



## M.E. / C.F.S. Society (S.A.) Inc.

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Ms Robyn Schutte  
Secretary  
Social Development Committee  
Parliament House  
North Terrace  
Adelaide SA 5000

23 August 2004

Dear Ms Schutte

The ME/CFS Society (SA) Inc welcomes the Social Development Committee's inquiry into multiple chemical sensitivity (MCS)

### Background

- The Society represents the estimated **3000 to 7000 people in South Australia** suffering from Myalgic Encephalopathy/Chronic Fatigue Syndrome (henceforth referred to as CFS) and their carers.
- Many people suffering from CFS also suffer from multiple chemical sensitivity (MCS). A membership survey which the Society conducted in 2001 found that **58% of members reported experiencing chemical sensitivity**.
- This finding is consistent with research worldwide which suggests that around half of all CFS sufferers also suffer from MCS.
- It is pretty clear that **exposure to chemicals itself is often a trigger for the onset of CFS**. The best-known example is that of "Gulf War Syndrome" where up to one in five veterans of that war have suffered CFS-type conditions as a result, they and others argue, of exposure to chemicals. Many CFS sufferers in this State trace the onset of their illness to exposure to chemicals. This is often the case with farmers and members in the Riverland and other areas where chemical spraying of crops is routine. These claims are not always easy to prove. But there is a strong and consistent pattern of such claims.
- Both CFS and MCS have struggled for formal medical acknowledgement in the past. But that situation is steadily changing and CFS is now listed in the World Health Organisation's International Classification of Diseases.

- **CFS is a condition with many and varying symptoms.**  
They include muscle aches and pains; unrefreshing sleep; poor concentration and memory ('brain-fog'); gastric problems; food intolerances; low blood pressure; reduced immunity; increased allergies; headaches; lymphatic problems; and post-exercise fatigue.
- **Chemical sensitivity is thus just one outcome of contracting CFS for many people. But it happens to be one of the most devastating.**  
CFS sufferers typically fight with enormous spirit to maintain the semblance of a normal life. They struggle hard to maintain normal social contacts. They do their best to keep in paid employment and thereby have the wherewithal for a normal life. And they strive to continue to be full participants in civil society via their involvement in politics, community service, culture, sport, hobbies and so on.
- **Yet society puts considerable barriers in their way.**  
As CFS sufferer Marian Tattersall of Finnis has noted in a submission to the Society: "My own MCS necessitates my living in social and physical isolation." When people like her leave their domestic environment, which they have done their best to make safe for themselves, they confront a maze of barriers. These are not the visible barriers, such as stairs, steps, narrow doors and so on, which face mobility-impaired citizens. They are instead a complex maze of chemical-related hazards. You can't see them and you might not always be able to smell them, unless yourself chemically sensitive. But they are just as real a problem to a chemically-sensitive person as a flight of stairs to a person in a wheelchair. These barriers are detailed below in responses to the inquiry's terms of reference.

### Some key propositions

- **Improving the lot of South Australians coping with multiple chemical sensitivity requires a holistic response by government.**  
ME/CFS Society members dealing with government agencies on matters relating to chemicals often find themselves confronting a pigeonhole or silo mentality.  
  
To take one example: in April 2004, a member raised an enquiry about government standards on the placement of cigarette disposal bins near the doorways of tourism, cultural and other venues. (Cigarette smoke is one of the most common barriers to participation faced by MCS sufferers and where bins are placed plays a large role in where smokers gather.) The enquiry since then has bounced from agency to agency. No agency seems clear if it is primarily its responsibility. Is it a health problem? An occupational health and safety issue? A disability access issue? At the time of writing it now seems that a meeting of several agencies – all expressing goodwill on the matter – will be held shortly to discuss what to do with this. The point is: the issue of safe and healthy access to public spaces is a health issue; a disability access issue; an occupational health and safety issue; and an issue of social justice and social inclusion. So what is required is 'joined-up' thinking within government.
- **Government attitudes to this area of disability are way behind those to more visible forms of physical and intellectual disability.**  
It is quite disheartening to see the number of major policy statements and strategies on disability issues that make no reference at all to multiple chemical sensitivity as being as real a problem for some people as visible barriers and hazards are for others.

*The Society suggests that the Committee take a random sample of government documents dealing with this and see if it can find any that go much beyond references to access for only mobility-, vision- and hearing -impaired citizens.*

To take one example: the Women's and Children's Hospital in 2000 developed a Disability Discrimination Act Action Plan. This long document deals with a wide range of issues. But it makes no mention of perhaps the most notorious access issue at the hospital: the hazard to the many sick children, their family and friends who suffer from respiratory problems posed by people smoking right by the hospital's entrances, and especially that on Kermode St. When queried, the hospital's administration replied that sensitivity to cigarette smoke and other chemicals is not dealt with in the Disability Discrimination Act. At the least the hospital's silence on this matter suggests a failure of imagination -an inability to look under one's nose and a preference for working from formulaic codes.

Cigarette smoke is by no means the worst challenge to proper access to hospital treatment by MCS sufferers. But it is the best-known aspect of MCS. And so the silence on this matter in key public policies is really quite stunning.

- **Multiple chemical sensitivity is not a problem for just a small number of South Australians.**

There was considerable resistance and inertia within government circles when the first wave of disability advocates – people like the late lamented Jeff Heath and Richard Llewellyn – began hammering at the need for public spaces and venues to be fully accessible to mobility-impaired persons. The cost of providing access was commonly seen as disproportionate to the benefits to accrue to just a few people. And yet we have learned since then that; for every person in a wheelchair who uses a ramp, perhaps ten or more elderly people, parents with prams and pushers and a range of others will use it.

The same ratio holds true for efforts to deal with chemical sensitivities. For every person who truly cannot enter or stay in a public space because of chemical hazards, there will be another five or ten whose health and wellbeing is compromised more subtly. They can continue to function –but well below their normal standard.

- **In dealing with multiple chemical sensitivity the government will improve the environmental sustainability of this State.**

The plight of MCS sufferers underlines that as a society we are pouring a huge and unnecessary quantum of toxins into our air, land and water. MCS sufferers have been likened to the canaries which miners used to keep in mines to alert them to the danger of leaking gases. Some of our citizens are falling over. They alert us to the overuse of chemicals in our State and it makes sense in 'green' terms to reduce the usage of those chemicals. Government itself as a massive enterprise can show the way with policies and procedures which steadily reduce the overuse of chemicals within all its agencies.

- **Tackling the problem of chemical sensitivity does not need to involve expensive infrastructure programs.**

One of the major points of resistance to the long campaign to improve access for mobility impaired people to social spaces, and thereby to full participation in the community, has always been concern at its high cost. As late as 23 June 2004, the Property Council of Australia issued a media release under the headline "No compromise for political correctness". The council attacked the disability lobby for its

strong stance in support of planned changes to Disability Discrimination Act-related rules on improved access to buildings. It concluded that the cost of upgrading buildings nationally could be as much as \$50 billion.

Whatever the truth behind this piece of political rhetoric, it reminds us that much thinking on both sides of arguments about disability tend to focus on changes to the physical environment.

Tackling chemical sensitivity is a different kind of campaign. Of course it is multifaceted and there will be costs –at times considerable - involved in finding ‘greener’ and non-toxic materials for buildings, fittings and so forth. But it calls more for sustained human effort to change common behaviours than large expenditures to change the built environment. It calls for imagination and persistence in government and its agencies but it does not necessarily carry with it massive costs to the public purse.

In some ways dealing with invisible problems and their impacts is harder than fixing up access routes for the mobility-impaired. How can we come to the point where workers who might be blocking chemically sensitive colleagues from continuing in work because they overuse perfumes and deodorants are brought to accept that their behaviour is no longer a matter of untrammelled private rights? This is a State where funding has always been tight but human ingenuity and collaborative effort have been for that reason all the more valued and enhanced. So tackling the social changes needed to make life more tolerable for the chemically sensitive is a manageable challenge for our community.

### **Responses to the terms of reference**

The Society has opted to focus on the last two terms of reference. Its comments reflect work done by a number of members to research the issue and to collate comment from a range of other members.

Several comments from members are attached. Several others were originally intended as comments but were in the event sent directly to the inquiry.

The committee should note that the detailed proposals below are almost all drawn from precedents being established in jurisdictions around the world. Though requiring considerable changes in practice in South Australia, they are thus not utopian.

## **V Chemical usage practices by State government departments and local government.**

### **Current chemical usage practices**

- Local councils and pest control boards use pesticides in public parks, streets and other spaces. to control weeds and other pests.
- Government agencies purchase and use a wide range of toxic chemical products in public buildings and services, eg public transport, such as building and renovating materials, cleaning and sanitary products, pesticides, solvents, and petrochemical- based products.
- PIRSA routinely uses pesticides (eg organic phosphates) in insect control.

### **Changes that could be made to reduce chemical exposure:**

#### **Pesticides/herbicides**

1. *Impose a moratorium on the use of herbicides by local councils and other government agencies in residential areas, public parks, streets, country roadsides and elsewhere.*

2. *Government departments should reduce their use of herbicides in their efforts to control declared weed pests. State government should develop medium- to long-term strategies to phase out reliance on herbicides.*
3. *The State Government needs to develop pesticide elimination/reduction programs for the control of insect pests such as termites in government buildings.*
4. *The State Government should develop mandatory integrated pest management programs across all government services to eliminate the unconsidered and excessive use of pesticides.*
5. *The State Government should establish pesticide legislation which should include as key elements:*
  - setting up a control board or departmental structure to drive the reform of pesticide use in SA
  - establishing a public register of people wishing to be notified of pesticide applications within a prescribed area
  - requiring prior public notification when any agency or enterprise intends to use pesticides and in situ signage providing 48 hours' warning of the intention to use pesticides in public areas, ( the signage to remain in situ for at least one week in areas where pesticides have been used)
  - requiring ordinary citizens to secure a licence, possibly from their local council's Environmental Officer, before applying any shop -bought pesticides on their private property
  - requiring persons intending to use pesticides on a property to notify their neighbours beforehand
  - requiring councils and commercial pesticide companies to maintain records of their activities, when areas were treated, with what, by whom and under what conditions.
  - Giving priority to integrated pest management programs and pesticide reduction strategies in commercial agricultural production.
6. *The State Government should develop a statewide pesticide reduction program aimed at involving all South Australians. Key elements could include:*
  - local councils setting up volunteer community street maintenance programs, similar to successful graffiti removal programs, that avoid the use of herbicides
  - State and local governments conducting a statewide public education campaign on the real risks of using household, garden, lawn, and other commercial pesticides.
  - developing strong educational programs on the use of protective equipment for workers.

### **Solvents / volatile organic compounds**

7. *Require all government agencies to comprehensively review their purchase of any materials containing organic solvents.*
  - Agencies should be required to choose solvent-free products where available. If there is no solvent free alternative then products containing the least amount of solvent and the least toxic solvents should be chosen.
8. *Strengthen building codes so that they take proper account of MCS.*  
 Adopting best practice here (based on good international models) would include:
  - selecting non- toxic or least toxic solvent- free, formaldehyde-free products when building or renovating.
  - banning solvent- based paints and staining products in government agencies.

- recognising that many water-based paints contain a significant percentage of solvents. (Agencies should use solvent- free water- based paints if possible or water -based paints containing the least amount of solvents. They should avoid water-based paints containing vinyl polymers.)
- avoiding the use of carpets wherever possible, and if they are unavoidable using least- toxic wool and natural fibre carpets without stain- resistant chemicals and pesticide treatments
- using safer floor coverings and flooring, natural linoleum or marmoleum, sisal matting, wool or cotton rugs, polished cement, terra cotta, or slate tiles, natural low terpene wood.
- avoiding PVC or vinyl flooring.
- avoiding particle board and multi-density fibreboard containing formaldehyde and toxic glues, or choose least toxic options. Phenol-formaldehyde is less toxic than urea-formaldehyde.
- avoiding wood containing copper chromium arsenate (perma-pine) and other pesticide treatments.
- avoiding toxic glues, tile adhesives, and silicon sealing agents, etc, wherever possible or use least toxic alternatives.
- avoiding clear floor finishes, use non-toxic, water-based alternatives.
- avoiding unnecessary plastic fittings
- choosing least-toxic furnishings, cotton, wool, and natural fibres. And eliminating the use of flame retardants
- establishing procedures covering situations where toxic renovation and maintenance products are used in buildings. (The work should be undertaken when employees are absent, time allowed for outgassing of toxic chemicals and the building kept well ventilated before staff return. )
- Where toxic building and maintenance products are used, providing public warning signage so that people with MCS can avoid exposure.

### **Stationery and Office Supplies**

9. *Require agencies to select non-toxic and least-toxic stationery and office supplies.*

Key elements include :

- avoiding solvent- based marker pens and correction fluid.
- isolating printers and photocopying machines from shared spaces and installing exhaust fans in areas where they are used.

### **Cleaning and Sanitary Products**

10. *Improve cleaning and related regimes in all State agencies. Key elements include:*

- avoiding harsh cleaning products, particularly those containing solvents, antibacterial agents, fragrances, caustics, chlorinated compounds and other irritants. ( Harsh cleaning agents are not necessary for normal sanitation. Use steam as much as possible for cleaning.)
- avoiding air fresheners, automatic aerosol dispensers and other fragrance-emitting devices, solid air fresheners and air fresheners in air conditioning systems.

### **Indoor air quality**

11. *Create state guidelines for improving indoor air quality in government buildings, schools, hospitals and public venues.*

Key elements include:

- maintaining good indoor air quality at all times.
- providing windows and doors that open to allow fresh air to circulate, repairing windows that need repair, re-opening windows that may have been closed for air conditioning purposes or security reasons.

- ensuring that air conditioning systems are in good repair, if necessary installing separate air conditioners with adequate fresh air intake in each room if air conditioning is a problem in “sick buildings” with central air conditioning. ( Fresh air intake should be away from sources of industrial emissions, vehicle exhaust, garden pesticides, or other pollutants. )
- ensuring that toxic products and supplies are not brought into public buildings.
- eliminating the use of unflued gas heaters and choosing electric heating and other utilities.
- using portable absorbent air filters where necessary.
- using indoor plants to absorb volatile organic compounds. (NASA has identified the common spider plant as very effective.)
- ensuring that indoor environments are kept free of mould.

### **Fragrances**

Personal fragrances are one of the most commonly reported products triggering symptoms of MCS. There are rare anecdotal reports of death from exposure to personal fragrance in severe cases of MCS. (Around 20% of the population suffer health problems from personal fragrances, including asthma. Persuading people to avoid these toxic products in public spaces is much harder than might be imagined and special public health education strategies will be needed to achieve this. People often have a very strong attachment to their personal fragrances, something strongly promoted by fragrance companies, and will refuse to give them up no matter how much harm they might be causing others. Apart from personal hygiene concerns, part of the problem is that the solvents used in these products are addictive intoxicants. Spraying on perfume can be just like drinking a hit of scotch whisky, but, as with nicotine in tobacco years ago, most people are unaware of this addictive aspect of personal fragrances.

#### *12. Develop educational programs to encourage users of public buildings to reduce and ideally do away with the use of perfumes, after shave, cologne and fragranced personal care products.*

(The US EPA recognises that these are indoor air pollutants, just like tobacco smoke.)

Key elements include:

- developing personal fragrance control policies in government buildings which require staff not to use these products at work.
- encouraging members of the public to voluntarily avoid personal fragrances through signage such as "For the health and safety of everyone, including people with multiple chemical sensitivity, this building is a smoke and fragrance free. Thank you for not using personal fragrances when accessing this building."
- ensuring non-smoking regulations in public buildings are adhered to (and extending and enforcing smokefree zones at entrances as allowing smoking here in effect creates barriers to entry to public spaces).

#### *13. Government agencies and local government bodies should :*

- avoid the use of fragranced products in public buildings, eg automatic fragrance dispensers, fragranced cleaning and sanitation products, toilet paper, solid air fresheners, *carpet cleaners, detergents, essential oils, etc*
- negotiate with the owners of buildings where agencies are tenants to achieve best practice in *this regard*
- disseminate information about best practice in the use of fragrances to other building owners
- embed in grant programs to the operators of venues – eg in tourism, the arts, recreation and sport – stipulations or advice about best practice on the use of chemicals and fragrances. (Accommodation venues routinely overuse deodorisers and air-fresheners. In some cases it is somewhat poignant that operators have

worked hard to ban smoking from their premises -but then greet the visitor with a wall of cheap fragrances in the reception area. For the chemically sensitive the average country motel is for that reason alone a no-go area.)

### **Petrochemicals**

14. *Government agencies and local government bodies should avoid petrochemical-based products wherever possible or otherwise use least toxic alternatives.*
  - Transport authorities should be required to phase in bio-diesel and electric vehicles for our public transport system
  - Steps should be taken, including the provision of advisory signage for as long as is necessary, to modify driver habits such as leaving vehicles idling near entrances to buildings.
  - State and Federal governments should work together to discourage the use of diesel-driven vehicles

### **VI. The ways in which South Australians with Multiple Chemical Sensitivity might more effectively access sources of support through government agencies.**

South Australians suffering from Multiple Chemical Sensitivity want above all to know that public authorities in this State have:

- clearly recognised MCS as a major public health, equity and access issue
- have taken steps to remove chemical barriers as much as possible
- begun educating public sector employees and health professionals about the difficulties facing people with MCS so that they have access to safe care and their disability rights are recognised.

Specific areas for attention include the following:

#### **Health care**

State government needs to address as a matter of urgency the barriers facing people with MCS requiring health care. For seriously impaired sufferers, attempting to seek treatment in hospitals, surgeries and health centres can itself be a hazardous experience. Regrettably attitudes to chemical sensitivities amongst health-care workers are often marked by indifference. Nurses are notorious for the rates of cigarette smokers in their ranks. Many staff at all levels use personal fragrances and yet refuse to acknowledge this as a problem for sufferers from MCS, asthma and other respiratory conditions. As for all large public buildings, hospitals present a mass of materials containing volatile organic compounds which are lethal to MCS sufferers (and, as we keep repeating, are not too flash for much healthier citizens either). And finally, and perhaps most difficult, hospitals are permeated with residues of chemicals used in the treatment of illness and injury.

So what are some of the most urgent steps which the Committee might recommend be taken to start improving this situation?

15. *The Department of Human Services should develop and disseminate statewide MCS protocols for all public hospitals, clinics, community health care centres and sexual health care services so that people with MCS can access general health care without harm.*
16. *The Department of Human Services should sponsor medical education forums on MCS so that doctors and other health care providers are properly educated and do not discriminate against people with MCS out of ignorance.*

- Some sectors of the medical profession in South Australia are dismissive about the role of chemical sensitivity in CFS. This is despite the Society's findings that over half of its members rate chemical sensitivity as a problem. And it ignores the more standard finding internationally that around 40% of CFS sufferers are chemically sensitive and that avoiding chemical exposures helps to alleviate the effects of CFS.

17. *State government should investigate the feasibility of establishing a specialist Environmental Medical Unit (EMU) for the evaluation, diagnosis, treatment and care of people with MCS.*

- The unit should include research, respite and convalescent facilities. It would be a purpose-built facility constructed from non-toxic materials, with non-toxic fittings and furnishings. Its staff would be trained in the principles of environmental medicine. They would be able to conduct food and chemical sensitivity challenge testing. They would carry out overall health assessments, identify individual deficiencies in biochemistry, etc., and provide appropriate treatment recommendations on nutritional supplementation, chemical avoidance regimes, etc. The EMU would also provide a training ground for doctors to learn skills in environmental medicine.
- A private EMU was set up at Manly Hospital, NSW, in the 1980s by Dr Mark Donohoe, but has since closed. A smaller private EMU exists in Melbourne under Dr Colin Little. Currently there are no public health facilities in Australia offering an EMU or equivalent service. Canada has two EMUs, one of them part-funded with public money. The USA has several private EMUs. Such units are not cheap. But the alternative is to leave some of our citizens stranded at home without access to sometimes life-saving health care.

## Education

Chemically sensitive students with CFS who wish to attend schools or tertiary institutions often suffer from the failure of educational authorities to treat their needs seriously and to create safe environments for them.

18. *The Department of Education and Children's Services should*

- develop and disseminate statewide MCS protocols for schools and TAFE institutes . The Department should draw on the advice of MCS and CFS/MCS students and parents in shaping the protocols.
- conduct awareness-raising programs for teachers regarding the needs of MCS students.

19. *The State's universities should be asked to give higher priority to improving conditions for chemically sensitive students and staff.*

At a time of incessant funding challenges, they have not showed themselves particularly interested in spending money on tackling even the most politically high-profile area of chemical sensitivity: the need to restrict cigarette smoking so that reactive students and staff can safely participate in the full gamut of university activities. But nor have they shown much imagination and the will to discourage smoking. The lack of any (inexpensive) signage on the main bridge/walkway into the Barr Smith Library at the University of Adelaide is a classic example. It's not all about money.

## Housing

The ME/CFS Society is aware of a number of its members who have been forced to retreat to fairly isolated properties in order to survive. It is not their CFS but its related manifestation in

MCS which drives them to the margins of society and towards becoming our nearest modern equivalents to hermits. There's even a folk name for this in South Australia: "Kangaroo Island syndrome".

20. *The Housing Trust should develop a number of purpose-built ,chemical-free, state-funded houses for people with MCS in suitable areas away from industrial, agricultural and urban pollutants, but with good access to services.*

### **General policy**

As stated before, the Society believes that many relevant State (and Federal) policies on disabilities have great holes in them when it comes to taking account of "invisible" disabilities such as Multiple Chemical Sensitivity. The Human Rights and Equal Opportunity Commission and the Equal Opportunity Commission do consider MCS to be a legitimate disability. But we are at a fairly early stage in terms of how such recognition is given effect in practical public policy.

21. *The State government should develop a statewide MCS disability access policy and include MCS within all disability access guidelines and regulations.*

22. *The State government should institute training programs so that government employees have an understanding of the complex problems of MCS.*

For example one agency's receptionist recently refused to consider asking any member of its staff not to wear perfume or after-shave at an appointment with a person with MCS. The receptionist's response to the fragrance-free request was: "I won't do that. I know about people like you. We have a right to wear perfume". A complaint to the management and mention of the Equal Opportunity Commission position on MCS resolved the problem. But this kind of attitude to people with MCS is very common. There is a prevailing -and not altogether surprising -view that wearing fragrances is strictly a matter of private choice with no public ramifications. As with other issues, once again this is one where many generally healthy staff and customers find the use of strong fragrances to be at least offensive and at worst allergy-inducing. There are signs that, as society becomes more aware of the toxic impacts of many chemicals, informal pressure will increasingly be brought to bear on over-users of fragrances. But the best way to accelerate such change is to give it official support.

It is worth re-iterating that a significant number of CFS sufferers are chemically sensitive and are socially excluded because of this. The ME/CFS Society views this parliamentary inquiry as an excellent opportunity for the rights of CFS/MCS sufferers to be recognised. It congratulates State Parliament for initiating it. The inquiry offers the chance to put South Australia in the forefront of progressive effort to open the doors to full participation in society for citizens bearing the burden of multiple chemical sensitivity.

The ME/CFS Society gratefully acknowledges the assistance of Mr Lorenzo Pizza in researching and compiling the information.

Yours sincerely

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ME/CFS SOCIETY (SA) INC