

Talking *Power*

2006 Issue 1

Official Journal of the M.E./C.F.S. Society (SA) Inc.

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Society*



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ME/CFS Society (SA) Inc.

The ME/CFS Society (SA) Inc. is a non-profit organisation (Registered Charity 698) which aims to:

- promote recognition and understanding of the disease among the medical profession and the wider community
- provide information and support for people with ME/CFS and their families

Patron

Her Excellency Marjorie Jackson-Nelson AC, CVO, MBE, Governor of South Australia.



Medical Advisor

Dr Peter Del Fante – GP, BSc DipCompSc MBBS (Hons) MSc (Public Health Medicine), Medical Director of the Western Division of General Practitioners.

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Talking Point

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Persons with ME/CFS:	\$22
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Management Committee 2004/2005

The Society is directly administered by a voluntary committee elected at the Annual General Meeting.

President: Peter Cahalan

Vice-President: (vacant)

Honorary Secretary: Peter Mitchell

Treasurer: Geoff Wilson

Management Committee Members: Adrian Hill; Emma Wing

Contact Details

Any correspondence should be directed to:
ME/CFS Society (SA) Inc. PO Box 383,
Adelaide, SA 5001.

Note: It is our policy to ignore anonymous correspondence.

The Society has an office: Room 510, 5th floor, Epworth Building, 33 Pirie St, Adelaide.

At the time of printing the office hours are:

Wednesdays 10am to 3pm (subject to volunteer availability).

Our email address is: sacfs@sacfs.asn.au.

Our Web site address is: www.sacfs.asn.au.

Our youth Web site address: www.sayme.org.au.

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All donations of \$2.00 or over are tax deductible and a receipt will be issued.

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All communication both verbal and written is merely to disseminate information and not to make recommendations or directives.

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Always consult your medical practitioners before commencing any new treatments.

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Queensland ME Quarterly, Queensland ME/CFS Syndrome Society, PO Box 938, Fortitude Valley Qld, 4006.

ChaMEleon, ACT ME/CFS Society, Shout Office, Collett Place, Pearce ACT 2607.

ME/CFS News, ME/CFS Society W.A. Inc., c/- WISH, PO Box 8140, Perth, WA 6000.

The CFIDS Chronicle, CFIDS Association, PO BOX 220398, Charlotte, NC28222-0398, USA.

Perspectives, Myalgic Encephalomyelitis Association, Stanhope House, High Street, Stanford le Hope, Essex SS17 0HA, UK.

Country Network, Journal of the Northern Rivers ME/CFS/FM Support Assoc. Inc. PO Box 6024 Lismore NSW 2480.

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Annual General Meeting

The Minutes of the Annual General meeting held on Saturday November 12, 2005, as taken by **Peter Mitchell**.

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ME/CFS SOCIETY (SA) INC
Minutes Annual General Meeting
Saturday November 12, 2005 1-3 pm
Venue: DIRC, 195 Gilles St, Adelaide

Minutes Secretary: Peter Mitchell

1. Introduction

The Chair and President, Peter Cahalan, opened the meeting by welcoming all present.

2. Present

There were approximately 20 people in attendance. The names in the appendix were those recorded. 29 Proxies were received, along with other apologies as noted in the appendix.

3. Minutes of previous General Meeting

The minutes of the AGM held on November 13, 2004 were presented, read and accepted as correct.

Moved: Margaret Wing, seconded Emma Wing
Carried

4. Election of Management Committee

Peter Mitchell, as returning officer, reported that he had received no new nominations for the Management Committee by the time of close of nominations. The ongoing members of the Committee are: Peter Cahalan; Geoff Wilson; Margaret Wing; Adrian Hill; Emma Wing; and Peter Mitchell.

5. Election of Office Bearers

The following nominations were received by the time of close of nominations:

- Geoff Wilson for Treasurer
- Peter Mitchell for Secretary

They were declared elected unopposed. The constitution, copies of which were available at the meeting, is silent on

the matter of length of tenure of Office Bearers.

Motion: That Secretary and Treasurer positions be filled for a period of two years

Moved: Peter Cahalan, Seconded: David Shepherd
Carried

6. Treasurer's Report

Geoff Wilson presented the Treasurer's report, and presentation of audited Financial Statements. In summary, the Society had another reasonable year financially, bolstered by an anonymous donation of \$12,000 (the 4th year in a row that this donor had made such a donation), and an ongoing donation from the BankSA staff fund of \$1000. There had been a decrease in funds of just over \$6000 for the year.

Motion: that the financial reports for the period ending June 30, 2005 be accepted

Moved: Jenny Gay, seconded Margaret Wing
Carried

7. President's Report

Peter Cahalan began his report by acknowledging the major event for the year, the visit to SA by Professor Kenny De Meirleir of Brussels. This visit was the result of work and funding by the Alison Hunter Memorial Foundation, because of the excellent networks in SA. Prof De Meirleir spoke to a public meeting at Norwood of about 300 people, one of the largest ME/CFS meetings in SA ever. Over the following two days in June, Prof De Meirleir participated in a forum of doctors and researchers at Adelaide University. The forum stressed the biological base of CFS, and reached agreement on the promotion of the Canadian protocol. Also discussed were new testing regimes, another area in which Prof De Meirleir has been providing leadership. An excellent report of the forum has since been shared with our members.

A second major achievement this year has been the fruits of our work on multiple chemical sensitivity (MCS). This was seen in a recent forum with members of the parliamentary committee which has produced a key report on MCS for the government. A key recommendation has been the

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formation of an interagency working party on MCS. This appears to be an important moment in time to push this issue of MCS forward.

Thirdly, we have been pleased with the progress of our Society's communications strategy in 2005. Our outstanding website is one of the best ME/CFS sites in the world. It receives an average of 80 unique visitors per day, every day. Our ebulletins began as a way of promoting the website but now have a life of their own, going out every week to over two-thirds of our members. We have now also begun using SMS messages to those members who wish to receive them: 95 currently. For those members without internet or mobile phone access, we have Linda Brett telephoning to keep in touch and *Talking Point*. Our magazine has come out quarterly, edited by Peter Scott, our webmaster. And we have produced a number of DVDs of seminars and forums. In these ways we believe we are keeping members informed and involved in the Society. We will continue to look for new ways of communicating.

Other activities in 2005 included:

- Progress on the Schools Resource Kit by Peter Mitchell and a number of supporters. This should lead to a kit for parents, students and teachers in 2006.
- A meeting with Open Access staff and parents.
- SAYME website re-activated.
- The research database has been initiated via Adelaide University.
- The *ME/CFS Guidelines* are now in use in SA, and spreading. We have been asked to produce 3000 for practitioner sin NSW and 500 for Victoria. They have been praised by doctors as simple and straightforward for busy professionals.
- Developing connections: we are pleased with the ongoing links with the Alison Hunter Memorial Foundation. We have excellent relations with our counterparts in Victoria, which may lead to more national focus on ME/CFS in future.
- SAYME has had a slow year, however they have maintained monthly meetings. The SAYME website is now back online and there has been a lot of interest in an online discussion group. There should be a Xmas SAYME magazine.

Other thanks for 2005:

- To Donna Briese, who retired from the committee in 2005 and from her role as office co-ordinator. I think many members would know Donna from her work on the phone line, but Donna put in enormous amounts of effort in so many areas to help other people with

ME/CFS.

- To Mike Ritter our office Information and communications technology coordinator.
- To Emma Wing for huge efforts leading SAYME, and in the office and elsewhere.
- Badge Day/s. We have raised very useful amounts in this way in 2005. Thanks to Adrian Hill, David Shepherd, Bow Thompson, Carol Carroll and the Paproths in Port Pirie.
- Support Line leaders: thanks to Elaine Balfort, Vicki Foote, Alex Harris, and Merindah Whitby. Also to our regional support leaders including Marion Hansen and David Shepherd, both in attendance at the AGM
- To Linda Brett for her outstanding support in the office and to Freya Thompson in more recent times.
- To Sarah White for leadership in SAYME.
- To Val McKeown, for reportage of the July forum: not an easy task!
- To the whole Management Committee for their great work in 2005.

I particularly want to thank Marg Wing for her years of dedicated service and leadership to Management Committee, the office, finances, catering, etc etc. Marg will not be continuing with the Management Committee, and we will miss her greatly.

Peter set out these future directions: continuing to improve our communications with members; having a stronger program of lectures and seminars, 2 to 3 major seminars next year, with 2 people working specifically on that focus; continuing to focus on young people and their families; continuing to explore opportunities for links with other societies, including the Victorian CFS Society; possibly sharing premises with another society.

We have achieved much from a base of about 20 active volunteers, but we have a huge resource base, and we look forward to utilising little bits from many people.

In conclusion, Peter wished members all good health and, if that was not possible, then a strong spirit.

Motion: that the President's report for 2004/5 be accepted

Moved: Val McKeown, seconded Margaret Wing

Carried

8. Any other business

Meeting ended 1:45pm approx.

Note: a DVD was made of the meeting and a copy is held in the Society's office.

Multiple Chemical Sensitivity Inquiry

This special feature focuses on an Inquiry into Multiple Chemical Sensitivity that was authored by the Social Development Committee of the Parliament of South Australia and tabled in Parliament in July 2005.

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The feature is in two parts:

1. **The Inquiry**
2. **The Government's Response and Community Rebuttal**

Part 1: The Inquiry

The full Inquiry is available at www.parliament.sa.gov.au/committees/committees.asp?doCmd=show&intID=45 (see link to 22nd Tabled Report). The following is the Executive Summary and Recommendations.

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.

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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 farther 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

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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 admin-

istering 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

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- interstate protocols and procedures such as the Royal Brisbane Hospital draft MCS protocols, and other relevant overseas protocols on MCS;
- 9.2 convene a working group of representatives from relevant Government departments and agencies, health service providers, and community organisations, to consider developing appropriate protocols and procedures that enable greater access to health care services for people with MCS.

Measures to Minimise Chemical Exposure in the Community

Recommendation 10

That relevant State Government Ministers:

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

Extending Existing Support Services to Accommodate MCS Sufferers

Recommendation 11

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

Summary

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

larly 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

Social Development Committee of the Parliament of South Australia

Multiple Chemical Sensitivity Inquiry

Part 2: The Government's Response and Community Rebuttal

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The Government's Response to the Inquiry was written mainly by officers in the Department of Health and tabled in Parliament in November 2005.

The Community Rebuttal to the Response to the Social Development Committee Inquiry into MCS was authored by Peter Evans on behalf of the SA Task Force on MCS and has been endorsed by Peter Cahalan on behalf of the ME/CFS Society. It was written in February 2006.

The Government's Response: General Comments

The Committee is to be congratulated on tackling this difficult but important issue, and for completion of its report. The Committee has witnessed the fact that there are wide-ranging views on the central question of causation of MCS, and this is principally because there is currently no scientific or medical consensus on the cause or diagnosis of this condition. Indeed, many who work in this field believe that the term "MCS" is a misnomer, as it is not proven that chemicals are the sole causal factor. This point of lack of consensus on causation and diagnosis must be reinforced, since progress to achieve such consensus is certainly required if there is to be significant advancement in the various clinical, toxicological and social impact areas that were addressed by the Committee.

In spite of the strong submissions made to the SDC on the uncertainty associated with diagnosis and treatment, the Committee appears to have moved to a view that chemicals are the cause of MCS and has

based its recommendations on the premise of chemical causation. DH advises that it is not proven that chemicals are the sole causation of MCS. Consequently, the Department believes that it is extremely difficult for SDC or others to identify priority areas of action while the central question of causation remains unresolved. Notwithstanding, it is evident that MCS leads to morbidity in some people and may represent a significant cost to society.

Following is the response of DH to specific recommendations of the SDC. DH notes that some of these recommendations were also referred to other Departments and that recommendations 4 and 6 were referred only to PIRSA. Since SDC has recommended that DH convene an across-Government Working Party for dealing with several MCS issues, the Department has assumed a lead-agency role and has incorporated the responses of the other departments into this document.

The Community Rebuttal: Opening Comments

The Government's Response to the Social Development Committee Inquiry into Multiple Chemical Sensitivity is unacceptable to people living with MCS and the community-based groups that support them. The Response is inflammatory and escalates the existing conflict between the people affected by MCS and the authorities that obstinately refuse to address the problem. The Department of Health claims that it has "assumed a lead-agency role" that incorporates the response of other departments. Rather than showing leadership it is clear that sceptical elements within government are seeking to undermine the good work of the Social Development Committee and the decades of effort by people living with MCS in trying to bring this serious and growing public health crisis to the attention of authorities.

The Response has referred to the term MCS as a "misnomer, as it is not proven that chemicals are the sole

causal factor". The tiresome debate surrounding the nomenclature of MCS has been used by sceptics and the chemical industry to obfuscate the facts and prevent action on MCS. The main objection to the term MCS arises from the fact that, since the discovery of allergy related antibodies in the 1960s, conventional immunologists have used the term "sensitivity" to describe immune system mediated allergy-type reactions and the alternative term "intolerance" to describe non-immune system mediated sensitivity reactions. According to this conventional understanding, MCS must not be described as "sensitivity" because there is little evidence that the condition is mediated by the immune system. This dogmatic objection to the term MCS has not resulted in any benefit to those people who actually live with the condition. Moreover, MCS sceptics must realise

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that they do not hold a monopoly over the evolution of medical nomenclature. The term MCS is in common use in medical literature and objections to the term are immaterial when considering the actual signs and symptoms of the illness and the available evidence of their association with chemical exposures.

The Response has focussed on the "lack of consensus on causation and diagnosis" surrounding MCS. Those who are ideologically opposed to the recognition of MCS will likely never be satisfied with any understanding of MCS until a diagnostic marker becomes available for the condition and the physiological mechanisms behind MCS are fully elucidated. That the sceptics should demand such a level of proof before beginning to address the problem is entirely unreasonable given the very poor state of research and medical interest in MCS. It may be many decades before a single diagnostic marker becomes available, if at all. However, despite this so called "lack of consensus" people with MCS and the clinicians and researchers who support them have made great progress in the medical and scientific understanding of the disorder. Unfortunately, this work has been almost entirely ignored or treated with antipathy by the mainstream. This problem of academic bias and its resulting discrimination against people with MCS must be addressed if the questions of causation and diagnostic consensus are to be resolved.

Objections to the recognition of MCS are generally based on ignorance and utilitarian economic principles rather than good medical science, where meticulous clinical assessment of the patient is fundamental to first-class medical practice. Often these objections come from academics and scientists who have no experience whatsoever in the clinical management of the patient with MCS. The fact that the Department of Health has no existing protocols with regard to the diagnosis and management of MCS is a clear example of how government bureaucracy has abjectly failed to engage with the issue.

MCS can very easily be diagnosed on clinical presentation using internationally accepted criteria. Medical practitioners in South Australia are already applying this diagnosis and the Social Development Committee heard evidence from the Department of Health that nearly 1% of South Australians have been medically diagnosed with MCS. The Committee concluded that "up to 6 percent of the population may have MCS, with between 10-25 percent experiencing sensitivity to chemicals".

If people with MCS were not pointing to a chemical causation for their disease it is unlikely that the level of controversy surrounding their diagnosis would exist. To quote

Bartha *et al* in "MCS: A 1999 Consensus", published in Archives of Environmental Health, Vol 54:

The millions of civilians and tens of thousands of Gulf War veterans who suffer from chemical sensitivity should not be kept waiting any longer for a standardized diagnosis while medical research continues to investigate the etiology of their signs and symptoms.

The Response has correctly stated that the Social Development Committee "appears to have moved to a view that chemicals are the cause of MCS". However, the Department of Health has advised that "it is not proven that chemicals are the sole causation of MCS". The Social Development Committee is composed of sensible, intelligent people who undertook an unbiased review of the medical and scientific data on MCS and received an unprecedented number of national and international submissions, including many from people with MCS and the community groups that support them. Given the wealth of evidence that MCS is associated with chemical exposures it is not surprising that the Committee should have formed the view that chemicals are the main cause of MCS. In its negative response to the Committee's findings the subtext from the Department of Health is that MCS is a psychological condition, a kind of mass psychosis affecting up to 6% or more of the population. In fact, there is very little evidence for a psychogenic aetiology in MCS and this view is most likely to be based on academic bias and commercial conflicts of interest. To quote Caress and Steinemann in "A Review of a Two Phase Population Study of Multiple Chemical Sensitivities," published September 2003, Vol 111, No 12 of Environmental Health Perspectives:

"A significant percentage (27.5%) [of people with MCS] reported that their hypersensitivity was initiated by exposure to pesticides, whereas an equal percentage (27.5%) attributed it to solvents. Only 1.4% had a history of prior emotional problems, but 37.7% developed these problems after the physical symptoms emerged. This suggests that MCS has a physiologic and not a psychologic etiology."

The covert promulgation by the Department of Health of the unscientific view that MCS is a psychological entity requiring no organised response from governments threatens the maintenance of public health and endorses the continuing discrimination against people with MCS.

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The Department of Health has stated that it "believes that it is extremely difficult for SDC or others to identify priority areas of action while the central issue of causation remains unsolved. Notwithstanding, it is evident that MCS leads to morbidity in some people and may represent a significant cost to society".

The debate surrounding MCS is comparable to other contemporary environmental crises, such as global warming. Despite clear evidence of the role of human activity in climate change, sceptics continue to cast doubt on these data and have inhibited governments from taking clear action to address the problem. Often these sceptics have links to those industries that are major producers of greenhouse gasses. The same situation is true of MCS, with chemical industry representatives and scientists with links to the chemical industry attempting to deny and distort evidence of the association between chemical exposures and MCS. Unfortunately, there are MCS sceptics within government who have historical links to the chemical industry, either directly or indirectly through chemical regulatory mechanisms, and whose prior training and existing mind-set makes them incapable of supporting reforms in chemical use in order to protect public health and human rights. What is required from government and the Department of Health is a far more precautionary approach with respect to the use of toxic chemicals and a willingness to creatively review current toxicological paradigms in order to include MCS.

The Social Development Committee heard medical evidence that the incidence of MCS is increasing in the community. The cost of MCS to society is already large with one Canadian study, which found 2% of Canada's population seriously disabled with MCS, estimating the cost of environmental illness in that country to be around \$13 billion dollars annually when lost productivity is included. As more people become affected by MCS the cost to society will increase. Also, as evidence of the link between MCS and chemical exposures increases, so will there be increasing demands from people with MCS for just compensation for their chemical injury. The angry public rallies seen recently with respect to asbestos related diseases are an example of what the future holds for MCS. However, in the case of MCS, public anger is likely to be directed against governments, rather than individual companies, for allowing the widespread use of toxic chemicals under regulatory mechanisms that have clearly failed to protect public health.

There is now a significant body of epidemiological and clinical data spanning more than fifty years to show that toxic chemical exposures are capable of initiating MCS and that the most effective treatment for MCS is the avoidance

of chemicals, foods and medications that trigger symptoms. The Department of Health's efforts to deny the link between chemical exposures and the reality of the experience of people with MCS is an attempted negation of their basic human rights.

Unfortunately, it is not entirely surprising that government institutions with responsibility for public health appear incapable of responding appropriately to the emergence of MCS. To quote Pamela Reed Gibson, PhD, Associate Professor of Psychology at James Madison University, in her booklet *Understanding and Accommodating People with Multiple Chemical Sensitivity in Independent Living*, published by the Independent Living Research Unit, with funding assistance from the US Department of Education:

MCS is an illness that is caused by industrialism, it is an indictment of industrial culture because it directly points to chemicals as a cause of disability, and it is totally incongruent with industrial culture. We are a culture that does "risk assessment" of each of our chemicals allowing a certain number of people to get sick or die from exposure to each chemical. While the EPA continues to compile lists of cancer causing agents, the field of health psychology continues to look for the "cancer personality" that supposedly renders some persons more psychologically prone to the development of cancer. We are experts at ignoring the obvious. While babies on the U.S. - Mexico border are born without brains, our industries continue to dump wastes into the air and water of that geographic region. Our institutions are created out of the same industrial paradigm that allows this contamination, and are therefore not only not positioned to respond in any constructive way, but are in many cases set up to deny and distort the reality of chemical-induced disability. This cultural set-up makes for personal struggles in a number of venues.

The Government's Response to the Social Development Committee Inquiry into MCS has been to fully support less than a handful of the most conservative recommendations (numbers 3,4,6, and 9.1), while giving only in-principle support to six (numbers 1,2,5,7,8, and 10), and rejecting two crucial recommendation that would assist people with MCS to equitably access health care services (numbers 9.2 and 11).

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There are numerous unacceptable inconsistencies in the Response, notably those surrounding equitable access to services and public spaces for people with MCS. People

living with MCS and the community groups that support them therefore call on the government to give its full and unqualified support to all the Social Development Committee's recommendations and to implement them within a reasonable time frame.

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The Recommendations

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

The Government's Response:

Supported in principle

Through two telephone surveys, the Department has already gathered data from over 4,000 individuals and determined that MCS has a prevalence of about 1 per cent in SA. Whether further surveys can be done will depend on priorities for resources within the Department for surveillance activities.

Surveys have been conducted elsewhere and have shown various incidence rates. It is difficult though to compare surveys, since the wording of questions has not been standardised and the state of MCS knowledge in the public and medical practitioner arenas is likely to be different in different countries. Therefore, any further surveys conducted in SA will need to be carefully designed and interpreted.

The Rebuttal:

The Department of Health has stated that: "the Department has already gathered data from over 4,000 individuals and determined that MCS has a prevalence of about 1 per cent in SA. Whether further surveys can be done will depend on priorities for resources within the Department for surveillance activities."

National and international epidemiological data have shown that up to 6% or more of the population may have moderate to severe MCS, with up to one third of the population reporting some form of chemical sensitivity. Experienced MCS researchers are warning that those people in the larger chemically sensitive group may be at risk of developing more severe and permanent symptoms of MCS. This situation must be monitored closely in the public interest.

The Social Development Committee heard medical evidence that the incidence of MCS is increasing in the community. MCS researchers generally agree that, with the current situation regarding chemical use, it is inevitable that

cases of MCS will increase. In order to monitor this expected increase the Department of Health must demonstrate a responsible interest in this matter and be provided with sufficient resources. Any impediments to a full understanding of the incidence of MCS due to variations in survey questions and medical knowledge can be adequately resolved through careful attention to the problem. The government's response to MCS must be based on accurate population data and the accumulation of that data should be given priority.

This recommendation should be fully supported by Government.

2. That DH:

- 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 MCS, 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.**

The Government's Response:

Supported in principle

The Department has already engaged with several of these stakeholders in discussions over recent years on various aspects of MCS. Importantly, consistent recognition of causes and symptoms is required. Once this is achieved, DH will consult and promulgate as appropriate.

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The Rebuttal

The Department of Health's objection to providing unqualified support for this recommendation is based on its demand that there be full consensus regarding the diagnosis and causes of MCS. Until this is achieved the Department appears to intend to remain silent on the issue. Given the long history of denial of MCS and the well resourced efforts of the chemical industry to prevent recognition of MCS, it is extremely unlikely that such consensus will be achieved in the near future.

What is required from the Department of Health here is strong leadership in promoting the MCS debate and responsible information dissemination to the public, not vacillation and silence. Waiting for complete consensus before proceeding with any public education campaign is unacceptable.

This official mind-set of denial and inaction on emerging public health issues has been seen far too often. For many years the tobacco industry successfully denied evidence of links between smoking and cancer and the public is still waiting for adequate controls on smoking in public areas. Asbestos manufacturers knew as early as the 1940s that asbestos was linked to lung disease but it has only been in recent years that adequate controls on asbestos were introduced, and only then because of the actions of those people affected by asbestos related diseases.

The Department of Health should be reminded that there is still no complete medical consensus that HIV is the cause of AIDS and we have seen the results of the "waiting for consensus" strategy in recent years in Africa, where governments have denied their people access to life saving antiviral medications on the basis that HIV might not be the cause of AIDS.

The public has a right to be accurately informed of the MCS debate so that people can make their own choices as to whether they wish to be exposed to chemicals associated with MCS. Medical education on MCS is also urgently needed as people with MCS need access to informed medical services, instead of being shunted from one ignorant practitioner to another during their prolonged medical odyssey. A broad education campaign on MCS is vital if this is to occur.

This recommendation should be fully supported by Government.

3. That DH 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.

The Government's Response:

Supported

The Department will convene an MCS Reference Group. PIRSA and the EPA have indicated to DH their willingness to participate in this group.

The Rebuttal:

The MCS Reference Group should be convened as soon as possible within the first six months of 2006 and its Terms of Reference clearly outlined. It is vital that membership of the group includes people who actually live with MCS and that the group operate under MCS disability access principles.

Although the establishment of an MCS Reference Group is a progressive step forward, simply continuing to discuss MCS is not sufficient to address the problem.

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

The Government's Response:

Supported

PIRSA will continue to provide assistance to all citizens reporting specific incidents of chemical trespass, including people with MCS, through investigation of the reported trespass incidents and provision of information and advice.

The Rebuttal:

While support for the continuance of PIRSA's Chemical Trespass scheme is welcome, this recommendation does not go nearly far enough to protect the public from chemi-

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cal exposures associated with initiating and exacerbating MCS, notably pesticides. Current arrangements with respect to incidents of chemical trespass are principally reactive and do little to pro-actively prevent the serious problem of involuntary chemical exposures. What is actually needed here is pesticide legislation requiring mandatory prior notification of pesticide applications to a register of people with MCS, or others who wish to be informed of possible health risks caused by other people's use of chemicals. Penalties must apply for failing to notify.

An example of how current pesticide standards and associated legislation have failed to protect people with MCS was reported to the SA Task Force on MCS around Christmas 2005. A mother and her young child, both of whom suffer with severe MCS, were made extremely ill and forced out of their home due to their neighbour's failure to notify commercial pesticide use, as previously agreed. All attempts by the mother to secure state assistance for emergency MCS accessible accommodation failed. The mother and child spent their Christmas alone, on an isolated property, with no amenities, in a tent ripped by gale force winds, as they could not return to their pesticide contaminated home without experiencing severe sensitivity reactions. This situation is blatant and immoral human rights abuse.

Government must introduce prior notice pesticide legislation.

5. That the MCS Reference Group convened by DH 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. This would include identifying current best practice models of No-Spray Registers among Councils to inform the reference group's best practice guidelines.

The Government's Response:

Supported in principle

The Department is aware that some Councils have already commenced no-spray registers, and so would draw on the experience of those Councils in expanding such a program.

The Rebuttal:

The Department of Health has pointed to the fact that some Councils have already established No-Spray Registers and intends to build on existing experience to expand such programs.

The Government should be aware that any existing arrangements with Councils for No-Spray Registers are not based on any acknowledgement of the health problems associated with herbicides but merely offer residents the opportunity to be responsible for the maintenance of the footpath weeds directly outside their property in exchange for an agreement not to spray herbicide in that area. These no-spray agreements are frequently breached by Council contractors, who have no training in MCS and who are educated to believe that herbicides are safe for everyone when used as directed.

People with severe MCS have reported serious and potentially life threatening herbicide sensitivity reactions when Councils spray herbicide up to one kilometre or more from their homes. These people are often being forced to relocate during and shortly after their Council's herbicide activities. People with MCS also report severe herbicide sensitivity reactions from using public areas that have been treated with herbicide up to five days prior. At present there is no recognition of the breach of basic human rights this situation represents. If Councils are benefiting economically from their use of what they claim is relatively inexpensive herbicide, then the rights of people with MCS to enjoy the amenity of their own homes and to safely access public areas must be recognised in order that they can be protected and adequately compensated for any losses.

No-spray arrangements with local Councils must take the above factors into account. Furthermore, the need to routinely spray herbicides in residential areas must be questioned. The Social Development Committee found evidence that the herbicides used by Councils are associated with MCS. The Committee described these herbicides as "particularly pernicious" for people with MCS and recommended No-Spray Registers. However, if these chemicals are so noxious to a minority of the population to require no-spray registers, why are they being routinely sprayed in our streets and parks?

The wider community is increasingly intolerant of chemical herbicide use in public areas. On Dec 2, 2005, a public health protest rally was held outside Local Government House calling on the Local Government Association and all local Councils to end the routine use of herbicide in residential areas. This event marks the beginning of a con-

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tinuing community campaign for more responsible herbicide use by local government.

This recommendation should be fully supported by Government, together with ending the routine use of herbicide in residential areas.

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 to chemical use, as outlined under Control of Use legislation.

The Government's Response:

Supported

PIRSA already works with organisations and individuals to implement best practice in chemical application including legal obligations under the Agricultural and Veterinary Products (Control of Use) Act 2002. This work will continue as an integral component of ongoing efforts to improve the management of chemical applications risks generally.

Local government is a significant user of pesticides either directly or through contractors for pest and weed control. PIRSA staff regularly contact Council planners, Environmental Health Officers and Animal & Plant Control Board Officers on a range of pesticide use issues.

Best practice in relation to no-spray registers is proposed for consideration by the MCS Reference Group (Recommendation 5). The results of the deliberations of the Reference Group can flow through to Councils by various means, directly to individual Councils or to Councils as a group via the Local Government Association.

The Rebuttal:

While support for this recommendation is welcome, it must be acknowledged by government that existing standards in chemical regulation have failed to adequately protect public health or the basic human rights of the minority with MCS. In most cases Councils are already using best-practice

guidelines for herbicides, with their contractors' use of herbicide being overseen by the Department of Health.

Continuing reliance on failed best practice guidelines is an integral part of the MCS problem. A new paradigm of chemical regulation which recognises chemical sensitivity as the serious public health problem it has become and which reduces overall human exposure to toxic chemicals is urgently required. Governments at all levels must be actively involved in these necessary chemical reforms.

- 7. That the DH 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.

The Government's Response:

Supported in principle

This recommendation poses some difficulty, as the lack of consensus on chemical causation means that improving access to public facilities for MCS sufferers may not be as simple as reducing chemical exposures voluntarily or legislatively. Nonetheless, institutions would need to be made aware that some MCS sufferers do have specific needs.

DFC, through the Client Services Office (CSO), is keen to address the disability access issues faced by people with disabilities in relation to public facilities and services in the community. However, MCS does not fall within the scope of disability for this purpose since DFC currently regards MCS as a chronic medical condition, as opposed to a disability.

People affected by MCS would not appear to benefit from the wide range of disability services which are currently offered by DFC. These being respite services, independent living training, accommodation services, therapy services, home care and family support services, etc. Indeed, in addressing disability access issues as stated in this Recommendation, the expertise of DFC is, in the main, addressing issues arising from people's physical, cognitive, neurological and sensory impairments and relate mainly to making modifications to physical environment through the fitting of rails, ramps, hearing loops, easy-read signs, etc. These are not the same access issues which are faced by MCS sufferers.

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The Rebuttal:

While giving in-principle support to this recommendation the Department of Health then attempts to back-pedal with claims that “the lack of consensus on chemical causation means that improving access to public facilities for MCS sufferers may not be as simple as reducing chemical exposures voluntarily or legislatively”. While acknowledging that “institutions would need to be made aware that some MCS sufferers do have specific needs” the Department then seeks to deny people with MCS disability status and the need for a broad MCS disability access strategy across its services.

It is not acceptable that the Department of Health attempt to stall social action on MCS solely on the basis of official uncertainty regarding the exact causes of the condition. There are now numerous clinical studies which have concluded that avoiding chemical exposures is the most effective treatment for MCS. Some people with severe MCS may have extreme intolerances to very low levels of exposure which makes accommodating their needs difficult. However, people with MCS generally agree that any reduction in chemical exposures is of benefit. Products identified as commonly triggering symptoms of MCS include, cleaners, pesticides, tobacco smoke, fragrances, new building materials, volatile solvents and petrochemicals. Offering people with MCS reasonable access to services by limiting and controlling those products associated with MCS is not impossible. What is required from authorities is a committed determination to undertake this task.

The Response states that the Department of Families and Communities “is keen to address the disability access issues faced by people with disabilities in relation to public facilities and services in the community. However, MCS does

not fall within the scope of disability for this purpose since DFC currently regards MCS as a chronic medical condition, as opposed to a disability.” Clearly the Department of Families and Communities is actively discriminating against people with MCS by attempting to deny them disability status.

In its opening General Comments the Department of Health acknowledges that “it is evident that MCS leads to morbidity in some people and may represent a significant cost to society”. It is, therefore, difficult to understand how the Department of Families and Communities justifies its position that a “chronic medical condition” leading to “morbidity” does not result in disability. This attempt by the Department of Families and Communities to exclude people disabled with MCS from access to its services is reprehensible and based on economic rather than medical considerations. With respect to recognising MCS as a disability the 1996 New Mexico, USA, Senate Inquiry into MCS, which was undertaken by the Governor’s Committee on Concerns of the Handicapped, made the following comments:

One concern raised to the Committee was that it would be a costly and improper expansion of benefits to imply any legitimacy to the concerns of persons experiencing MCS especially to accept it as a “disability”. We find this argument a distraction and based on an assumption with which we take great exception. Accommodating persons with disabilities is not a great expense and is well justified by the advantage both to the person with a disability and the accommodator in that a fuller spectrum of society is served. Even if one is considered to have a “disability” there is no automatic right to any benefit: the disability must prevent

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work to obtain social security benefits, it must affect mobility to get a parking placard, and it must "substantially limit a major life activity" to be entitled to accommodation. Further the accommodation must be reasonable and not considered a personal service. These determinations are made on a case by case basis and it is the functional limitation, not the title given the condition, that determines medical necessity, a precondition to any medical benefits.

Below is an incomplete list of South Australian organizations that have agreed to adopt specific MCS disability access strategies to date, either as general policy or for specific events and circumstances.

- Adelaide City Council
- AIDS Council of South Australia
- Art Gallery of South Australia
- Australian Democrats
- Australian Greens
- Barossa Meats
- Bear Men of Adelaide
- Catholic Church of the Holy Name
- Department of Health
- Department of Primary Industries and Resources
- Disability Action
- Disability Advocacy and Complaints Service of SA
- Disability and Rehabilitation Professionals' Association
- Disability Information Resource Centre
- Feast Festival
- Health Consumers Alliance
- Local Government House
- ME/Chronic Fatigue Syndrome Society of SA
- Onkaparinga City Council
- People Living with HIV/AIDS
- Pilgrim Uniting Church
- Pocketwomen
- Royal Adelaide Hospital
- South Australian Task Force on MCS
- South Australian Tourism Commission
- South Australian Housing Trust

These strategies generally focus on fragrances, pesticides, cleaning products, building and maintenance products, tobacco smoke, vehicle exhaust, maintaining indoor air quality and prior notification and signage where toxic products are in use.

There are now numerous models of MCS disability access policy available. One good example is from the Job Ac-

commodation Network (JAN), a service funded by the Office of Disability Employment Policy of the US Department of Labor. JAN's publication "Worksite Accommodation Ideas for Individuals Who Experience Limitations Due to Chemical Sensitivity or Environmental Illness (EI)" can be accessed at www.jan.wvu.edu/media/MCS.html.

The Department of Families and Communities claims that "People affected by MCS would not appear to benefit from the wide range of disability services which are currently offered by DFC. These being respite services, independent living training, accommodation services, therapy services, home care and family support services, etc. Indeed, in addressing disability access issues as stated in this Recommendation, the expertise of DFC is, in the main, addressing issues arising from people's physical, cognitive, neurological and sensory impairments and relate mainly to making modifications to physical environment through the fitting of rails, ramps, hearing loops, easy-read signs, etc. These are not the same access issues which are faced by MCS sufferers."

For obvious utilitarian and commercial reasons the chemical industry has been keen to ensure that MCS is not recognized as a disability. Unfortunately, governments have too often been complicit in this aim. The Department of Families and Communities should be aware that the Human Rights and Equal Opportunity Commission and the Equal Opportunity Commission recognise medically diagnosed MCS as a disability under the state and commonwealth legislation. If refusing to recognize chemical sensitivity as a legitimate disability is truly the current position of DFC, it would be interesting to see this position challenged in the courts.

It is very hard to see how people disabled with MCS might not benefit from the range of disability services offered by DFC, provided appropriate MCS disability access accommodations were also made available. This attempt to exclude MCS as a disability by DFC is another clear example of the institutionalised discrimination facing people with MCS. The Department must develop a more constructive position that includes the disability needs of people with MCS. The Minister for Disabilities must clarify DFC's position on the status of MCS as a disability. Non-acceptance of MCS as a disability is not acceptable to people living with MCS and a growing proportion of the wider community, including the disability sector.

This recommendation should be given full and unqualified support by Government.

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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 Government's Response:

Supported in principle

Many issues around MCS will require national leadership and commitment to funding in the areas of aetiological research, development of diagnostic and clinical management guidelines, and understanding of national prevalence and trends.

The Office of Chemical Safety within the Commonwealth Department of Health & Ageing is in the process of conducting a major review on MCS. The findings of this review will be important for informing an agenda item for AHMAC. DH will respond to the findings of this review as appropriate.



The Rebuttal:

Without a clear commitment from government to develop an MCS research agenda together with a constructive position on MCS this issue will continue to flounder, with the response to the problem being developed primarily within the community.

Pamela Reed Gibson's comments in "Understanding and Accommodating People with MCS in Independent Living" are enlightening in this instance:

It is expected that many more people will develop MCS in coming years due to environmental contamination. Many of the people in my study have had MCS for decades (the average time was 15 years). Therefore, if MCS is environmentally caused, many people suffered their initial sensitizing exposure many years ago. How many more people are developing MCS now as a result of increasing air, water and food contamination? And events such as the World Trade Center destruction set up large portions of the population to develop environmentally induced illnesses that may or may not develop into MCS. It is crucial that our institutions recognize and respond to the plight of these people in order to be positioned to help the increasing numbers who will request help. However, I do not expect that this recognition will begin in the hierarchical/professional institutions such as universities and medical centers, but rather in grassroots types of settings where people have ongoing contact with people with the problem. The MCS support groups have begun the fight for recognition of this disability. Centers for independent living are perhaps the next level where this work can continue with your help.

South Australian communities are already responding to MCS without the support of government agencies. This situation will result in growing political pressures if governments continue to ignore the MCS problem.

The Office of Chemical Safety has indicated that its review of MCS, which is scheduled to be completed before the end of March, 2006, will seek to move beyond the entrenched position of official denial evident in the current MCS debate towards a more pragmatic approach. OCS expects to work collaboratively with the state Department

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of Health in bringing MCS to the attention of the Australian Health Minister's Advisory Council.

This recommendation should be fully supported by Government.

9. That the DH:

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 DH 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.

cluded in the membership of the hospital protocols Working Group and that community organisations supporting people with MCS and medical clinicians experienced in the care of patients with MCS be closely consulted in the development of any MCS hospital protocols. The expressed needs of people with MCS must be central to the protocol, which must not be hindered by medical claims of "lack of consensus".

The Minister for Health is called on to provide accurate timelines with respect to the formation of the MCS hospital protocols Working Group.

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.

The Government's Response:

Supported

This will require cross-portfolio coordination. DH will convene a Working Group to develop consistent protocol and procedures for dealing with MCS sufferers in hospitals.

The Rebuttal:

The Department of Health has agreed to convene a Working Group "to develop consistent protocols and procedures for dealing with MCS sufferers in hospitals." The challenges in achieving MCS hospital protocols should not be underestimated, particularly when faced with the intransigence of the medical establishment with respect to understanding and recognising MCS. Again, the comments of the New Mexico Senate Inquiry into MCS from the Governor's Committee on Concerns of the Handicapped are informative:

One principle not well accepted in the medical community but highly regarded by the Committee is to respect the wishes of the individual to the extent possible. Persons with physical disabilities are usually the best judge of what they want and need. We do not need a bureaucrat or social worker to tell us "what is best for us" even though many programs still use this service model.

It is vital that people who actually live with MCS be in-

The Government's Response:

Not supported at this time

DH is already supporting moves to establish Working Groups and review teams under Recommendations 3 and 9.1.

The Rebuttal:

In rejecting this recommendation the Department of Health has stated that it "is already supporting moves to establish Working Groups and review teams under Recommendations 3 and 9.1.", which relate to the establishment of an MCS Reference Group "to maintain ongoing communication and provide up-to-date information on developments in the MCS debate" and the development of MCS hospital protocols "to provide greater access to chemically sensitive patients requiring medical services."

It is highly inconsistent that the Department of Health should support measures to assist people with MCS to access hospitals, yet has refused to consider developing similar protocols in other areas of health care. People with MCS often avoid hospital based services due to the fact that they are highly chemically polluted environments. Frequently the most appropriate health care services for people with MCS are those that are provided at home or in the community. Without MCS protocols these services are difficult and sometimes impossible to access. To refuse people with MCS with proper assistance with access to non

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-hospital based health care is to endorse the continuing institutionalised discrimination against people with MCS. As a matter of social justice and equity, MCS disability access protocols must be developed for community-based health care services. Even relatively simple strategies such as fragrance controls would be of significant benefit.

The Minister for Health must explain why the Department of Health is seeking to exclude people with MCS from equitable access to health care services that are not hospital based.

This recommendation should be fully supported by Government.

10. That the relevant State Government Ministers:

- 10.1 lobby 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 ensure that local Councils are informed of the findings of Federal Government research on alternative measures for weed control.
- 10.3 lobby 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 to chemical use, including the adequacy of health and safety labelling information on chemicals associated with MCS.

The Government's Response:

Supported in principle

As an initial action in support of this recommendation, DH will refer the SDC report to the Office of Chemical Safety and the Australian Pesticides & Veterinary Medicines Authority for their consideration. It should be noted that chemicals other than herbicides are causally related to MCS by MCS sufferers.

PIRSA will refer the SDC report to the Co-operative Research Centre for Weed Management for their consideration.

The Environment Protection and Heritage Ministerial Council has initiated the development of a national chemicals framework to provide guidance on better and more consistent management of chemicals in Australia. This includes pesticides, industrial chemicals, chemicals in food and therapeutic substances.

The Rebuttal:

The Department of Health has stated that: "It should be noted that chemicals other than herbicides are causally related to MCS by MCS sufferers." In making this statement the Department appears to dismiss as mere hearsay amongst people with MCS the numerous studies across North America and Europe that have consistently pointed to a range of chemicals initiating MCS. The subtext from the Department here is that MCS is some kind of Pavlov's dog reaction, with people with MCS "training" each other to react adversely to chemicals through a conditioned response. This position is absurd and has no basis in fact.

With respect to the causes of MCS, the Social Development Committee found research based evidence that "herbicides, such as Glyphosate, pesticides, solvents and sterilisers, have been associated with the condition" and described the herbicides used by local Councils as "particularly pernicious" for people with MCS.

Local Councils have responsibilities under the Public and Environmental Health Act, Sect 17, which states:

PUBLIC AND ENVIRONMENTAL HEALTH ACT, 1987 – Sect 17

Control of Offensive Activities

- 17 (1) If an activity:
- (a) gives rise to a risk to health, or
 - (b) results in the emission of offensive material or odours, the authority may, by notice in writing to the person responsible for the activity, require that person to desist from the activity or to observe requirements stipulated in the notice in relation to the carrying on of the activity.
- 17 (2) A person who, without reasonable excuse, fails to comply with a notice under subsection (1) is guilty of an offence. Penalty: Division 5 fine. Expiation fee: Division 6 fee.

In Canada, where MCS is widely recognised, local government bans on both the public and private use of pesticides

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and herbicides have been supported by the Canadian Supreme Court under similar legislation to the Public and Environmental Health Act. However, the Local Government Association has advised that, with respect to the use of herbicides, it intends to ignore the MCS problem and "continue to ensure compliance with State and Federal requirements". This position is totally unacceptable to people with MCS. The continued use of herbicides in residential areas by local Councils in Australia cannot be justified by referring to failed standards in chemical regulation. The practice of routinely spraying herbicides widely across residential areas is not safe for a significant percentage of the population and must be discontinued. It is only a matter of time before people with MCS start taking legal action against local Councils for compensation for damages under common law.

There is no reason why local governments in Australia cannot immediately enact pesticide reforms similar to those seen in a growing number of international jurisdictions. Although Councils and others might benefit from formal research into alternative weed controls, people with MCS and those who might be at risk need immediate protection from the herbicides used by local Councils. Safer and relatively cost effective alternatives to chemical herbicides are already available, including the use of steam. What is absent here is the political motivation to address the problem. The Government must strongly support community initiatives to end the routine use of herbicides in residential areas by local Councils.

With respect to any review of the current chemical regulatory structure, in the face of the failure of this system to protect people with MCS and those at risk, local and state governments cannot abrogate their public health responsibilities. Any national review of chemical regulation must be accompanied by the development of MCS prevention, disability access and health care strategies that respect the right of people with MCS to safely access services and public spaces.

The Office of Chemical Safety has advised that the Environment Protection and Heritage Council's initiative for improved management of chemicals in Australia is still in development. However, people with MCS have not been consulted at any stage of this initiative and it is unlikely that their needs will be included in the outcome. This situation will not be tolerated by people with MCS whose health and safety must be seen as central to any regulatory reforms.

This recommendation should be fully supported by Government.

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.

The Government's Response:

Not supported at this time

While it is recognized that some MCS sufferers require equipment such as air/water purifiers, oxygen and respiratory masks, these aides are outside the scope of assistance provided by the Department of Families and Communities (DFC) through the Independent Living and Equipment Program. Discussion under Recommendation 7 outlines the current rationale for DFC support of people with disabilities. This Recommendation 11.1 largely falls outside the domain of the Minister for Disability.

This Recommendation would best be revisited subsequent to the outcomes of the review mentioned in Recommendation 8. As with most of the proposals from the Social Development Committee regarding MCS, progress relies heavily on whether MCS can be defined as a bona fide medical condition with consensus aetiology, diagnosis and treatment.

The Rebuttal:

The Department of Families and Communities' position of denial of MCS as a recognised disability is outlined in its response to Recommendation 7. In refusing to support Recommendation 11.1, the Department denies people with MCS equitable access to health care services and the use of equipment that is vital to their health and welfare. Again we see DFC endorsing the continued discrimination against people with MCS and it would be interesting to see the Department's position challenged in the courts.

11.2 That the DH consult with existing service providers such as the Southern Chronic Illness Links Network, with regard to extending its existing support services for people with chronic illnesses to support people with MCS across South Australia.

The Government's Response:

Not supported

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As MCS is not recognised as a defined medical condition in Australia, DH is unable to extend its stretched resources to assist MCS patients at the loss of assistance to sufferers of recognised diseases.

The Rebuttal:

In rejecting this final recommendation the Department of Health made the following statement: "As MCS is not recognised as a defined medical condition in Australia, DH is unable to extend its stretched resources to assist MCS patients at the loss of assistance to sufferers of recognised diseases."

This statement is an example of why people with MCS and their supporters are regularly protesting on the steps of

Parliament House and elsewhere. The Department of Health's position on MCS is reminiscent of that surrounding chronic fatigue syndrome, prior to its formal recognition, where people severely disabled and often bedridden with CFS were cruelly denied assistance to access basic aids such as wheel chairs on the basis of their diagnosis. Clearly the Department has learnt nothing from this past experience.

The Department's final comments on the validity of MCS are highly offensive and discriminatory and do nothing to progress the debate or address the problem. The Minister for Health must apologise for these comments and ensure that people with MCS are provided with equitable access to services.

This recommendation should be fully supported by Government.

The Community Rebuttal: Conclusion

The official MCS debate is most often couched in medico-scientific terms. In fact, although a more complete scientific understanding of MCS is vital, the MCS dilemma is fundamentally a human rights issue. The emergence of MCS can be compared to that of HIV/AIDS, particularly during the early years of the epidemic. In his presentation to the Consumer Health Forum's Continuing Consumer Representative Training workshop, Peter Canavan, the National Treatments Portfolio Convenor of the National Association of People Living with HIV/AIDS, made the following comments on consumer participation:

I want to start with a particular notion which sometimes gets called "centrality of HIV people", but which really just means HIV positive people being seen as crucial to the decisions which will affect our health and our lives: in policy, in research, and in the doctor's surgery.

Early in the epidemic, people with HIV coined the phrase "talk to us, not about us". There had been a lot of "talking about". In the media, people talked about us as either dying, "innocent victims", or potential threats and dangers to public health and morality. At scientific conferences, people talked about us as a puzzling set of diseases and infections, but also as a kind of career move – solve "positive people", and you might get the Nobel prize.'

After a while, positive people, sick of being

talked about, decided to intervene with an unambiguous message; these are our lives, our bodies, and our choices. So talk to us as if we matter. We are the reason you are here. In many ways, this approach has been the enduring hallmark of our response as HIV positive advocates. That it should be we, the people living with HIV and AIDS, who, where possible, represent ourselves to government, in clinical research, or around any other table where significant decisions affecting our lives and health are likely to be taken".

People with MCS have been marginalised, excluded and treated with indifference for too long by governments, by chemical regulators, by healthcare services. If authorities wish to understand and solve the phenomenon of MCS they must begin speaking directly with the people who are most closely affected by the problem; that is people who actually live with MCS. For decades people with MCS have been bullied and forced by governments, under an oppressive system of chemical regulation, to endure sickening and disabling chemical exposures in order just to live. This situation will no longer be tolerated and governments must now understand that the inclusion of people with MCS must become central to any decision making process that affects their welfare, health and lives.

Accordingly, people with MCS call on the South Australian Government to give its full and unqualified support to all of the recommendations of the Social Development Committee Inquiry into MCS.

Studying – CFS/ME style

The following article, originally entitled "Dealing with the effects of brain fog," is by **David Lindsey**, and deals with the problems of studying while suffering with CFS/ME. It is taken from Meeting Place, the quarterly journal of the Associated New Zealand Myalgic Encephalopathy Society Inc.

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Talking Point – 2006 Issue 1

One of the things that makes study difficult for people with CFS/ME is that it operates to a schedule. Assignments have to be done on time, lectures are held regularly and inflexibly, presentations have to be given on the appointed day and time and exams are sat at the prescribed time whether you are feeling up to it or not. This is difficult both physically and mentally. For me, brain fog prevents me from operating at my best in an environment that is intellectual by definition.

Because sometimes I am feeling well and other times I am not, my performance fluctuates. In off-times I am often mistaken for being lazy, unco-operative or disinterested, but it is simply because I can't use my brain in the required fashion. I am judged in this manner all the more so because in my on-times I am known to be an exceptional student.

My brain fog prevents me from stringing concepts together. This means that I can't think things through very easily and also I can't follow conversations because I lose the thread of the argument. My responses are slow, sluggish and dull. Brain fog also impairs my memory so that I can't remember what was just said, what was actually meant, or what I wanted to say myself!

Brain fog is very frustrating, knowing that you can do so much more than you are tries my patience, but I have had to just accept the situation and work within it. It is, of course, impossible to say how much my grades have suffered, but it is clear that they must have.

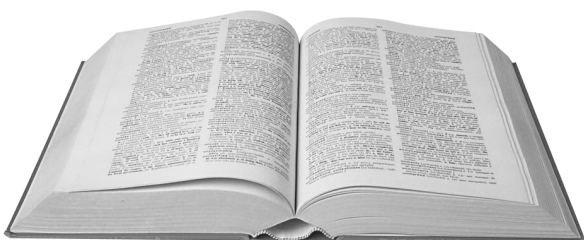
It has taught me to be thankful for what I have, however, and never to take good health for granted.

To cope with this situation, the strategies I have adopted are:

- Working like crazy when I feel well in order to make up for the times I'm not. I'm not sure if this is a good idea in the long term, but CFS/ME makes me want to overcome the odds and show everyone I can do it.



- Placing a lot of emphasis on relationship building rather than just on academic performance. This means getting to know the lecturer so that it is known that I am interested and not lazy, even when I am having an off day.
- Doing assignments at any time of the day or night when I feel up to it, not just when most people would do them. For me, the early evenings are a good time, although I have been known to write great essays at 3am!
- Having an alternative activity to go to when my brain is not up to the task I have set myself. This might be something in the garden, a chore around the house, reading a novel or walking the dog – hard for someone who is physically weak, I know, but whatever you can cope with at the time – do that. Come back to the study later when the fog has cleared a little.
- Making sure I start assignments well in advance so that I have plenty of 'up-times' to get it done; being well prepared for oral presentations, etc.
- Persevering – knowing that the bad times come when everything seems too much and being able to ride it out and wait for it to pass. Remember that others have been through it too and have succeeded.
- Relaxing – enjoy the journey as much as the destination. Know that your worth does not depend upon your success. Doing your best is succeeding.
- Looking after myself physically, including staying warm, eating a healthy diet.
- Having supportive family, spouse, friends, etc. is very helpful. Having a buddy to share with is also helpful. Being a member of a CFS/ME Society and/or support group is also important so you know you are not alone.



A carer's perspective

By **Roderick Floud**.

M.E. (CFS/ME) is a painful and frightening illness. Torn from normal life, unable to do the simplest tasks, someone with M.E. has to come to terms with the lack of knowledge about why it has happened, how long it will last and whether it will ever be over.

The impact on a carer is different, but still acute. As my wife and daughter near recovery after respectively 11 and 14 years with M.E. I remember bewilderment, anger, resentment, helplessness and isolation, all stemming from love, concern and confusion about the disease and its treatment. It is not, I imagine, like caring for someone who has a condition, chronic or even life-threatening, which is well-explained in the textbooks.

When reassurance begins to wear thin

In some ways caring for an M.E. patient is like caring for anyone who is ill. One gives physical and emotional support, takes over childcare or household duties and explains what is wrong to friends and colleagues. But one difference is the way that M.E. usually begins as a viral illness from which recovery is slow and uncertain.

Most people soon despair of recovery from a virus; aches and pains seem endless. The carer has to reassure, soothe and be confident that it will soon be over. So caring for M.E. begins with reassurance, encouragement and optimism. But as the days turn into weeks and weeks into months, reassurance begins to wear thin. The patient ceases to believe it and so does the carer.

My wife tells me that my daily enquiries as to how she was feeling and my promises that she would improve both upset her. She felt that I was expecting an improvement; she felt guilty that she could not tell me what I wanted to hear. Rather than my reassuring her, she was helping me by looking on the bright side; this was exhausting and emotionally distressing.

Hope alternated with despair

The slow onset of the disease is magnified by the uncertain outcome. Most people with M.E. recover to some extent, but we do not know to whom, when, or by how much recovery will occur. The carer is therefore in the same limbo as the patient. I shared the constant search for new remedies, the thoughts about practical ways of alleviating the condition and the usually unspoken question: "Why me?" All lead to a kind of roller-coaster existence; hope alternates with despair.

Even sympathy is a problem. As I knew how terrible an existence it was for my wife and daughter, I often found it hard when people said, "But it must be awful for you". Worse, of course, was any implication that Cynthia and Sarah had brought the illness on themselves. But perhaps, as a man, I found sympathy of any kind hard to take.

Caring for people with M.E. can be very hard. Here are some practical and emotional hints:

- Ask for or, if you can, buy help. I tried for a long time to cope, as one might with another illness, rushing home from work to cook and look after the house. I did this for too long. I was fortunate to have a high income and could buy assistance, but one should enlist relatives, friends and neighbours to help.
- Talk about it, both to the person you are caring for and to others. It helps to relieve the emotional pressure which builds up inside. Everyone should be told about M.E. to dispel all the myths and prejudices.
- Explore state benefits to get financial help. The carer is vital in this; someone with M.E. can easily be too ill to fill in the forms and explain how sick they really are. I

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The Shed

By *Mary Campbell*.

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I'd been looking forward to it all week: putting up the shed. The idea took me back to my childhood on the farm, to the feeling of creating something with my own two hands. There was something immediately satisfying in the product of physical labour, a sense of achievement, of making something needed and useful.

The day began with a takeaway breakfast and then a drive in the country. The winter air was oddly warmer once we reached the property. We began on the foundations and the frame. I helped move the shed up the slope about 100m. From then on I managed to keep busy by helping hold things steady and giving advice and suggestions because no one else had put up a shed before. Meanwhile others did the hard digging, hammering and cutting with the saw.

The weather, while warmer than in town, was cold. There was an unrelenting icy wind. Lunch came and went.

I was filling in trenches with dirt to make them level when my body decided to give out. At first I thought it would pass. I found a patch of sun and lay down. On the uneven ground with leaves and twigs underneath I tried to relax and watch the clouds. Casey came by to ask if I was okay. "Yeah, I'm fine", I answered. I lay a bit longer. But while the sun was warm, the wind still whipped my skin. My body ached as I stood up and walked to the car. I noticed there were tools on the seats, measuring tape, hammer and esky. It seemed like far too much effort to try and move

them all, plus, what would happen if someone wanted to use them? So I walked to the other vehicle, same thing, only this time jumpers and bags and water. I closed the door, and turned to find Casey by my side. "What's up mate? You alright?" He asked. "I'm not feeling so good, I'm kinda crashing." "How about we lie you down in the car. We'll roll the seat back and you can rest for a bit until you feel better?" He cleared the seat and pushed it back.

So I rested. At first I lay there angry with myself, for not being able to keep going. Wishing I was healthy again, thinking back to when I could keep up with the rest of them, and feeling useless. Here I was lying down while there was work to do. But although the shed was important to me, it wasn't worth risking my health for. I slept for a couple of hours and woke to the car door opening "Just grabbing more screws. How are you feeling?" Brodie asked. "I'm better than I was..." I assured him. "But not quite up to getting back out there," my head throbbed. "Want me to drive you closer to the action?" He asked. Everyone was joking as they worked.

As I was driving home that evening Brodie sent me a message. "Hey Mary, thanks for all the help and advice you gave us today. We couldn't have done it without your brains and girl power. Thanks again. – Brodie."

Mary Campbell © 2005



Finally, it's official – stress makes you sick



Australian scientists have proved what many people have suspected for years: stress makes you sick.

Researchers at Sydney's Garvan Institute have discovered that a hormone known as neuropeptide Y (NPY), often released during times of stress, can stop our immune system functioning properly.

The institute's associate professors Fabienne Mackay and Herbert Herzog said their findings, published in the *Journal of Experimental Medicine*, prove a link between the brain and the immune system.

The research paved the way for understanding and preventing stress-related colds, flu, depression and even cancer, they said. "Until now there has mostly been circumstantial evidence of a link between the brain and the immune system, but now we have that connection," Professor Mackay said.

"During periods of stress, nerves release a lot of NPY and it gets into the bloodstream, where it inhibits the cells in the immune system that look out for and destroy pathogens (bacteria and viruses) in the body."

The research also opens the door for new opportunities for therapeutic intervention.

"This discovery will be vital in helping us develop a whole new generation of drugs that can stimulate immune defences in people who have high levels of stress," Professor Mackay said.

Under extreme periods of stress, the NPY hormone can also stop TH1 cells (also known as "helper" cells) from attacking bacteria and viruses, she said.

Professor Mackay said exploiting this TH1 inhibitory mechanism to prevent immune responses getting out of control would be essential in responding to diseases including rheumatoid arthritis, multiple sclerosis, Crohn's disease, type one diabetes and lupus.

But she said medication could take years to develop and there was a lot more to understand about stress and its effect on the immune system. "In the meantime, it is important that we understand how bad stress is for all of us," she said. "The best thing to do is to remove stress from our lives just by reorganising the way we live, changing our lifestyle and using things like yoga and relaxation to the best of our ability."

Medical Editor's Comments:

This has been reproduced from The Age newspaper, November 2005. Another link in the fascinating psychoneuroimmunology puzzle!

Reprinted with permission from Emerge, Autumn 2006, with special thanks to Emerge's Medical Editor, Dr Nicole Phillips.

The Ten Commandments for Reducing Stress

1. Thou shalt not be perfect or try to be.
2. Thou shalt not try to be all things to all people.
3. Thou shalt leave things undone that ought to be done.
4. Thou shalt not spread thyself too thin.
5. Thou shalt learn to say "NO".
6. Thou shalt schedule time for thyself and for thy supporting network.
7. Thou shalt switch off and do nothing regularly.
8. Thou shalt be boring, untidy, inelegant and unattractive at times.
9. Thou shalt not even feel guilty.
10. Thou shalt not be thine own worst enemy, but thine own best friend.

From: Diagnosing and Treating Chronic Fatigue Syndrome, September 2005, Dr Sarah Myhill: www.drmyhill.co.uk.

CFS redefined. Again.

Chronic fatigue syndrome – a clinical empirical approach to its definition and study. *BMC Medicine* 2005, 3:19; doi:10.1186/1741-7015-3-19. WC Reeves, D Wagner, R Nisenbaum, JF Jones, B Gurbaxani, L Solomon, D Papanicolaou, ER Unger, SD Vernon, C Heim. Article URL: www.biomedcentral.com/content/3/1/19.

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Researchers at the Centres for Disease Control and Prevention (CDC) and Emory University have published research supporting a new definition for chronic fatigue syndrome (CFS). Authors led by Dr. William Reeves of CDC propose a more objective approach to the classification of patients than any of the previous definition papers (Holmes, 1988; Fukuda, 1994; with “enhancements” published by Schluderman, 1991 and Reeves, 2003). Using assessment tools that quantify functional impairment and symptom occurrence, duration and severity, the research team was able to identify CFS patients with precision. The Medical Outcomes Survey Short Form-36 (SF-36), the Checklist Individual Strength (CIS), the Multidimensional Fatigue Inventory (MFI) and the CDC Symptom Inventory were used to document clinical status. Those subjects who met CFS case criteria (Fukuda) had significantly worse impairment, more severe fatigue and more frequent and severe symptoms than other subjects in the study who were ill but did not meet the CFS definition. The authors report that the CFS patients exhibited scores similar to patients with congestive heart failure.

The definitions and criteria for CFS have been scrutinised, critiqued and revised. Most definitions, including those published by groups in England, Australia and Canada, have been written by consensus panels of experts, most of whom see patients in tertiary or referral-based clinics. This latest definition will require validation by other groups and, ultimately, adoption by other investigators in the field before it can be considered to replace the 1994 definition. The study authors propose that this tool-based approach will be easier for clinicians to use in patient care settings and will aid in the comparability of research through the selection of more homogenous patient cohorts. They also suggest that these tools can be used to monitor the cyclic pattern of the illness and to assess response to specific interventions. The article was published on December 15, 2005 in the open access on-line journal *BioMed Central Medicine*.

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had to attend a social security tribunal to fight a decision to withdraw benefit because my daughter was too ill to appear herself!

- Try to keep your own job going; it can be a good distraction. Neither my wife nor daughter were ever quite wheelchair-bound, so I was never faced with making a choice between my job and caring. Steering a university through financial crises was stressful, but it was also different; it seemed to use a different part of the brain and to reduce the worry of the M.E.
- Be prepared for prejudice and to be wounded by the attitudes of others. I was deeply hurt to be accused by a colleague of putting my family before the university; I felt that I had tried to look after both. Hurtful, also, was the implication that Cynthia and Sarah were just depressed.

- Holidays are important. One of our worst mistakes was a holiday in the Alps where Cynthia and Sarah froze while I walked frenetically to shut out the emotional pain. But eventually we found a friendly hotel that was a haven for us all.

Above all keep hoping

Above all, one has to keep hoping but not turn that hope into pressure on oneself or on the sufferer. It is worth trying everything and I trust that, for you as for us, one treatment will turn out to be the one that works.

At the time of writing this article Roderick Floud was a provost of Guildhall University and president of Universities UK.

He is now president of London Metropolitan University.

This article taken from InterAction, the quarterly magazine of UK charity Action for M.E., September 2001.

Chronic fatigue gene signs found

Scientists believe they have pinpointed biological markers of chronic fatigue syndrome which could help develop a test and treatment for the condition.

From **BBC News**, 21/7/2005.

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CFS, or ME, makes people feel extremely tired, and can cause weakness, headaches, and disrupted sleep.

Scientists, now based at St George's Hospital, London, found differences in the way genes are expressed in white blood cells of people with CFS/ME.

But others say the *New Scientist* findings may not explain all cases.

It is also due to be published in the *Journal of Clinical Pathology*.

The scientists say their findings fit with the understanding that a virus, such as Epstein-Barr, may trigger CFS/ME because that illness might alter how genes are expressed.

CFS/ME often first appears as a flu-like illness, but does not then go away.

'Hijacked'

The researchers compared levels of gene expression in the white blood cells of 25 healthy people and 25 who had CFS using DNA chip technology.

They found differences in the behaviour of 35 of the 9,522 genes they analysed.

Further genetic testing showed 15 of the genes were up to four times more active in people with CFS, while one gene was less active.

Several genes the team pinpointed play important roles in mitochondria, the "powerhouse" of cells.

One of the products of these genes is EIF4G1, which is involved in the protein production in mitochondria.

EIF4G1 is hijacked by some viruses, so cells may compensate by increasing gene expression.

The genetic differences lead to changes in how blood proteins behave which could allow the development of a blood test for CFS, the team say.

Other genes are involved in regulating the immune system or playing important roles in nerve cells.

The team will now carry out further research on 1,000 CFS patients and healthy people.

Not 'made-up'

Dr Jonathan Kerr who led the research team, which is currently in the process of moving to St George's, said: "The involvement of such genes does seem to fit with the fact that these patients lack energy and suffer from fatigue."

He added the work could also potentially lead to a treatment for the condition.

"We have shown that a significant part of the pathogenesis resides in the white blood cells and in their activity

"It will open the door to development of pharmacological interventions."

Dr Russell Lane, a neurologist in Charing Cross Hospital, in London, said: "This exciting new work shows that some aspects of this complex illness may be understandable in molecular terms, and that CFS is not a 'made-up' illness."

Chris Clark, chief executive of Action for ME, told the BBC News website: "The prospect of having a diagnostic test is very encouraging because many people with ME can currently take well over a year to find out what is wrong with them."

Dr Neil Abbot of Merge, a charity which funds research into CFS/ME, said: "CFS/ME can have very different effects on patients.

"We're not looking at just one condition with a definitive patient group.

"So it might be hard to get a gene signature which works for everyone, but it is still very interesting."



Information about ME/CFS

What is ME/CFS?

Myalgic Encephalopathy/Chronic Fatigue Syndrome (ME/CFS) is characterised by **severe, disabling fatigue and post-exertional malaise**. Fatigue is just one symptom – there are a multitude of others. ME/CFS is a not uncommon medical disorder that causes significant ill health and disability in sufferers.

Myalgic Encephalopathy/Chronic Fatigue Syndrome (ME/CFS) is also known by other names such as Post Viral Fatigue Syndrome, Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) and Myalgic Encephalomyelitis.

It is now officially recognised by the World Health Organization International Classification of Diseases and by recent international and Australian guidelines on ME/CFS.

Prevalence

ME/CFS affects all social and ethnic groups. There is a predominance of females (2 to 1) and a bimodal distribution with peaks between 15-20 year olds and 33-45 year olds. The prevalence of ME/CFS varies between 0.2% and 0.5% of the total population. In South Australia this translates to between 3,000 and 7,000 cases at any one time.

Main characteristics of ME/CFS

Disabling fatigue for at least 6 months, along with cardinal symptoms such as:

- muscle aches and pain;
- unrefreshing sleep or altered sleep patterns;
- neuro-cognitive dysfunction (e.g. poor concentration and memory);
- gastro-intestinal symptoms (e.g. irritable bowel);
- orthostatic intolerance (e.g. low blood pressure);
- and unusual headaches.

A hallmark of the condition is that symptoms are usually **worsened** with minimal physical and mental exertion.

Diagnosing ME/CFS

Note that there are many *other conditions* which may need exclusion by your doctor before a diagnosis of ME/CFS may be made. These include, Hypothyroidism, Hyperthyroidism, Diabetes Mellitus, Addison's disease and Multiple Sclerosis, just to name a few.

ME/CFS may also *co-exist* with or mimic symptoms associated with: fibromyalgia; multiple chemical sensitivity; Irritable Bowel Syndrome; depression; anxiety disorders; and somatoform disorders.

This can make the diagnosis of ME/CFS and any coexisting conditions difficult.

Definition

There are many definitions of ME/CFS. The Fukuda Criteria (1994) is still considered the international benchmark for use in ME/CFS research, and is often used as a de facto clinical definition. However, many see the criteria as being vague and over inclusive. Furthermore, they downplay (i.e. make optional) post-exertional malaise and other cardinal ME/CFS symptoms.

The term Chronic Fatigue Syndrome may convey the perception that sufferers are simply overtired. However, fatigue is just one of a multitude of symptoms.

The Canadian Expert Consensus Panel published the first diagnostic ME/CFS criteria for clinical use in 2003. In contrast to the Fukuda Criteria, this new definition made it compulsory that to be diagnosed with ME/CFS, a patient must become symptomatically ill after minimal exertion. It also clarified other neurological, neurocognitive, neuroendocrine, autonomic, and immune manifestations of the condition.

A modified tick chart of the Canadian Clinical Criteria is included in the document "ME/CFS Guidelines: Myalgic Encephalopathy (ME)/ Chronic Fatigue Syndrome (CFS): Management Guidelines for General Practitioners – A guideline for the diagnosis and management of ME/CFS in the community or primary care setting", available on our website and distributed to all GPs in SA.

How is ME/CFS treated?

All treatment should be patient-centred and involve supportive counselling, lifestyle management and the setting of realistic goals. There is no known cure for ME/CFS. Management is geared at improving functionality and symptom control through an effective therapeutic alliance between the patient and their GP.

Therapy for ME/CFS is intended primarily to relieve specific symptoms. It must be carefully tailored to meet the needs of each patient. Sleep disorders, pain, gastrointestinal difficulties, allergies and depression are some of the symptoms which may be relieved through the use of medications and other interventions.

Lifestyle changes including appropriate rest, reduced stress, dietary measures/restrictions and nutritional supplementation may be of benefit. Supportive therapy, such as counselling, can help to identify and develop effective coping strategies.

There is still a great deal of controversy surrounding the issue of whether people with ME/CFS should undertake intentional exercise. Most ME/CFS patient groups recommend that sufferers pace themselves by starting with gentle exercises and slowly increasing levels of exercise without causing a significant relapse of symptoms. It is important to maintain physical fitness if possible, but we recognise that exercise is not always the best possible use of sufferer's limited energy reserves.

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Support Groups

Adelaide Support Group

The Adelaide Support Group meets on the fourth Tuesday of each month.

Venue: Uniting Pilgrim Church, 14 Flinders Street, Adelaide (behind Adelaide City Council).

Time: 12:00 pm to 2:00 pm.

Contact: Darryl Turner.

Phone: The office on (08) 8410 8929 to confirm attendance.

Glenelg Support Group

The Glenelg Support Group meets on the third Wednesday of each month.

Venue: Cinema Centre Coffee Lounge, Jetty Road, Glenelg.

Time: 1:00 pm.

Contact: Marion Hansen.

Phone: Marion on (08) 8234 2342.

Northern Metropolitan Support Group

Contact: Merindah Whitby.

Phone: Merindah on (08) 8287 3195.

Northern Yorke Peninsula CFS Support Group

Venue: Community Health Centre Wallaroo.

Phone: Jane on 8826 2097.

Southern Fleurieu Support Group

Second Thursday alternate months: April, June, August, December.

Phone: Melanie Stratil (Dietician) 8552 0600 for venue details.

Murray Bridge Group

The Murray Bridge group is not meeting at present.

Please ring to register your interest.

Phone: Fran McFaul (Dietician) 8535 6800.

Please note that meeting times are subject to change.

If you are attending a meeting for the first time please call the contact or the Information and Support Line for confirmation of meeting days and times:

8410 8930 or 1800 136 626

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Prognosis

The prognosis for ME/CFS patients is variable. Most will generally improve in functionality to some degree over time, usually 3 to 5 years. However, symptoms may fluctuate or relapses may occur from time to time. Early intervention and positive diagnosis often result in a better prognosis. However, a significant proportion of patients will remain quite debilitated for longer periods of time.

Support Contacts

SA Support Groups

Adelaide City Office 8410 8929

Glenelg Marion 8234 2342

Murray Bridge Fran 8535 6800

Northern Yorke Peninsula David Shepherd 8862 1665

Southern Fleurieu Melanie 8552 0600

Misc. Support Contacts

North Eastern Julie 8264 0607

North Eastern Pat 8264 9328

SAYME Liz 8278 2093

SAYME Parents Marg 8276 5353

Country Support Contacts

Auburn Kay Hoskin 8849 2143

Barossa Valley Dennis 8563 2976

Mt. Gambier Di Lock 8725 8398
or
0438 358 398
(mobile)

Murray Bridge Fran 8535 6800

Port Lincoln Jade and Pauline 8683 1090

Port Pirie Marj 8633 0867

Riverland Kathy Southeren 8586 3513

Victor Harbor Melanie 8552 0600

Whyalla Peter 8644 1897

Yorke Peninsula (central) Caroline 88374335

Yunta Gloria 8650 5938

Youth Support: SAYME

South Australian Youth with ME/CFS

The idea behind having a Youth group is to get young people with Chronic Fatigue Syndrome together at the same place at the same time to relax, chill out, and to have a bit of fun within the limits of their condition and to develop a network of friends with Chronic Fatigue Syndrome that understand the issues we face. Together we can help each other through the tough times.

The Youth group is open to young people up until the age of 30. Please contact Emma Wing in the office on Wednesdays on **8410 8929** for a program of events or if you would like to receive our quarterly magazine. We would love to meet you.



If undeliverable return to:
ME/CFS Society (S.A.) Inc.
GPO Box 383
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