claims may have the support of a sympathetic medical practitioner initially, these claims were reassessed by government medical officers which often led to conflicting opinions on the existence of MCS and consequently, loss of income support.

*“...I have 40 or more people in my practice who get no Centrelink or disability support, who have been moved out of it, because they are told to do something they just can't do...”*⁴⁶⁹

Information provided in a submission from Centrelink noted that a number of programs may be of assistance to people with MCS. Claims are assessed on a case by case basis and may include the Disability Support Pension (DSP); Newstart Allowance (Incapacitated) and Sickness Allowance. Provision of a doctors report and attendance at an independent medical assessment are among the eligibility criteria for a DSP. Income and asset assessments for individuals and their partners, also

⁴⁶⁴ Linder, written submission, pp1-2.

⁴⁶⁵ Nicholls, written submission, [p2](#).

⁴⁶⁶ Nicholls, oral evidence, Hansard, pp165-6.

⁴⁶⁷ Heinrich, cited in Myalgic Encephalopathy/Chronic Fatigue Syndrome (ME/CFS) Society SA, written submission, pp1-2.

⁴⁶⁸ Reynolds, written submission, [p2](#).

⁴⁶⁹ Donohoe, oral evidence, Hansard, [p117](#).

apply. Centelink also informed the Inquiry that it does not hold statistical data specifically for MCS.

The Inquiry was informed that among those who lose financial support from Centrelink, or are unable to qualify for assistance, many fall back on savings, family assets, and rely on family support.

In relation to Worker's compensation, the Inquiry learnt that research had not been undertaken in SA to determine the costs associated with the loss of productive labour. Dr Mark Donohoe explained to the Committee that approximately two percent of the workforce in NSW was affected by MCS, such that they were unable to work.

*"If roughly 2 per cent of people cannot work, 2 per cent productivity does translate to a large amount of cost to Australia."*⁴⁷⁰

The Inquiry heard that WorkCover in NSW has sought expert advice on MCS to address the absenteeism and disability caused by the condition, which, according to Dr Donohoe, had become

*"...a burden and a cost to WorkCover".*⁴⁷¹

The WorkCover consultations also analysed workers' compensation data in an attempt to obtain a clearer picture of the incidence and industrial base of MCS.⁴⁷² Subsequent to these consultations, the Inquiry learnt, WorkCover was to:

*"... convene a working party to develop guidance material...to assist general practitioners and others, including workers, on 'best practice' management of workers who present with symptoms of Multiple Chemical Sensitivity."*⁴⁷³

WorkCover in SA advised the Inquiry that MCS was not a condition that had been prominent or of great cost or concern to the scheme. WorkCover's lack of a specific classification code for MCS, however, has meant that the authority is unable to ascertain the number of individuals seeking compensation, who may have the condition. When asked by the Committee how many claimants WorkCover currently had who were suffering from the condition, Dianna Alder, Manager of Self Insured Operations and Systems at WorkCover told the Committee that:

*"We do not know because we do not code it that way."*⁴⁷⁴

It was explained that each claim was based on a doctor's diagnosis, and that the most prominent condition, such as asthma or dermatitis, and not the symptom of a condition was coded.⁴⁷⁵

⁴⁷⁰ Ibid., p98.

⁴⁷¹ Ibid., p98.

⁴⁷² Parliament of NSW Legislative Council Questions and Answers, Third Session of the Fifty-Second Parliament, Tuesday 3 December 2002, p1, <http://www.parliament.nsw.gov.au/prod/lc/lcpaper52.nsf/>

⁴⁷³ Ibid, p1.

⁴⁷⁴ Alder, oral evidence, Hansard, p209.

⁴⁷⁵ Kearney, oral evidence, Hansard, p200.

B. ISSUES ARISING FROM MCS

Issues and Implications

While a range of issues relating to MCS have been brought to the Inquiry's attention, two central issues have consistently emerged from the evidence presented. Foremost of these is the lack of recognition of MCS as a valid medical diagnosis and as a condition that can lead to severe disability. Many individual submissions in particular made reference to the hardship that a lack of formal recognition presents suffers.

One of the primary difficulties associated with the lack of recognition of MCS is that of access. Issues relating to access arise in relation to workplaces and public services and facilities, including hospitals. Access to support services was also a particularly significant issue for the many sufferers who experienced severe and disabling MCS symptoms. While disability access issues were a primary concern, it was also noted that difficulties with regard access apply more broadly and impact on people who may experience less severe symptoms. A view commonly held was that MCS sufferers were prevented from accessing many public spaces due to the reactions they experienced to chemicals in many indoor and outdoor environments.

LACK OF RECOGNITION

The lack of recognition of MCS as a disease is pivotal to many of the difficulties experienced by sufferers. The lack of a medical classification not only creates difficulties in diagnosis and treatment but in relation to worker's compensation, Commonwealth Government income support payments, and in accessing services. The predicament of many MCS sufferers was summed up in one submission which explained that:

*"The main impediment to MCS sufferers, anywhere in Australia, accessing support through Government agencies is the current status of the illness...In a nutshell, it does not exist...the condition has no ICD code...our primary and most urgent requirement is for MCS to be recognised as a non-psychiatric condition and a legitimate disability. Once that is achieved, then all else should follow as a matter of course, with sufferers granted access to the same medical...and social services...to which all other Australians are currently entitled."*⁴⁷⁶

Many individuals in their submissions noted the difficulties experienced due to the lack of recognition and consequently lack of understanding toward MCS sufferers from medical practitioners and the general public. Some sufferers believe that they have received unfair treatment by some doctors and that they consequently felt discriminated against.⁴⁷⁷

Many submissions related personal accounts that indicated there is a lack of public awareness and understanding of the condition. One sufferer described the impact of the lack of recognition and understanding surrounding MCS:

"My ill health has affected my family, I lost many friends who simply did not understand the nature of my illness, my social life became non existent and I had to close down my business and go onto a disability pension. This was a nightmare in itself, trying to get help and

⁴⁷⁶ Australian Chemical Trauma Alliance Inc., written submission, p3.

⁴⁷⁷ [MCS Workshop Report, p1, submitted as part of evidence presented by the SATFMCS, 20 September, 2004.](#)

*understanding when there was no acknowledgment of an injury called Multiple Chemical Sensitivity.*⁴⁷⁸

Another sufferer described her experience in relation to fragrance use by others:

*“One of the most discouraging issues to me...- and also voiced by other sufferers of MCS - is the lack of understanding by others of the effect their use of perfumes and fragrances has on sufferers of MCS.”*⁴⁷⁹

It was noted in a number of submissions that public education on MCS is lacking and that there is also a lack of accurate information on MCS. Many sufferers believed that more should be done to educate the public, health care professionals and carers, on the condition itself, as well as the health problems sufferers experience from perfumes and fragrances, smoke, environmental pollution, and pesticide and herbicide use.⁴⁸⁰

It was noted by the Committee that determining if MCS exists as a disease is a necessary and important step toward ensuring that health providers have clear guidelines for diagnosis, treatment, and prevention of the condition. Recognition of MCS would also ensure that people with the condition receive more compassionate treatment, appropriate and adequate health care and greater understanding in the community at large.

Evidence Based Medicine and MCS

The Inquiry learnt that the medical profession strongly supports an evidence based approach particularly when considering new disorders and diseases. Evidence-based medicine requires medical practitioners to identify, appraise and apply up-to-date research findings as the basis of clinical decisions in everyday clinical practice.⁴⁸¹

As previously noted in this report, an extensive evidence based review which involved collecting and analysing the evidence on CFS was undertaken by the Royal Australian College of Physicians.⁴⁸² The lack of consensus on the causes of MCS and the widely varying positions on diagnosis and treatment has led the RACP to conclude that a nationally coordinated evidence based review of the condition is required to establish guidelines to assist medical practitioners.

The Inquiry heard that medicine commonly fails to accept a disease until the mechanisms are known and proven. Dr Mark Donohoe told the Committee that it was, however, important to distinguish between whether MCS was a disease, from whether people displaying the symptoms of the condition are disabled and ill, and require support. Dr Donohoe informed the Inquiry that:

“Illness is a state perceived by the individual, and represents the “distance” between their current state of health and their self-assessed optimal state of health. Disability is the loss of

⁴⁷⁸ Byl, written submission, p1.

⁴⁷⁹ Casey, written submission, p1.

⁴⁸⁰ MCS Workshop Report, pp3-5, submitted as part of evidence presented by the SATFMCS, 20 September, 2004.

⁴⁸¹ The term ‘evidence-based medicine’ was coined at McMaster Medical School in Canada in the 1980’s to label this clinical learning strategy, which people at the school had been developing for over a decade (Source: Medical Subject Heading (MeSH) <http://search.nlm.nih.gov>).

⁴⁸² RACP, written submission, p1.

*actual or potential function as a result of illness or injury. Disease is ...generally based on a presumed knowledge of pathophysiology.*⁴⁸³

Dr Donohoe pointed out that in the case of MCS:

*“...when people turn up with the symptoms and are disabled by them, the job that doctors often see themselves doing is to decide whether people...are sick. There is no doubt about these people being sick: the doubt is about how they are sick, and doctors will often mistake one for the other.”*⁴⁸⁴

It was acknowledged that research into the cause and mechanisms of MCS is building and that this contributes toward establishing an evidence base from which MCS can be evaluated. Concerns have been raised, however, with regard waiting until consensus is reached in the medical community before addressing MCS as a disabling illness. As Dr Donohoe explained:

*“...in medicine we...have a history of seeing patients with multiple sclerosis, asthma, asbestosis and migraine, having no concept as to why, for example, asthma will take off and triple or quadruple over a 20-year period, and denying what we see before us. I am keen to see that this does not extend into chemical sensitivities any longer than is absolutely necessary. Neither is this a question of evidence-based medicine. If you put no effort into researching something—which is true for chemical sensitivities—you do not gather evidence. Until evidence has gathered, one cannot discuss whether there is evidence for or against a hypothesis.”*⁴⁸⁵

The Committee heard that while the growing body of evidence on MCS has played an important part in moving the debate forward, further research is required. One of the key obstacles to further investigation of MCS is access to research funding. Dr Donohoe told the Committee:

*“To this day most research in medicine is funded by people who have an interest in the research showing a result, and there is no-one who has a vested interest in showing that chemical sensitivities occur. If chemical sensitivities occur it is an economic problem for those producing the chemicals. Clearly, you would not want to have that research. So, you are unlikely to fund studies that will look at it openly.”*⁴⁸⁶

The need for independently funded research into MCS to eliminate bias and avoid vested interests, was raised in several submissions. The Committee was informed that the DoH's Environmental Health Special Interest Group and the Public Health Association of Australia (PHAA) jointly funded and ran a national workshop on CFS and MCS in Adelaide in 2002 at which researchers, government officials and MCS sufferers reviewed knowledge and experience with an aim to determining research needs. This was the first time that such a workshop had been held in Australia. The outcomes of the meeting were presented in correspondence from the PHAA to the National Health and Medical Research Council (NHMRC).⁴⁸⁷ One of the key issues identified was that there is little research effort being extended to develop an understanding of the complexities of MCS and other conditions. The NHMRC was urged to:

“make an exploration of CFS and MCS/IEI a priority health issue;

⁴⁸³ Donohoe, written submission, p3.

⁴⁸⁴ Donohoe, oral evidence, Hansard, p100.

⁴⁸⁵ Ibid., p100.

⁴⁸⁶ Ibid., p113.

⁴⁸⁷ Fitzgerald, oral evidence, Hansard, p18.

create a collaborative working group, involving key stakeholders, to develop strategies to progress future directions about these conditions in Australia; and manage CFS and MCS/IEI using a public health framework.”⁴⁸⁸

In response the NHMRC advised that:

“...national health priorities are recommended by the National Health Priority Action Council, a subcommittee of the Australian Health Minister’s Advisory Council. Public health strategies and frameworks are handled by various areas of the Population Health Division...[in] the Department of Health and Ageing.”⁴⁸⁹

While it was acknowledged that the development of diagnostic criteria and treatment regimes should be evidence based, which necessitates further research, it was explained that as a general rule, the NHMRC does not direct researchers to undertake research in a particular area. Research is also funded through the NHMRC’s Strategic Research Development Committee (SRDC). It was explained that in targeting research, a priority setting process is undertaken by the SRDC through consultation. The PHAA was advised that their correspondence had been submitted to the SDRC, however, a decision had been made to retain and enhance existing priorities for research funding for the 2003-2005 triennium.⁴⁹⁰

THE NEED FOR FURTHER RESEARCH

A number of measures were identified in evidence and submissions with regard addressing the issue of the lack of recognition of MCS. The provision of Federal Government funding to enable further research into the condition was considered a key initiative that would improve the lives of people with MCS. The SATFMCS has argued that:

“Research into MCS is essential if better methods of diagnosis, treatment and prevention are to develop. An improved understanding of the causes of MCS is pivotal in establishing sound environmental public health policies and offering fair compensation to people with MCS.”⁴⁹¹

Many individuals in their submissions to the Inquiry also identified further research as central to gaining recognition of the condition. One sufferer pointed out that:

“...what is ultimately needed is treatments for MCS, and the only way these are likely to be discovered is through medical research.”⁴⁹²

Dr Jim Fitzgerald from the DoH told the Committee that further research, and a national research agenda in particular, was necessary. He observed that:

“Paramount is the need for clinical or laboratory based research that attempts to define mechanisms of MCS causation, whether they be chemical, psychological, perhaps both, and

⁴⁸⁸ Public Health Association of Australia (PHAA) correspondence to the National Health and Medical Research Council, (www.phaa.net.au/Advocacy_Issues/NHMRC1.htm,) submitted as Attachment 1, p2, Fitzgerald, written submission.

⁴⁸⁹ National Health and Medical Research Council correspondence to the PHAA, submitted as Attachment 2, p1, Fitzgerald, written submission.

⁴⁹⁰ Ibid., pp1-2.

⁴⁹¹ South Australian Task Force on Multiple Chemical Sensitivity (SATFMCS), written submission, p68.

⁴⁹² Nicholls, oral evidence, Hansard, p165.

*maybe even involve genetic predisposition factors, as suggested in some research. Such research may assist development of diagnostic criteria and treatment options.*⁴⁹³

Dr Fitzgerald told the Committee that:

*“Since MCS is a poorly understood disorder and has no medical or scientific consensus on its aetiology, it poses difficulties for chemical regulators and for public health officials who are asked to develop effective public health interventions. How one can ensure that MCS sufferers are not socially excluded is an important question and one which has no immediate answer. As such, ongoing research into MCS is important but would require recognition as a priority issue by the National Health and Medical Research Council. Epidemiological studies are needed documenting adverse reactions and quantitating chemical exposures. Double blind trials would [also] be helpful...”*⁴⁹⁴

Dr Fitzgerald advised that leadership at the national level is needed to direct the research agenda.

*“...a relevant research agenda for MCS needs to be tackled with national leadership, with the National Health and Medical Research Council and the federal Department of Health and Ageing playing a key role.”*⁴⁹⁵

It was explained to the Committee that recommendations regarding a research agenda for CFS and MCS had been presented to the NHMRC but that no action had been taken on the proposed recommendations. He voiced the concerns of a number of witnesses with regard the difficulty of getting MCS on the national health agenda and pointed to the need for considerable lobbying from State Ministers and advocacy groups across Australia.⁴⁹⁶

In addition to research on the aetiology of MCS, it was suggested to the Committee that there was also a need for further research on the prevalence and economic impact of the condition. No national studies on the prevalence of MCS have been conducted in Australia, and it was proposed, further surveys with larger sample numbers would enable an estimate of the national prevalence of MCS to be made.⁴⁹⁷

Dr Mark Donohoe advised that surveys of the economic impact of MCS would enable the Federal Government to make an assessment of the cost to the nation of the condition. According to Dr Donohoe, the question that needs to be addressed is:

*“... 'Is there or is there not a problem?' You identify the problem and say, 'What does it cost?' That is what Access Economics does every week of the year. It grabs another illness or another disease—it does not matter whether it is bipolar disorder or diabetes—[and] translates it to a cost to the nation....”*⁴⁹⁸

⁴⁹³ Fitzgerald, oral evidence, Hansard, p20.

⁴⁹⁴ Ibid., p20.

⁴⁹⁵ Ibid., pp20-21.

⁴⁹⁶ Ibid., p24.

⁴⁹⁷ Ibid., p20.

⁴⁹⁸ Donohoe, oral evidence, Hansard, p115.

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.

THE ISSUE OF ACCESS

Acknowledging MCS as a Disability

The Inquiry was informed through a number of sources that as a consequence of the lack of medical recognition of MCS, it was difficult for many sufferers with severe and disabling symptoms to have their condition recognised as a disability. Despite available evidence, many sufferers were often unable to qualify for a Disability Support Pension (DSP). One sufferer informed the Inquiry that although she had been assessed as permanently disabled by medical specialists and had been unable to work for over two years, her applications to Centrelink for a DSP had been rejected. It was explained that:

"The Centrelink [appointed] doctor informed me my illnesses are "ill defined" and he would...only ask me about my chronic fatigue symptoms...He declined to read the detailed Specialist medical report despite my requesting he do so. The doctor...informed Centrelink I ...had a "short term" illness which would "improve – Centrelink informed me I was not given a disability impairment rating on this basis..."⁴⁹⁹

Disability Access and MCS

A significant number of people disabled by MCS symptoms are also unable to access support services. The Bridges and Pathways Institute Inc. (BPII)⁵⁰⁰ informed the Inquiry that 60% of its 5000 client contacts suffer from MCS.⁵⁰¹ A study undertaken by the BPII in 2002 found:

⁴⁹⁹ Webb, written submission, p1.

⁵⁰⁰ The Bridges and Pathways Institute Inc. was established to create partnerships and solutions for chronic and complex illnesses. The Centre incorporates members of the following organisations:

- National Partnerships for Fibromyalgia, Chronic Fatigue Syndromes (Australia);
- SA Fibromyalgia, Chronic Fatigue Syndromes Gateway to Information and Support;
- Complex Chronic Illness Primary Health Care Best Practice Research and Evaluation Project;
- Southern Chronic Illness Links Network; and
- Chronic Disease Self-management/ Sharing Care Initiatives.

⁵⁰¹ Bridges and Pathways Institute Inc., written submission, p1.

“...unexpected high levels of disability in the study sample (80% were housebound and 76% were not registered at local health and support services)...”⁵⁰²

The study also found that despite the high levels of disability and social isolation, participants did not have access to prevention and rehabilitation services, to any planned strategies to limit the impact of their illnesses, or to General Practitioners or other providers with whom they could work to improve their health care outcomes. It was noted that:

“The services they used were ad hoc because ...they had been refused care and had lost confidence in both the health and community support services for long-term and/or permanently disabled illnesses such as their own”.⁵⁰³

Many respondents to the study noted that:

“...their priorities were environmental and community access issues which other people take for granted as part of everyday life. They repeatedly raised the subject of lack of acceptance of their different and multiple chemical reactions and how these excluded them from participating in every day activities (shopping, eating out, socialising...) and their difficulties in finding suitable accommodation/housing.”⁵⁰⁴

Participants at a workshop on MCS held in 2004, submitted that people with MCS are denied civil participation due to the chemical barriers they experience.⁵⁰⁵ It was explained that people with chemical sensitivities confront a “maze of barriers” when venturing beyond the confines of their own homes.

“These are not...visible barriers, such as stairs, steps, [and] narrow doors...which face mobility-impaired citizens. They are instead a complex maze of chemical-related hazards. You can’t see them and you might not always be able to smell them, unless you are chemically sensitive. But they are just as real a problem to a chemically-sensitive person as a flight of stairs to a person in a wheelchair.”⁵⁰⁶

It was noted that the presence of chemicals in many indoor and outdoor environments, including public buildings and facilities, educational institutions and in public housing, present disability access issues for people with MCS.

MCS and Disability Discrimination

The Inquiry was informed that many sufferers believe they experience discrimination due to the lack of recognition of MCS as a disability. Issues regarding discrimination on the grounds of disability access have been raised in evidence presented to the Inquiry in relation to workplaces, health care facilities, and more broadly in relation to Commonwealth Government income support payments and entitlements.

The Inquiry learnt that MCS is covered under the Australian Disability Discrimination Act 1992, and the SA Equal Opportunity Act 1984 in relation to physical impairment and disability. As

⁵⁰² Bridges and Pathways Institute Inc., Report on Service Needs, Priorities and Self-Management Issues for Consumers with Complex Chronic Illnesses: A Pilot Study Conducted in the Southern and Hills Districts of Adelaide (June-December, 2002): Working Paper 4- Complex Chronic Illness Best Practice Research & Evaluation Projects 2000-2005, September 2004, p9.

⁵⁰³ Ibid., p9.

⁵⁰⁴ Ibid., p9.

⁵⁰⁵ MCS Workshop Report, p3, submitted as part of evidence presented by the SATFMCS, 20 September, 2004.

⁵⁰⁶ Myalgic Encephalopathy/Chronic Fatigue Syndrome (ME/CFS) Society SA, written submission, p2.

noted earlier in this Report, a complaint of discrimination had been brought to the Equal Opportunity Commission (EOC) in SA and that this has subsequently been settled by conciliation between the parties involved. The EOC advised the Inquiry that it had also received two other complaints, however, these had been declined by the Commission.⁵⁰⁷

The Inquiry was further informed that acceptance of MCS as a recognised disorder by employers, service providers, and the medical profession would assist in determining cases of discrimination against MCS sufferers who were unable to access public spaces due to their disability. As clear guidelines on the status of MCS are currently unavailable, a key issue arising in such cases is whether attempts had been made to provide reasonable accommodation of the needs of MCS sufferers. Determining what constitutes a reasonable accommodation is problematic. While it is necessary to accommodate disability under law, the need to provide some form of access must be balanced against the level of access requested by people with MCS, and whether making such accommodations might place an unjustifiable hardship on the service provider.⁵⁰⁸

In its submission to the Inquiry the SATFMCS has noted that in some cases people with MCS have been able to negotiate alternative workplaces and practices. The SATFMCS notes that a lack of information about MCS in the business community has made negotiating arrangements to accommodate MCS sufferers difficult. Disability access for MCS sufferers has, however, been incorporated in the policies of some SA workplaces. The Inquiry was informed that the AIDS Council of SA was the first community based workplace in the State to develop a workplace strategy on MCS which includes disability access as part of its OHS policy.⁵⁰⁹

As noted in Section Three of this Report, a number of overseas reviews and inquiries on the issue of disability access have been undertaken. Among these, the Report to the Legislature on MCS conducted in 1996 in New Mexico by the Governor's Committee on Concerns of the Handicapped, found that the experiences of discrimination faced by people with MCS were not unlike those experienced by people with more visible disabilities. People with MCS it was found:

*"...face a barrier of scepticism that amounts to discrimination."*⁵¹⁰

Increasing Access for MCS sufferers

It has been noted that through the provision of reasonable accommodations, people with MCS can be encouraged to:

*"...continue to contribute their skills, ideas, creativity, abilities and knowledge."*⁵¹¹

Measures that recognise MCS as a disabling condition and provide access for sufferers are warranted on the basis that:

⁵⁰⁷ Correspondence received from Michael Guarna, Principal Policy Adviser, Equal Opportunity Commission, via email, 8 June 2005.

⁵⁰⁸ Correspondence received from Michael Guarna, Principal Policy Adviser, Equal Opportunity Commission, via email, 17 June 2005.

⁵⁰⁹ South Australian Task Force on Multiple Chemical Sensitivity (SATFMCS), written submission, p63.

⁵¹⁰ Governor's Committee on Concerns of the Handicapped, Report to the Legislature on Multiple Chemical Sensitivity (MCS), Pursuant to Senate Joint Memorial 10 (1996), [New Mexico, US](#), 27 August 1996, p5.

⁵¹¹ State of Louisiana, Governor Kathleen Babineaux Blanco, Proclamation (Multiple Chemical Sensitivity Awareness Proclamation), April 2004, Louisiana, USA (cited in correspondence received via email from Mr. Peter Evans, 16 May 2004).

“...people with MCS need the support and understanding of family, friends, co-workers and society as they struggle with their illness and adapt to new lifestyles.”⁵¹²

MEASURES TO ACCOMMODATE MCS SUFFERERS

The Inquiry was advised of a wide range of measures that could be introduced to accommodate MCS sufferers. Measures that were consistently referred to included the introduction of protocols and procedures for hospitals and health care facilities; measures to accommodate MCS sufferers in workplaces and the community at large such as a MCS Register; and extending existing support services for people with complex, chronic illness to accommodate MCS sufferers.

Policies and protocols for safe access to health services

The lack of policies and protocols for patients with MCS to enable access to health care services, including hospitals, has been identified as a key access issue by many sufferers. It has been noted that where medical professionals have supported the recognition of MCS and where the public is educated on the condition, sufferers are more likely to be accommodated.

Dr David Gillis from the RAH told the Inquiry that policies that recognise MCS are needed:

“...because a lot of public hospitals are worried about these patients: they do not know what to do with them, and they are worried about all the associated things. If there were set protocols then that would reduce the difficulties.”⁵¹³

As previously noted in Section Three of this Report, while the OH&S Sub-Committee at the Southern Fleurieu Health Service has no formal policy on MCS, it has adopted a procedure for minimising chemical exposure to staff and clients. The chemical sensitivities procedure applies to all staff at all times, and encourages staff to refrain from using highly scented personal products such as perfumes, aftershaves, and deodorants. It was noted that the procedure is less stringent about some other personal products such as shampoos in a bid to:

“...strike a sensible balance so as not to inconvenience staff excessively.”⁵¹⁴

It was also pointed out that during building renovations some attention was paid to using less toxic paints, and that air filters have been fitted to reduce volatile chemical load in offices and group rooms where sensitive clients or staff members are present. The provision of information about MCS, it was noted has been useful in educating staff and ensuring compliance.⁵¹⁵

The Inquiry was advised that no other hospital or health service guidelines on MCS are in place in SA. Dr Wendy Scheil from the DoH informed the Inquiry that in accordance with the recommendations from the Generational Health Review, all operational aspects of health care facilities in SA, such as the introduction of protocols for MCS, are the responsibility of Regional Executives. Concern about current practice or proposed changes to current practice can, however,

⁵¹² Ibid., p1.

⁵¹³ Gillis, oral evidence, Hansard, p159.

⁵¹⁴ Correspondence received from Mel Reid, Senior Dietitian, Southern Fleurieu Health Service, via email, 31 May 2005, p1.

⁵¹⁵ Ibid., p1.

be brought to the attention of the Portfolio Executive from either the DoH or the regions, where a decision regarding the best way to proceed would be made.⁵¹⁶

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.

MCS Registers

Evidence presented to the Inquiry has established that the use of herbicides, particularly by local Councils to control weeds significantly impacts on MCS sufferer's ability to access public outdoor spaces. To address this issue, many submissions proposed that a MCS Register be established. By providing the details of individuals with MCS, the Register would inform relevant agencies to limit chemical exposure near the home of individuals listed. It was noted that while some local Councils have already begun using a general No-Spray register, many did not, and many did not clearly identify MCS individuals.

It was also noted that some contractors employed by some Councils with No-Spray registers, did not adequately fulfil their obligations to safeguard MCS sufferers. It was explained in a number of submissions that prior warning of spray campaigns would enable MCS individuals to make the necessary arrangements to safeguard themselves and was a necessary component of a MCS Register. The Inquiry heard that the DoH has liaised with some local Councils with regard establishing a communication process to notify MCS sufferers when pesticides are sprayed so that these residents can take adequate precautions.⁵¹⁷

Accommodating MCS Sufferers in the Workplace

As previously discussed in this Report, an association between a wide range of chemicals commonly found in many workplaces and MCS have been identified in research. Evidence presented has shown that chemicals such as perfumes and other personal fragrance products, as well as Electro Magnetic Radiation emissions (EMR), can trigger MCS symptoms. Due to the

⁵¹⁶ Correspondence received from Dr Wendy Scheil, Principal Consultant – Medical, Acute Care and Clinical Services, Department of Health (SA), via email, 3 June 2005, p1.

⁵¹⁷ Fitzgerald, oral evidence, Hansard, p19.

large number, and low levels of chemicals that can initiate or trigger MCS symptoms, the Inquiry was informed that the willingness of employers to accommodate people with MCS is a key factor in enabling many sufferers to remain at work.⁵¹⁸ It has been argued that recognition of MCS in Occupational Health and Safety policies would have benefits for MCS sufferers as well as people with other health problems such as asthma. Replacing chemicals with safer alternatives and reducing emissions were some of the approaches identified in submissions that were considered necessary aspects of OH&S strategies. In her submission, Adelaide physician Dr Judy Ford informed the Inquiry that:

*“In many cases, better...[OH&S] will reduce the risk of initial exposure and hence the development of acute sensitivity. However overall reduction in chemical pollution is most desirable for this and a myriad of other health conditions, including asthma...”*⁵¹⁹

Recognition and the development of a position statement on MCS in workplaces was also seen to assist in improving access in workplaces. In a submission from the Department of Labour in New Zealand, it was explained that its Occupational Safety and Health Service (OSH) has developed an operational position on MCS. It is the view of the OSH’s Departmental Medical Practitioners and experts on Departmental panels, that MCS is a real condition, however, the Department believes that each diagnosis must be made on a case-by-case basis. The Committee was informed that the OSH Position Statement acknowledges the complexity of this issue noting that:

*“If a person reports that they think they have the condition known as Multiple Chemical Sensitivity (MCS), there may or may not be a real condition. However, there is no way of proving or disproving it because the diagnosis basically rests on a person’s statements. Each diagnosis would be made on a case-by-case basis. It is well known that what a person believes and expects about their symptoms can have an effect on the subsequent course of health effects.”*⁵²⁰

The statement also acknowledges that:

*“...exposures that provoke...[MCS] may occur at many times below the OSH Workplace Exposure Standards (WES). The WES always acknowledges that some (a very few) sensitive people will suffer ill health effects from exposures well below the WES, as the WES is set to protect (only) the great majority of people...protecting people against the levels that trigger symptoms of MCS would be prohibitively expensive, impractical for employers and probably not achievable.”*⁵²¹

The OSH position is that WES should not be taken as a “working limit” and that employers are encouraged to eliminate workplace exposures altogether, or ensure that they are as low as practicable. It is recognised that some employees who report MCS may have to accept that there are some environments in which they will be unable to work, and while it may not be possible for some employers to accommodate some sufferers, negotiations are advised to ascertain the level of protection an employer can and will provide.⁵²²

⁵¹⁸ South Australian Task Force on Multiple Chemical Sensitivity (SATFMCS), written submission, p63.

⁵¹⁹ Ford, written submission, p1.

⁵²⁰ Department of Labour, New Zealand, [written submission](#), Occupational Safety and Health Service (OSH) Position on Multiple Chemical Sensitivity, p2.

⁵²¹ Ibid., p2.

⁵²² Ibid., p2.

The Inquiry was also informed that the Minister of Labour in New Zealand has placed the subject of MCS on the agenda of the Ministerial Advisory Panel on Work-Related Gradual Process, Disease and Infection for ongoing consideration.⁵²³

Measures to Minimise Chemical Exposure in the Community

The Inquiry heard that there are adequate measures currently in place in Australia to regulate exposure to chemicals in the community at levels far below those likely to represent a health risk to the general population. However, Dr Jim Fitzgerald from the DoH told the Inquiry that the issue of how the current regulatory environment can take into account MCS sufferers who appear to be extremely sensitive, is not evident. The Committee was told that a nationally coordinated forum would assist in exploring and developing approaches to address this issue.⁵²⁴

Evidence presented has also proposed that further research into the affects of chemicals is also needed. Dr Fitzgerald informed the Inquiry that:

“...the MCS problem is compounded because often chemicals in the environment exist as mixtures which are difficult to assess. Chemicals within mixtures may react independently, additively, antagonistically or synergistically. As such, further research may be warranted to examine the effect of mixtures on MCS individuals.”⁵²⁵

Many submissions indicated that adequate notification should be provided to the public before, during, and after pesticides are applied in or near public buildings, to allow MCS sufferers and the concerned public to make informed choices about accessing these areas. The use of warning signage to indicate use of toxic products was one component of a number of MCS disability access policies that have been implemented by non-government agencies in SA.⁵²⁶ According to Dr Fitzgerald, the DoH has identified Best Practice guidelines on this issue.⁵²⁷

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.

⁵²³ Ibid., p1.

⁵²⁴ Fitzgerald, oral evidence, Hansard, p20.

⁵²⁵ Ibid., pp20-1.

⁵²⁶ Evans, oral evidence, Hansard, p72.

⁵²⁷ Fitzgerald, oral evidence, Hansard, p19.

Extending existing support services to accommodate MCS sufferers

The Inquiry was informed that MCS sufferers require support on many levels. Many require practical aides and items to modify their homes and lifestyles. As one sufferer pointed out:

“People with MCS need reading boxes, wheelchairs, air filters, water filters, environmentally friendly homes, schools, childcare centres, walking aids, tutors, carers, the list is endless...”⁵²⁸

Above all sufferers require support through understanding. The Inquiry was informed that the Southern Chronic Illness Links Network conducts self-management courses, educational programs and friendship activities, predominantly in the southern metropolitan area for people with complex, chronic medical conditions. It has been proposed that this service could be extended to accommodate people with MCS across South Australia.

In its submission, the BPPI has proposed that MCS, ME/CFS, Fibromyalgia and other associated poorly understood chronic illnesses could be identified as a ‘cluster group’ which could then be:

“...addressed and evaluated under the same prevention, early intervention, educational and outcome focussed management approaches to care.”⁵²⁹

The submission argues that as the only known treatment for MCS is that of minimising exposure to chemicals, this should include reducing chemical exposure in the environment. It is also important to implement measures that inform service providers to enable understanding, respect and acknowledgement of chemical sensitivity reactions, and thereby greater access to support services.⁵³⁰ It was explained that:

“Providing equal access to services and thus validating people with MCS would be a large step toward limiting the compounding social dislocation and multiple losses that lead to unnecessary poor health outcomes and dependence on the health and welfare system.”⁵³¹

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.

⁵²⁸ Individual written submission, name withheld, p1.

⁵²⁹ Bridges and Pathways Institute Inc., written submission, p2.

⁵³⁰ Ibid., p2.

⁵³¹ Ibid., p2.

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.

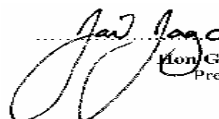
It is apparent to the Committee that MCS not only impacts on the health of sufferers but on their ability to remain actively involved in the world around them. The Committee recognises that many sufferers become socially isolated in an attempt to safeguarding themselves from the harmful affects of the 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

LIST OF WITNESSES

The following organisations and individuals provided oral evidence to the Committee's Multiple Chemical Sensitivity inquiry.

Wednesday 4 August 2004

Dr Bruce Wauchope, General Practitioner

Dept of Health

Dr Jim Fitzgerald, Principal Toxicologist,
Hazardous Substances, Environmental Health Service

Wednesday 25 August 2004

Prof Brian Goble, Ecology Research Centre

Monday, 13 September 2004

Dept of Health

Dr Wendy Scheil, Principal Consultant (Medical), Acute Care and Clinical Services

Local Government Association

Mr Chris Russell, Director, Policy and Public Affairs

Mr Wally Iasiello, Director, Technical Services, Port Adelaide Enfield Council

Mr Dennis Cock, Senior Risk Manager, LGA Mutual Liability Scheme

Monday, 20 September 2004

South Australian Taskforce on Multiple Chemical Sensitivity

Mr Peter Evans

Ms Dorothy Casey

Mr Bruce Rothe

Ms Tanya Lockett

Mr Jon Pullen

Mr Paul Lawrence

Monday, 11 October 2004

Dr Mark Donohoe, Medical Practitioner, NSW

Monday, 25 October 2004

Primary Industries and Resources

Mr John Kassebaum, Manager, Rural Chemicals Program

ME/CFS Society (SA) Incorporated

Dr Peter Cahalan

Monday, 8 November 2004

Dr David Gillis, Staff Specialist, IMVS Dept of Human Immunology

Mr Seth Nicholls

Monday, 22 November 2004

Dr Robert Loblay, Clinical Immunologist, Royal Prince Alfred Hospital, NSW

Wednesday, 1 December 2004

Workcover

Ms Diana Alder, Manager, Self Insured Options and Systems

Ms Leeanne Kearny, Supervisor, Coding

Dr Fiona Young

Lecturer in Biotechnology, Dept of Medical Biology, Medical School, Flinders University

LIST OF SUBMISSIONS

Written submissions to the Multiple Chemical Sensitivity inquiry were received from the following 167 individuals and organisations (including 2 who requested their name be withheld).

Organisations

Allergy & Environmental Sensitivity Support & Research Association

Allergy Sensitivity & Environmental Health Association

Allergy UK

AMNZIMRT

AOPIS (Australian airline pilots)

Association for the Chronic or/& Environmental Injury Illness (Italy)

Australian Chemical Trauma Alliance Inc (Vic)

The Australian Greens: Port Adelaide Branch

Australian Pesticides & Veterinary Medicines Authority
Quality Assurance & Compliance

AVCARE (National industry group representing manufacturers of agricultural & veterinary chemical)

Bridges & Pathways Institute Inc
Centre for Community Excellence working with chronic illness

Central Community Legal Service

Chemical Sensitivities Self Help Group (WA)

Croydon Conservation Society

ECO-Buy (Municipal Association of Vic)

Econeco Pty Ltd

EMR Safety Network International

Fragrance & Chemical Sensitivity Support Group

GASPiNG (Nurses support and guidance group)

Informed Choices (USA)

ME/CFS Society (SA) Inc

National Industrial Chemicals Notification & Assessment Scheme: (NICNAS)
Business Management Group

Ohio Network for the Chemically Injured (USA)

SA Council on Reproductive Technology

Support Network for the Aldehyde and Solvent Affected (SNFTAAS – NZ)

South Australian Task Force Multiple Chemical Sensitivity (SATFMCS)

The Royal Australasian College of Physicians

The United Trades and Labor Council of SA

WA Multiple Chemical Sensitivity Self Help Group

Zero Waste SA

South Australian - Local Government

City of Adelaide

City of Norwood Payneham & St Peters

Alexandrina Council

City of Port Adelaide Enfield

The Berri Barmera Council

City of Port Augusta

The District Council of Ceduna

The City of Prospect

Campbelltown City Council

City of Salisbury

City of Holdfast Bay

District Council of Streaky Bay

District Council of Lower Eyre Peninsula

Southern Mallee District Council

City of Marion

The City of Unley

City of Mitcham

City of Victor Harbor

City of Mt Gambier

The City of Walkerville

Rural Council of Murray Bridge

District Council of Yorke Peninsula

Individuals: Australia

South Australia:

Blight Ms Alison

Blockow Ms Julie

Cherry Ms Catherine

Culhane Ms Anne

Dowsett Mr Warren

Evans Mr Peter

Ford Dr Judy

Heard Ms Susan

Holgate Mr Philip

Ivy Ms Julie

Linder Mr Ken

Lockett Ms Tanya

Matthews Ms Meredith

Nichols Mr Seth

Tattershall Mrs M

Tonkins Ms Joanna

Villis Ms Sophia

Yuill Ms Skye

ACT:

Gugler Ms Ann

Williams Ms Lesley

New South Wales

Budd Dr Laurence;

Consultant Paediatrician

Fitzsimmons Ms Leo & Mrs Veneta

Guthrie Mr Graham

Lee Ms Deborah

Pollak Dr John Hon Research Associate
Dept Anatomy & Histology,
University of Sydney

Thompson Mr Murray

Todhunter Ms Susan

Victoria:

Brand Ms Josephine

Bround Ms Josephine

Byl Mr Peter

Ghims Ms Ayin

Hall Ms Jacie

Jeffery Ms Karen;
Occupational Health & Safety Consultant

Kennedy Ms Anne

Limburg Col Allan

Major Ms Marie

McGill Mrs Diane

Sanzaro Ms Liz

Tosch Ms Susan

Trudeau Ms Rosemary

Queensland:

Bauer Ms Sybil

Buchan Ms Nancy

Buckland Ms Diane

Hoge Ms Amanda

Laurie Ms Kay

Lillis Ms Deborah

Martin Ms Karen

Maw Dell

McCrea Ms Barbara

Prideux Ms Barbara

Reynolds Mr Neil

Simpson Ms Joanne

Spehr Mr Terry

Stuart Ms Kaye

Webb Ms Heather

Western Australia:

Caladeen Ms Rosemary

Ellies Ms Jean

Garrett Ms Shirley

Gilmore Mr Robert

Hyatt Ms Candace

Ryan Ms Mary

Sulman Ms Dianne

Tasmania:

O'Donnell Ms Patricia

Individuals: Overseas

USA:

Applegate Ms Carolyn

Ballou Ms Laurel

Barkemeijer de Wit Ms Jeanne

Bowron Ms Ellie

Caple Mr Edward

Celona Ms Valerie

Coustier Ms Astrid

Gerber Ms Karen

Goldstein Ms Lotus

Hawkins Mr Joe Pat

Henderson Mr Robert

Hirschfeld Ms Nancy
Informed Choices

Hyatt Ms Candace

Jastrzebski Ms Brigid

Jenkins Ms Karen

Katherine

Kelly-Givens Ms Karin

Knudsen Ms Karen

Linsley Ms Linda

Moore Ms Carolyn

Mozingo Sandy

Pall Professor Martin
Professor of Biochemistry & Basic
Medical Sciences
Washington State University

Ridings Ms Janine

Robson Ms Daliya

Ross Mr Steve & Mrs Julie

Shannon Ms Ruth

Smith Ms Dawn

Smith Mr Stephen

Stamm Rosenfeld Ms Marjorie

Swan R

Temple Ms Toni
President Ohio Network
for the Chemically Injured

Troiano Ms Peggy
Beacon of Hope

Canada:
Gourd Ms Francoise

Poulin Ms Bonita

Quinn Ms Joanne

Rowat Mr Steven

Sml Proudfoot Ms Sandra

New Zealand:
Harding Ms Vicki

Houlbrooke Ms Catherine

Jeffreys Dr Toni

Pickford Ms Alison

Watkins Ms Jenni

United Kingdom:
Bruce Mr Richard

Lam Ms Mary

Purdy Mr Neil

Purdey Mr Nigel

Rogers Ms Roslyn Anne

Italy:
Manfredi Ms Carla

Francesca (name withheld)

Denmark:
Molhave Ms Birgit

ACRONYMS

The following acronyms have been used throughout this report

ACC	Adelaide City Council
ACOEM	American College of Occupational and Environmental Medicine
ACTA	Australian Chemical Trauma Alliance Inc.
AERP	Adverse Experience Reporting Programs
Agvet	Agricultural and veterinary
AICS	Australian Inventory of Chemical Substances
AIDS	Acquired Immune Deficiency Syndrome
AOPIS	Aviation Organophosphate Information Site
APVMA	Australian Pesticides and Veterinary Medicines Authority
ASEHA	Allergy, Sensitivity & Environmental Health Association (Queensland)
Avcare	National Association for Crop Production and Animal Health
BPII	(The) Bridges and Pathways Institute Inc.
CCLS	Central Community Legal Service
CCOHS	Canadian Centre for Occupational Health and Safety
CFIDS	Chronic Fatigue and Immune Dysfunction Syndrome
CFS	Chronic Fatigue Syndrome
DAIS	Department of Administrative and Information Services
DAP	Disability Action Plan
DDA	Disability Discrimination Act 1992 (South Australia)
DDT	Dichloro-Diphenyl-Trichloroethane
DGLC	Ground level pollution concentrations
DHEA	Dehydroepiandrosterone
DoHA	Department of Health and Ageing (Commonwealth)
DSP	Disability Support Pension (Centrelink)
EMR	Electro Magnetic Radiation
EOC	Equal Opportunity Commission
EPA	Environmental Protection Agency (Australia)
EPA	Environmental Protection Authority (USA)
EPHC	Environment Protection and Heritage Council
FACNEM	Fellow of the Australian College of Nutritional & Environmental Medicine
FM	Fibromyalgia

FSANZ	Food Standards Australian New Zealand
GASPing	Glutaraldehyde Affected Support Persons injured nurses group
GP	General Practice or General Practitioner
ICD	International Classification of Diseases
ICD-10-AM	Australian version of the International Statistical Classification of Diseases and Related Health Problems (10 th revision)
IEI	Idiopathic Environmental Intolerance
IgE	Immunoglobulin
IMVS	Institute of Medical and Veterinary Science
LGA	Local Government Association
MCS	Multiple Chemical Sensitivity
ME/CFS	Myalgic Encephalopathy/Chronic Fatigue Syndrome
MSDS	Material Safety Data Sheets
NCCH	National Centre for Classification in Health
NHMRC	National Health and Medical Research Council
NICNAS	National Industrial Chemicals Notification & Assessment Scheme
NIOSH	National Institute for Occupational Safety and Health (US)
NLM	National Library of Medicine (USA)
OCHS	Occupational Health and Safety
OCS	Office of Chemical Safety
OHS	Occupational Health and Safety
OHS&W	Occupational Health Safety and Welfare
PACIA	Plastics and Chemical Industries Association
PCB	Polychlorinated biphenyl
PEC	Priority Existing Chemical
PEG	Propylene glycol
PHAA	Public Health Association of Australia
PIC	Prior Informed Consent
PIRSA	Department of Primary Industries and Resources (South Australia)
POP	Persistent Organic Pollutant
RACP	Royal Australian College of Physicians
RADS	Reactive Airways Dysfunction Syndrome
RAH	Royal Adelaide Hospital
RBH	Royal Brisbane Hospital

SATFMCS	South Australian Task Force on Multiple Chemical Sensitivity
SRDC	Strategic Research Development Committee (of the NHMRC)
TGA	Therapeutic Goods Administration
WES	Workplace Exposure Standards
WHO	World Health Organisation
YMCA	Young Men's Christian Association

GLOSSARY

Aetiology (also spelt 'Etiology')	1. The study of the causes. For example, of a disorder. ⁵³²
Agent Orange	An herbicide and defoliant containing 2,4-D and 2,4,5-T and trace amounts of dioxin. Agent Orange was used as a defoliant in the Vietnam War. There has been concern about Agent Orange as a carcinogen and teratogen (cause cancer and birth defects). ⁵³³
Allergy	1. A misguided reaction to foreign substances by the immune system, the body system of defence against foreign invaders, particularly pathogens (the agents of infection). The allergic reaction is misguided in that these foreign substances are usually considered harmless. The substances that trigger allergy are called allergen. Examples include pollens, dust mite, moulds, danders, and certain foods. People prone to allergies are said to be allergic or atopic. ⁵³⁴
Amino acid	Any of a class of 20 molecules that are combined to form proteins in living things. The sequence of amino acids in a protein and hence protein function are determined by the genetic code. ⁵³⁵
Antibody	A protein found in the blood that is produced in response to foreign substances (eg bacteria or viruses) invading the body. Antibodies protect the body from disease by binding to these organisms and destroying them. ⁵³⁶
Antifungal	A drug used to treat fungal infections. ⁵³⁷
Antigen	A substance that is capable of causing the production of an antibody. ⁵³⁸
Antioxidant	Any substance that reduces oxidative damage (damage due to oxygen) such as that caused by free radicals. ⁵³⁹
Asthma	A common disorder in which chronic inflammation of the bronchial tubes (bronchi) makes them swell, narrowing the airways. Asthma involves only the bronchial tubes and does not affect the air sacs (alveoli) or the lung tissue (the parenchyma of the lung) itself. ⁵⁴⁰
Attention Deficit Hyperactivity Disorder	A disorder in which the prominent symptoms are hyperactivity, inattention, and impulsivity. Also referred to as ADD (attention deficit disorder). ⁵⁴¹
Autonomic (Autonomic nervous system)	The autonomic nervous system is that part of the nervous system which controls body functions not under our direct voluntary control, such as the

⁵³² <http://www.medterms.com>

⁵³³ <http://www.medterms.com>

⁵³⁴ <http://www.medterms.com>

⁵³⁵ Department of Health and Human Services, Center for Disease Control and Prevention, Atlanta, USA
(www.cdc.gov/genomics/gtesting/ACCE/FBR/CF/CFGlossary2.htm)

⁵³⁶ Department of Health and Human Services, Centers for Disease Control and Prevention, Atlanta, USA
(www.cdc.gov/ncidod/diseases/hepatitis/resource/glossary.htm)

⁵³⁷ <http://www.medterms.com>

⁵³⁸ <http://www.medterms.com>

⁵³⁹ <http://www.medterms.com>

⁵⁴⁰ <http://www.medterms.com>

⁵⁴¹ US Environmental Protection Agency (<http://www.epa.gov/envirohealth/children/background/glossary.htm>)

	blood pressure, pulse rate, operation of the bowel and bladder and sweating. ⁵⁴²
Autosuggestion	Self-hypnosis: hypnosis induced by oneself. ⁵⁴³
Biochemical	Relating to biochemistry, the application of the tools and concepts of chemistry to living systems. ⁵⁴⁴
Biotransformation	The series of chemical alterations of a compound (for example, a drug or nutrient) which occur within the body, as by enzymatic activity. ⁵⁴⁵
Cacosmia	The imagining of unpleasant odours, particularly putrefactive odours. ⁵⁴⁶
CFS	Myalgic Encephalopathy/Chronic Fatigue Syndrome (ME/CFS) is “an illness characterised by persistent fatigue, neuro-cognitive symptoms, and a variety of multi-system symptoms. The core symptoms include excessive fatigue, general muscular and joint pain, mental fogginess, and often gastrointestinal problems. Other symptoms include fatigue following stressful activities, headaches, sore throat, sleep disturbances, low grade fever and depressed mood. The symptoms fluctuate in severity and persist for a prolonged period.” ⁵⁴⁷
Chemical compound	A substance formed by chemical union of two or more elements or ingredients in definite proportion by weight. ⁵⁴⁸
Chemical trespass/spray drift	The movement of pesticide away from the target area during or after ground or aerial spraying (usually in the form of droplets, particles or vapour). ⁵⁴⁹
Cholestipol	A medication used to treat cholesterol by preventing the cholesterol in bile (the digestive product secreted from the gallbladder) from being reabsorbed in the gut. ⁵⁵⁰
Chronic	Being long-lasting and recurrent or characterized by long suffering. ⁵⁵¹
Clinical	1. Having to do with the examination and treatment of patients. 2. Applicable to patients, for example, a laboratory test may be of clinical value (of use to patients). ⁵⁵²
Conditioned Response	A response evoked by a conditioned stimulus; one occurring to a stimulus that was incapable of evoking it before conditioning. ⁵⁵³

⁵⁴² University of Cape Town website (<http://web.uct.ac.za/depts/porphyria/patient/pat%20glossary.htm>)

⁵⁴³ Princeton University, Cognitive Science Laboratory (www.cogsci.princeton.edu/cgi-bin/webwn2.1)

⁵⁴⁴ <http://www.medterms.com>

⁵⁴⁵ <http://www.curcuminoids.com/glossary.htm>

⁵⁴⁶ <http://medical-dictionary.thefreedictionary.com/cacosmia>

⁵⁴⁷ Kassirer, J. and Sandiford, K. (Cullbridge Marketing and Communications), Socio-Economic Impacts of Environmental Illness in Canada, 15 November, 2000, pp6-7.

⁵⁴⁸ Princeton University, Cognitive Science Laboratory (www.cogsci.princeton.edu/cgi-bin/webwn2.1)

⁵⁴⁹ Department of Primary Industries and Resources (PIRSA), Fact Sheet: Working together to minimise chemical spray drift, complete reference, p1.

⁵⁵⁰ http://heartdisease.about.com/cs/cholesterol/a/choltri_3.htm

⁵⁵¹ Princeton University, Cognitive Science Laboratory (www.cogsci.princeton.edu/cgi-bin/webwn2.1)

⁵⁵² <http://www.medterms.com>

⁵⁵³ Dorland's Illustrated Medical Dictionary (http://www.mercksource.com/pp/us/cns/cns_hl_dorlands.jspzQzpgzEzzSzppdocszSzuszSzcommonzSzdorlandzSzdorlandzSzdmd_r_09zPzhtm)

Congenital	Any trait present at birth, whether the result of a genetic or non-genetic factor. ⁵⁵⁴
DDT (Dichloro-Diphenyl-Trichloroethane)	Dichlorodiphenyltrichloroethane : a colourless chemical pesticide or insecticide used to destroy disease-carrying, crop-eating insects. Although banned years ago in North America as a possible cause of cancer, it is still used in developing countries. ⁵⁵⁵
Defoliant	An herbicide that removes leaves from trees and growing plants. ⁵⁵⁶
Dehydroepiandrosterone	A natural steroid hormone produced from cholesterol by the adrenal glands. Dehydroepiandrosterone is structurally similar to testosterone and estrone and can be easily converted into those hormones. ⁵⁵⁷
Depleted uranium	A by-product of uranium enrichment, the most common chemical form of which is depleted uranium hexafluoride (DUF 6). ⁵⁵⁸
Dermatitis	Inflammation of the skin, either due to direct contact with an irritating substance, or to an allergic reaction. Symptoms of dermatitis include redness, itching, and in some cases blistering. There are two types of dermatitis: eczematous (eczema) and noneczematous (also called occupational). ⁵⁵⁹
Desensitisation	The process of reducing sensitivity, for example, to an allergen. ⁵⁶⁰
Diabetes	A condition in which the body either cannot produce insulin or cannot effectively use the insulin it produces. Types of diabetes include Gestational Diabetes, type 1 Diabetes and type 2 Diabetes. ⁵⁶¹
Dioxin	Any of a family of compounds known chemically as dibenzo-p-dioxins. Concern about them arises from their potential toxicity and contaminants in commercial products. Tests on laboratory animals indicate that it is one of the more toxic man-made compounds. ⁵⁶²
Ecology	The study of the interactions between organisms and their natural environment, both living and non-living. ⁵⁶³
Eczema	An inflammatory reaction of the skin in which there are typically vesicles (tiny blister-like raised areas) in the first stage followed by erythema (reddening), edema (swelling), papules (bumps), and crusting of the skin followed, finally, by lichenification (thickening) and scaling of the skin. ⁵⁶⁴
Epidemiology	The study of disease in human populations. ⁵⁶⁵
Ethylene glycol	A chemical compound widely used as an automotive antifreeze (coolant).

⁵⁵⁴ Oak Ridge National Laboratory (US) (http://www.ornl.gov/sci/techresources/Human_Genome/glossary/glossary_c.shtml).

⁵⁵⁵ <http://www.spaceforspecies.ca/glossary/d.htm>

⁵⁵⁶ National Safety Council, USA, website (www.nsc.org/ehc/glossary.htm)

⁵⁵⁷ Wikipedia, Free online Encyclopaedia (en.wikipedia.org/wiki/Dehydroepiandrosterone)

⁵⁵⁸ Institute for Energy and Environmental Research, Maryland, USA (<http://www.ieer.org/clsroom/glossary.html>)

⁵⁵⁹ <http://www.medterms.com>

⁵⁶⁰ Princeton University, Cognitive Science Laboratory (www.cogsci.princeton.edu/cgi-bin/webwn2.1)

⁵⁶¹ Canadian Diabetes Association (www.diabetes.ca/Section_About/dictionary.asp)

⁵⁶² National Safety Council, USA, website (www.nsc.org/ehc/glossary.htm)

⁵⁶³ Food and Agriculture Organization of the United Nations website (www.fao.org/docrep/003/X3910E/X3910E08.htm)

⁵⁶⁴ <http://www.medterms.com>

⁵⁶⁵ Massachusetts institute of technology (<http://web.mit.edu/environment/ehs/topic/HazCommTerms.html>)

	In its pure form, it is a odorless, colorless, syrupy liquid with a sweet taste. Ethylene glycol is toxic, and its accidental ingestion should be considered a medical emergency. ⁵⁶⁶
Ethylene oxide (EO)	An industrial chemical used as an intermediate in the production of ethylene glycol and other chemicals, and as a sterilant for foodstuffs and medical supplies. It is a colourless flammable gas or refrigerated liquid with a faintly sweet odour. ⁵⁶⁷
FM	Fibromyalgia syndrome (FM) is “a painful muscle disorder in which the thin film or tissue (myofascial) holding muscle together becomes tightened or thickened, causing pain. It shares many of the same symptoms as CFS”. ⁵⁶⁸
Formaldehyde	A colourless, pungent, and irritating gas, CH ₂ O, used chiefly as a disinfectant and preservative and in synthesizing other compounds like resins. ⁵⁶⁹
Free radical	A highly reactive chemical that often contains oxygen and is produced when molecules are split to give products that have unpaired electrons (a process called oxidation). Free radicals can damage important cellular molecules such as DNA or lipids or other parts of the cell. ⁵⁷⁰
Furan	A colourless toxic flammable liquid used in the synthesis of nylon ⁵⁷¹
Glutaraldehyde	A common chemical used in a variety of ways, including as a biocide, most commonly in disinfectants, as a hardener in X-ray film processing, as a fixing agent in electron and light microscopy, and in tanning. ⁵⁷²
Glutathione	An enzyme present in all plant and animal cells, composed of the amino acids glutamine, cysteine and glycine. Glutathione is synthesised within most cells of the body. In humans, it is found in all tissues and protects against potential damage from wastes and toxins. Glutathione may be effective in preventing accelerated ageing. ⁵⁷³
Glycaemic Index	An indicator of the ability of different types of foods that contain carbohydrate to raise the blood glucose levels within 2 hours. Foods containing carbohydrates that break down most quickly during digestion have the highest glycaemic index. Also called the dietary glycaemic index. ⁵⁷⁴
Glycol ether	A chemical family of solvents, some of which have been used in screen printing ink formulations; includes 2-methoxyethanol, 2-ethoxyethanol, and their acetates that are now restricted in US due to toxicity. ⁵⁷⁵
Glyphosate	Commonly known as Roundup, Glyphosate is a commonly used herbicide

⁵⁶⁶ Wikipedia, Free online Encyclopaedia (en.wikipedia.org/wiki/Ethylene_glycol)

⁵⁶⁷ Wikipedia, Free online Encyclopaedia (en.wikipedia.org/wiki/Dehydroepiandrosterone)

⁵⁶⁸ Kassirer, J. and Sandiford, K. (Cullbridge Marketing and Communications), Socio-Economic Impacts of Environmental Illness in Canada, 15 November, 2000, pp6-7.

⁵⁶⁹ National Safety Council, USA (www.nsc.org/ehc/glossary.htm)

⁵⁷⁰ http://www.cancerhub.info/reference/glossary.aspx?find=F

⁵⁷¹ Princeton University, Cognitive Science Laboratory (www.cogsci.princeton.edu/cgi-bin/webwn2.1)

⁵⁷² National Industrial Chemicals Notification and Assessment Scheme (NICNAS), Safety Info sheet No.2, http://www.nicnas.gov.au/publications/pdf/infosheet2.pdf

⁵⁷³ http://au.health.yahoo.com/041101/25/1uq3.html?r=967673105

⁵⁷⁴ http://www.medterms.com

⁵⁷⁵ Specialty Graphic Imaging Association (http://www.sgia.org/glossary/Gg.cfm)

used to control weeds.

Gulf War Syndrome	A highly controversial syndrome involving a constellation of illnesses experienced by 5,000 to 80,000 American veterans who were in the Gulf War. (The Veterans Administration considers those who served between August 2, 1990 and July 31, 1991 as "Gulf War Conflict" veterans.) Despite extensive (and expensive) research, no specific cause has been found for the Gulf War syndrome. Consequently, many physicians and scientists (but very few of the veterans with the syndrome) regard it as the result of psychological and social factors. A study reported in 2001 disclosed that the diagnosis depends upon who sees the patient and that mental health workers are more likely to believe that Gulf War illness is due to a physical factor such as a contagious or toxic agent, while general internal medicine physicians are more likely to think that the syndrome is a manifestation of mental illness. ⁵⁷⁶
Hayfever	A seasonal allergy to airborne particles characterized by itchy eyes, runny nose, nasal congestion, sneezing, itchy throat, and excess mucus. ⁵⁷⁷
Heme	A complicated molecule containing iron in the ferrous state, serves as a coenzyme in a variety of biochemical processes. It forms an essential part of the structure of haemoglobin and participates intimately in the uptake and release of oxygen by this protein. ⁵⁷⁸
Hexachlorobenzene	A pollutant once used as a pesticide for grain protection until banned by the US in 1976. It is still produced as a by-product during the manufacture of other chlorinated hydrocarbons. ⁵⁷⁹
Hives	A raised, itchy area of skin that is usually a sign of an allergic reaction. It can be rounded or flat-topped but is always elevated above the surrounding skin. It reflects circumscribed dermal edema (local swelling of the skin). The hives are usually well circumscribed but may be coalescent and will blanch with pressure. They typically last less than 4 hours but they may stay for days or weeks. The hives are also called urticaria. ⁵⁸⁰
Hypersensitivity	A broad term applied to disease symptoms following exposure to a previously encountered substance (allergen), often one which would otherwise be classified as harmless; essentially a malfunction of the immune system. ⁵⁸¹
IgE antibodies (immune proteins)	A type of antibody that is produced when one is exposed to an allergen. This type of antibody takes part in allergic inflammation. ⁵⁸²
Illness management	Related to factors which can make a difference to the way people live their day to day lives.
Immunoglobulin	A protein produced by plasma cells and lymphocytes and characteristic of these types of cells. Immunoglobulins play an essential role in the body's immune system. They attach to foreign substances, such as bacteria, and

⁵⁷⁶ <http://www.medterms.com>

⁵⁷⁷ <http://www.medterms.com>

⁵⁷⁸ <http://www.bartleby.com/65/co/coenzyme.html>

⁵⁷⁹ Great Lakes Information Network (http://www.great-lakes.net/humanhealth/about/words_h.html)

⁵⁸⁰ <http://www.medterms.com>

⁵⁸¹ University of Edinburgh, College of Medicine and Veterinary Medicine (www.link.med.ed.ac.uk/hew/tox/glossall.html)

⁵⁸² The University of Arizona, Health Sciences Center (<http://allergy.peds.arizona.edu/southwest/glossary.html>)

	assist in destroying them. ⁵⁸³
Immunology	The study of all aspects of the immune system, including its structure and function, disorders of the immune system, blood banking, immunization and organ transplantation. ⁵⁸⁴
Incidence	The number of new events of a specific disease during a particular period of time in a specified population. Incidence is different from prevalence; however, the two terms are frequently confused.
Inorganic	Compounds that do not contain carbon, such as minerals and water. ⁵⁸⁵
Ionising radiation	Any form of radiation that has sufficient energy to remove electrons from atoms, so producing charged particles called ions. It can consist of high energy particles (electrons, protons or alpha particles) or short wavelength electromagnetic radiation (ultraviolet, X-rays and gamma rays). ⁵⁸⁶
Irritable bowel syndrome	A common gastrointestinal disorder which can cause chronic recurrent discomfort but does not lead to any serious organ problems. ⁵⁸⁷
Kindling	Neural processes that mediate lasting changes in brain function in response to repeated, temporally spaced application of neuro-behaviourally active agents. ⁵⁸⁸
Leukaemia	Cancer of the blood cells. Strictly speaking, leukaemia should refer only to cancer of the white blood cells (the leukocytes) but in practice it can apply to malignancy of any cellular element in the blood or bone marrow, as in red cell leukaemia (erythroleukemia). ⁵⁸⁹
Mechanism	The means by which a particular effect is produced
Medline	Compiled by the US National Library of Medicine (NLM) the MEDLINE resource provides life sciences and biomedical information. ⁵⁹⁰
Methanol (methyl alcohol)	An alcohol that can be used as an alternative fuel or as a gasoline additive. It is less volatile than gasoline; when blended with gasoline it lowers the carbon monoxide emissions but increases hydrocarbon emissions. Used as pure fuel, its emissions are less ozone-forming than those from gasoline. Poisonous to humans and animals if ingested. ⁵⁹¹
Migraines	Usually, periodic attacks of headaches on one or both sides of the head. May be accompanied by nausea, vomiting, increased sensitivity of the eyes to light (photophobia), increased sensitivity to sound (phonophobia), dizziness, blurred vision, cognitive disturbances, and other symptoms. Some migraines do not include headache, and migraines may or may not be preceded by an aura. ⁵⁹²

⁵⁸³ <http://www.medterms.com>

⁵⁸⁴ <http://www.medterms.com>

⁵⁸⁵ <http://www.whatislife.com/glossary.htm>

⁵⁸⁶ Australian Academy of Science (www.science.org.au/nova/002/002glo.htm).

⁵⁸⁷ <http://www.medterms.com>

⁵⁸⁸ Rowat, S.C. Integrated Defense System Overlaps as a Disease Model: With Examples for Multiple Chemical Sensitivity, Reviews in Environmental Health, 1998 and Environmental Health Perspectives 106, Supplement 1, February 1998, Roberts Creek, British Columbia, Canada.

⁵⁸⁹ <http://www.medterms.com>

⁵⁹⁰ [Got this from your glossary points- no reference given](#)

⁵⁹¹ Environmental Protection Agency (US) (www.epa.gov/OCEPAt/terms/mterms.html)

⁵⁹² <http://www.medterms.com>

Multiple Sclerosis (MS)	A disease of the central nervous system (CNS) marked by numbness, weakness, loss of muscle coordination, and problems with vision, speech, and bladder control. MS is an autoimmune disease in which the body's immune system attacks myelin, a key substance that serves as a nerve insulator and helps in the transmission of nerve signals. The progress, severity and specific symptoms in MS are unpredictable. ⁵⁹³
Neurasthenia	A condition characterised by general lassitude, irritability, lack of concentration, worry, and hypochondria. The term was introduced into psychiatry in 1869 by G. M. Beard, an American neurologist. Used by Freud to describe a fundamental disorder in mental functioning, the term was incorrectly applied to almost any psychoneurosis and has been largely abandoned. ⁵⁹⁴
Neuro	Of the nerve or nervous system. ⁵⁹⁵
Neurogenic Inflammation	Inflammation caused by an injurious stimulus of peripheral neurons and resulting in release of neuropeptides which affect vascular permeability and help initiate pro-inflammatory and immune reactions at the site of injury. ⁵⁹⁶
Oestrogen	A hormone, produced mainly by the ovaries, responsible for female sexual development and female secondary sex characteristics. ⁵⁹⁷
Olfactory system (or Olfactory apparatus)	The entire system needed to have a sense of smell. This system involves at least 1,000 genes for the olfactory receptors. These genes are members of a large family of genes that encode signalling proteins required for the detection and discrimination of odours. Many of these olfactory genes are arranged in large clusters on chromosomes 6, 11, and 17, as well as distributed on other chromosomes.
Organic	Relating or belonging to the class of chemical compounds having a carbon basis (hydrocarbons are organic compounds). ⁵⁹⁸
Organic food/diet	In common usage, "organic" refers to foods cultivated and processed without fertilizers, insecticides, artificial colouring, artificial flavourings, or additives. ⁵⁹⁹
Organochlorine	A group of organic chemicals to which varying amounts of chlorine have been added. Organochlorine or chlorinated hydrocarbons (insecticides) are part of a broader class of halogenated hydrocarbons. ⁶⁰⁰
Organophosphate	A diverse group of chemicals used in both domestic and industrial settings. Examples of OPs include insecticides (malathion, parathion, diazinon, fenthion, dichlorvos, chlorpyrifos), nerve gases (soman, sarin, tabun, VX), ophthalmic agents (echothiophate, isofluorophate), and antihelmintics (trichlorfon). ⁶⁰¹

⁵⁹³ <http://www.medterms.com>

⁵⁹⁴ AllRefer.com - Psychology Encyclopaedia (<http://reference.allrefer.com/encyclopedia/categories/psych.html>)

⁵⁹⁵ tropmed.org/dictionary/coverpage9.htm

⁵⁹⁶ SOLVO Biotechnology (www.solvo.hu/glossary.html)

⁵⁹⁷ <http://www.fertilityuk.org/nfips02.html>

⁵⁹⁸ Princeton University, Cognitive Science Laboratory (www.cogsci.princeton.edu/cgi-bin/webwn2.1)

⁵⁹⁹ <http://www.nutribase.com/cookingt.shtml>

⁶⁰⁰ San Francisco Estuary Institute (www.sfei.org/rmp/glossary_new.html)

⁶⁰¹ <http://www.emedicine.com/med/topic1677.htm>

Pathophysiology/ Pathophysiological	The study of how normal physiological processes are affected by disease. ⁶⁰²
Pentachlorophenol	A wood preservative used to control fungal decay, termites or lyctid beetles. ⁶⁰³
Petrochemical	Any chemical derived from crude oil, crude products, or natural gas. ⁶⁰⁴
Phenol	1. A poisonous corrosive compound obtained by the distillation of coal tar that, in dilute solution, is an antimicrobial agent. Also called carbolic acid. 2. A generic term for any compound similar in structure to phenol (an organic compound with one or more hydroxyl groups attached to an aromatic or carbon ring). ⁶⁰⁵
Physiological	Having to do with the mechanism of body function. ⁶⁰⁶
Polychlorinated biphenyl	A family of highly toxic chemical compounds known to cause skin diseases and suspected of causing birth defects and cancer. ⁶⁰⁷
Polysymptomatic	Having multiple symptoms.
Porphyria	A diverse group of diseases in which the production of heme is disrupted. When heme production is faulty, porphyrins are overproduced and lend a reddish-purple colour to urine. All forms of porphyrias are inherited. The key clinical features are skin sensitivity to sunlight and/or by intermittent acute attacks of abdominal and nerve pain. ⁶⁰⁸
Post Traumatic Stress Disorder (PTSD)	A common anxiety disorder that develops after exposure to a terrifying event or ordeal in which grave physical harm occurred or was threatened. ⁶⁰⁹
Premature birth	Medically defined as a birth occurring earlier than 37 weeks. ⁶¹⁰
Prevalence	The total number of people with a specific disease or health condition living in a defined population at a particular time. Prevalence may be expressed as a number or a rate. Prevalence is different from incidence; however, the two terms are frequently confused.
Propane gas	A fuel produced from oil or natural gas. Propane gas is used for barbecues, water heaters, stoves and heaters. ⁶¹¹
Propylene glycol	A chemical compound, usually a tasteless, odorless clear liquid. It is used to absorb extra water and maintain moisture in certain medicines, cosmetics, or food products; as a solvent for food colours and flavours; as a food grade antifreeze; and to make artificial smoke for use in fire-fighters' training and theatrical productions. ⁶¹²

⁶⁰² www.epilepsy.org.au/epilepsy/epilepsyadult.nsf/Content/Glossary

⁶⁰³ (www.bugwood.org/gfcbook/glossary.html)

⁶⁰⁴ Ursa website (www.chevrontexacoursa.com/glossary/p.html)

⁶⁰⁵ <http://www.medterms.com>

⁶⁰⁶ http://instructl.cit.cornell.edu/courses/tox607/tox607_glossary.htm

⁶⁰⁷ Australian Government, Department of Environment and Heritage (<http://www.deh.gov.au/industry/finance/glossary.html>)

⁶⁰⁸ <http://www.medterms.com>

⁶⁰⁹ <http://www.medterms.com>

⁶¹⁰ Wikipedia, Free online Encyclopaedia (en.wikipedia.org/wiki/Premature_birth).

⁶¹¹ Belco Holding Limited website (www.belco.bm/bhl_pages/edugloss.html)

⁶¹² Wikipedia, Free online Encyclopaedia (en.wikipedia.org/wiki/Propylene_glycol)

Psychogenic (disorder)	Resulting from psychological or emotional disorders. ⁶¹³
Psychosomatic	Describes a physical condition that is influenced by psychological or emotional factors. ⁶¹⁴
Pthalate	A group of chemical compounds that are mainly used as plasticisers (substances added to plastics to increase their flexibility). They are chiefly used to turn polyvinyl chloride from a hard plastic into a flexible plastic. ⁶¹⁵
Reactive Airways Dysfunction Syndrome (RADS)	An asthma-like condition satisfying the following criteria:(a) a documented absence of preceding asthma or other ongoing bronchial disorders;(b) onset of symptoms after a single exposure incident or accident;(c) exposure to a gas, smoke, fume, or vapour, with irritant properties, present in very high concentrations;(d) onset of symptoms within 24 hours after the acute exposure, with persistence of symptoms for at least three months;(e) symptoms simulate asthma;(f) presence of reversible airflow obstruction on pulmonary function tests and/or the presence of non-specific bronchial hyper-responsiveness; and(g) other pulmonary diseases ruled out. ⁶¹⁶
Rhinitis	Inflammation of the nose lining (the nasal mucosa/mucous membrane). May be induced by many factors such as allergy (allergic rhinitis), hormones, drugs, and environmental factors. ⁶¹⁷
Semiconductor	An element, such as silicon, that is intermediate in electrical conductivity between conductors and insulators, through which conduction takes place by means of holes and electrons. ⁶¹⁸
Sensitizing	It is believed that the health problems of patients suffering from MCS often, but not always, appear to originate with some acute or traumatic exposure, after which the triggering of symptoms and observed sensitivities occur at very low levels of chemical exposure. The inducing chemical or substance may or may not be the same as the substances that thereafter provoke or “trigger” responses. (Sometimes the inducing substance is described as “sensitizing” the individual and the affected person is described as a “sensitized” person. ⁶¹⁹
Spontaneous abortion	A miscarriage or the unintended termination of a pregnancy before the twentieth week. ⁶²⁰
Sterilant	A non-selective chemical that kills any organisms. ⁶²¹
Syndrome	A set of signs and symptoms that tend to occur together and which reflect the presence of a particular disease or an increased chance of developing a particular disease. ⁶²²

⁶¹³ www.familypractice.com/references/Dictionary/dictionary.htm

⁶¹⁴ www.familypractice.com/references/Dictionary/dictionary.htm

⁶¹⁵ Wikipedia, Free online Encyclopaedia (en.wikipedia.org/wiki/Pthalates)

⁶¹⁶ Repatriation Medical Authority (RMA), Australian Government, Instrument No.85 of 2001 (<http://www.rma.gov.au/SOP/01/085.pdf>)

⁶¹⁷ www.rhinitisinfo.com/resources/glossaryNR.html

⁶¹⁸ Crucial Technology, A Division of Microsoft. www.crucial.com/library/glossary.asp

⁶¹⁹ Ashford, N. and Miller, C., Chemical Exposures- Low Levels and High Stakes (2nd edition). Van Nostrand Reinhold, New York, 1998, p7.

⁶²⁰ <http://www.infertilitycentral.com/fertility/infertility-glossary.html>

⁶²¹ British Columbia, Ministry of Water, Land and Air Protection (<http://wlapwww.gov.bc.ca/epd/ipm/docs/envirowe/gloss.htm>)

⁶²² <http://www.medterms.com>

Synthetic	A substance that is formulated or manufactured by a chemical process or by a process that chemically changes a substance extracted from naturally occurring plant, animal, or mineral sources. ⁶²³
Tonsillitis	Inflammation of the tonsil, typically as a result of infection by either a virus or bacteria. ⁶²⁴
Toxicity	The degree to which a substance can harm humans or animals. Toxicity can be acute, subchronic, or chronic. ⁶²⁵
Toxicogenic	Producing disease symptoms as a result of an introduced toxin. ⁶²⁶
Toxicology	The study of the nature, effects and detection of poisons and the treatment of poisoning. ⁶²⁷
Vitamin B12	A vitamin important for the normal formation of red blood cells and the health of the nerve tissues. Undetected and untreated vitamin B12 deficiency can lead to anaemia and permanent nerve and brain damage. ⁶²⁸
Volatile	Evaporating readily at normal temperatures and pressures. ⁶²⁹

⁶²³ Organic Farming Compliance Handbook, A Resource Guide for Western Region Agricultural Professionals (<http://www.sarep.ucdavis.edu/organic/complianceguide/glossary.htm>).

⁶²⁴ <http://www.medterms.com>

⁶²⁵ <http://www.medterms.com>

⁶²⁶ Auburn University, College of Agriculture (www.ag.auburn.edu/dept/entplp/courses/glossary.htm)

⁶²⁷ <http://www.medterms.com>

⁶²⁸ <http://www.medterms.com>

⁶²⁹ Princeton University, Cognitive Science Laboratory (www.cogsci.princeton.edu/cgi-bin/webwn2.1)

APPENDIX 1

APPENDIX 2

Royal Brisbane Hospital & Royal Women's Hospital and Health Service Districts



Initiator:

**Executive
Director of
Medical
Services**

Applies to:

All staff

**Authorisation
Date:**

DRAFT

Review Date:

TBA

**Previous Issue
Date:**

Authorised by:

.....
District Manager

Replaces:

80503/ALL: Multiple Chemical Sensitivity (MCS) Patients, Processes for

Policy

1. The Royal Brisbane Hospital & Royal Women's Hospital and Health Service Districts is committed to providing an environment that reduces exposure to incitants, for those patients who identify themselves as suffering Multiple Chemical Sensitivity (MCS / IEI).
2. It is recommended that a minimum of one staff member, in each department, on each shift be available to attend to the medical needs of an MCS / IEI patient.
3. Patients with MCS / IEI are to have all incitants recorded in the patient's medical record (according to the clinical history, incitants may or may not be recorded as allergens). Refer to policy *80501/PPP: Patient Alerts and Allergies Recording of*.
4. All members of the health care team should be informed of the admission of the patient to enable them to ensure adequate preparation for care.
5. Patients with MCS may be housed in a single room with ensuite facilities to reduce the potential for incitants exposure if appropriate.
6. The MCS / IEI equipment pack kept in DEM and CELS should be obtained and used when caring for the patient with MCS.

Standard

Discomfort for patients who believe they suffer MCS / IEI within the organisation is minimised.

Explanation

MCS / IEI are terms that have been used to describe physical symptoms said to be initiated by hypersensitivity to chemical exposure. MCS / IEI may be brought on by a wide array of chemicals found in hospitals and personal hygiene products used by staff. Patients may complain of headaches, myalgia, nausea, abdominal pain and other somatic symptoms. Patients with MCS / IEI may have other diagnosable medical, surgical or psychiatric illness. Most patients with MCS / IEI have a strong belief system about their condition and can become very distressed when exposed to incitants.

Common Triggers

Some of the chemicals that trigger MCS / IEI symptoms are known to be irritants or be potentially toxic to the nervous system. The products and other chemicals that cause problems vary among affected individuals and can include:

- Anaesthesia

- Artificial colours, flavours and preservatives in food, drinks and drugs
- Perfumes and fragrances
- Detergents and other cleaners
- Prescribed medications
- Smoke from tobacco products
- Solvents from felt pens etc.

Commonest Symptoms

- Respiratory symptoms
- Headache
- Fatigue
- Flu-like symptoms
- Mental confusion
- Short term memory loss
- Gastro - intestinal tract symptoms
- Cardiovascular irregularities
- Genito - urinary symptoms
- Muscle and joint pain
- Irritability and depression
- Ear, nose and throat complaints.

Process

Emergency Department

An MCS / IEI patient will often carry a medical alert. Staff will need to check with all patients if they have any alerts or / and allergies. If the patient is conscious and able to communicate, they are a valuable resource for temporary care instructions and their requests should where possible, be facilitated. In addition the following should be done.

- Subject to the clinical requirements of managing the condition necessitating admission, MCS / IEI patients should be treated in an area that is not close to:
 - Areas being remodelled or renovated
 - Highly trafficked areas within the hospital
 - Chemical storage and supply areas
 - Chemotherapy treatment areas
 - Computers and fax machines
- Utilise the MCS / IEI pack of equipment available in DEM or CELS, when caring for the patient (see appendix one).
- Wherever possible, liaise early with the patients general.
- Confirm with the patient their specific chemical sensitivities and mark them clearly on the alerts and allergy sheet of the medical chart. Refer to policy *80501/CPP: Patient Alerts and Allergies Recording of*. In addition:

- Ask patient to identify any serious reactions they have experienced and identify what exposures have caused such reactions in the past.
- Ask patient to detail what can be done to reduce the severity and list the information in the patient's medical chart.
- Check the patient's medical chart for previous documentation in relation to MCS / IES.
- Personnel other than those having direct care for the patient should avoid entering the area when the patient is being accommodated.
- Patients with MCS / IEI may be irritated by chemically treated papers or documents. A family member or other designated person may sign for the patient, but verbal consent with witnesses present should always be obtained and fully documented.

Environment

There are a number of simple changes that can be made in the general hospital environment to assist the care and comfort of patients with MCS / IEI. Of utmost importance is the air quality. The patient's room is probably the most important area in the hospital to concentrate on as the majority of the patient's time is spent there. While it is virtually impossible to ensure a completely chemical free environment, measures can be taken to prevent unnecessary exposure to incitants.

Prior to admission

1. **An equipment pack should be obtained from DEM / CELS and used appropriately.**
2. The MCS patient should remain in a single room with ensuite facilities if possible.
3. Cleaning staff should be contacted to ensure the room is cleaned prior to use, using the cleaning products supplied in the MCS pack. Once cleaned the room should be wiped down with plain water.
4. Aerosol cleaners, disinfectants or room deodorisers should not be used. All perfumed items should be removed from the room.
5. The room should be free of any mould or dampness. If necessary engineering should be contacted to change ceiling tiles and check ventilation systems for cleanliness.
6. Use the linen supplied to make the bed, alternatively patient supplied linen can be used.
7. Place a stop sign on the outer door with instructions to contact the nurse in charge prior to entering the room.
8. To minimise contamination allocate a member of staff to care for the patient and inform all health care personnel that will be looking after the patient about the admission.

During Admission

1. All hospital employees and visitors should check in at the nurse's station for instructions prior to entering the patient's room.
2. Keep the room doors closed at all times.
3. Hospital staff are to wash their hands and apply hypo allergenic, non latex gloves prior to entering the room.
4. Do not permit any flowers / plants / newspapers or treated paper in the patient's room.
5. Coordinate with cleaning personnel so no toxic chemicals are used in the general area during the patient's stay.
6. Daily cleaning of an MCS patient's room by the cleaning services should be minimal but include:
 - Dust with a clean cotton cloth moistened with only water
 - Use baking soda for tubs, sinks and toilet
 - Remove rubbish at least twice daily
7. Do not leave patient trays in the room after meals
8. Do not leave wet laundry and towels in the room. Remove immediately after patient is finished bathing.

Hospital Staff

MCS / IEI can be a debilitating condition. It is imperative that you take the advice of the patient and reassure them that you understand they are chemically sensitive. Patients with MCS / IEI can severely react to clothing, products and chemicals worn by others. The following steps will assist in preventing contamination of the area the MCS / IEI patient is housed.

1. Ensure as the staff member caring for the patient you are familiar with the condition and what constitutes an irritant.
2. Laundry soaps, fabric softeners, deodorants, shampoo, hair lotions, hair spray, make-up, hair mouse, gels and bath soaps can all contain perfume or masking fragrances and deodorisers, and should be avoided by staff during the patient's stay.
3. All staff members who are in contact with the MCS / IEI patient should ensure they obtain a supply of non perfumed personal hygiene products and sterile scrub caps and surgical gowns which are available in the MCS pack in CELS / DEM. As staff should
 - Be fragrant free
 - Use hypoallergenic products
 - Not use aerosol sprays
4. Staff members who smoke ideally should not care for the patient with MCS/ IEI.
5. Follow the patient's doctors suggestions for special orders regarding MCS / IEI.
6. Be on alert for any possible environmental triggers for the MCS when following normal hospital procedures. Refer to policy 49200/ALL: *Environmental Management Plan*.

7. The patient's medical and nursing team are responsible for coordinating with all other hospital departments the patient may be sent to. Whenever possible, arrange to have the patient treated in his / her room.

Dietary

MCS / IEI patients may have different food sensitivities and allergies. Referral of the MCS / IEI patient to the Department of Nutrition and Dietetics should be made as soon as admission is arranged. The patients should be allowed to bring in their own food if requested and consistent with clinical management.

Medications

MCS / IEI patients may have significant reactions to medications. Referral should be made to the pharmacist as soon as admission is arranged.

Do not use substitutes or generic drugs for medications unless unavoidable.

- Standard ingredients of medications should be known, as MCS / IEI patients react to things including but not limited to: dyes, preservatives, artificial sweeteners and flavourings.
- Drug reactions should be reported to the medical officer immediately. Observation for symptoms such as:
 - Muscle spasm
 - Local swelling, hives
 - Syncope
 - Hyperventilation
 - Seizures
 - Asthma
 - Severe anaphylaxis

Patient's Responsibility

MCS / IEI patients should carry a medical alert at all times. They are often well informed about regarding their condition and can educate others who they come into contact with. We need to ensure we inform the MCS / IEI patient of the following which will ensure their admission is as comfortable as possible.

1. The patient should provide advance notice to hospital management (at least 2-3 days) prior to any scheduled visit to the hospital stating particular sensitivities.
2. Patients may arrange to provide their own personal items that may not be readily obtainable at the hospital facility eg toothpaste, linen, personal care products. The hospital cannot meet every special requirement as patients with MCS have highly variable needs.
3. The doctor who treats the patients MCS should be contacted / or should contact the hospital to provide information that will facilitate the patient's care.

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Stakeholders Consulted

Executive Director of Medical Services RBH & RWH and HSD's
Deputy Executive Director of Medical Services RBH & RWH and HSD's
Director of Nursing RBH & RWH and HSD's
Divisional Nursing and Medical Directors RBH & RWH and HSD's
Director of Pharmacy RBH & RWH and HSD's
Director of Nutrition RBH & RWH and HSD's
Director of Engineering RBH & RWH and HSD's
Quality Improvement Unit, Division of Clinical Support Services, RBH & RWH and HSD's

Appendix One

Equipment in pack for Multiple Chemical Sensitivity Patients

(THIS IS NOT THE FINAL LIST I AM CURRENTLY REVIEWING THE LITERATURE TO FIND OUT WHAT IS NEEDED)

- Sterile Gowns
- Red armband
- Sterile linen
- Hygiene products
- Sterile drinking water
- Paper tape
- Stop signs
- Cleaning products
-
- Latex free equipment to include:
- Non Latex Gloves
-
-
-

Separate hygiene packs for staff will be avail

APPENDIX 3

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