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PUBLIC SUBMISSION: PRODUCTIVITY COMMISSION INQUIRY

INTO THE DISABILITY DISCRIMINATION ACT 1992

CHEMICAL INJURY / MULTIPLE CHEMICAL SENSITIVITY (MCS)

Ann Want - ACTA.

The Australian Chemical Trauma Alliance (ACTA) is an organization dedicated to providing support to individuals suffering chemical injury/ multiple chemical sensitivity (MCS).

A wide range of products and activities associated with modern times, have had an adverse impact on human health and well being. These products and activities are now considered essential to daily life and the economic wealth of nations. The convenience and wealth they offer is not without a cost. This is apparent with the worsening degradation and contamination of the environment and the resultant adverse effects suffered by a growing number of people.

A significant percentage of the population is chemically sensitive as illustrated in independent studies: 12.6% (Ref: S.M. Caress et.al 2001), 15% (Ref: California State Department of Health Services 1999 & the National Academy of Science Study 1981) (see appendix 1). The first part of this submission is based on the hundreds of case studies submitted to ACTA.

Individuals with MCS can react to chemical exposures at far below the concentration levels tolerated by most people. The case studies indicate that the majority of individuals can identify the specific circumstances which initiated their condition. Over-exposure to one or more chemicals seems to be the usual starting point. It can take the form of an overwhelming chemical exposure such as a chemical spill or massive pesticide exposure, or a long term low to medium level exposure to chemicals, common to our modern way of life, which appear to have a cumulative effect on the individual.

The hundreds of case studies obtained from members also indicate that MCS can begin at any age. This includes many, some quite disabling, symptoms that affect multiple organ systems, especially the neurological, immune and musculoskeletal systems. Following the

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initial trigger the sufferer becomes sensitive to a growing number of related and unrelated chemicals and/or non-toxic substances (eg certain foods, pollens). Although the concentration of the chemical involved may be low, in a sensitised individual a reaction can be provoked.

The case studies indicate that the chemical triggers are many and varied. Exposure may come from the air, food or water or through skin contact. All categories of chemicals are involved such as agricultural chemicals, industrial chemicals and chemicals found in personal care products. They include chemicals found in building materials – organic solvents, lacquers, paints, epoxy resins, glues, new particle board and plywood. Chemicals found in fabrics – synthetic textiles, new carpets, carpet glues and binders, dry-cleaned fabric, plastics, rubber pillows and mattresses, mothballs etc. Chemicals found in cleaning products – bleaches, disinfectants, polishers, and air fresheners and deodorisers. Chemicals found in pesticides, photographic chemicals, formaldehyde, cigarette smoke, vehicle fumes and pool chlorine. Chemicals found in food – in dried fruit, synthetic food colouring, chemical preservatives etc. Chemicals found in personal care products – scented products in general – found in ointments, perfumes, shampoos, soaps, after shave, deodorants, cosmetics also biological and synthetic drugs (either the drug is a problem or the preservative in it.). Office materials/equipment – printers, carbonless copy paper, newsprint, textas, correction fluid, glue etc.

The case studies show that symptoms are many and vary among individuals. They include:- chest pain, cardiovascular irregularities, shortness of breath, asthma, ringing/aching/itching ears, chronic throat problems, memory impairment, confusion, headaches, depression, sudden emotional responses, learning disabilities, concentration problems, slowing of reaction times, dizziness, overwhelming fatigue, muscle pain and weakness, joint pain, movement disorders, food intolerance, persistent infections, persistent skin rashes, flu-like symptoms, increased sensitivities to odours, gastrointestinal problems.

Individuals with MCS may become partially or totally disabled for several years or for life.

MCS sufferers are seldom able to display outward signs of their injury and become vulnerable to abuse as bludgers or cranks. The medical profession does not receive training in environmental toxicology and cannot readily identify the condition. Consequently sufferers are tagged as malingerers or in need of psychiatric help. This attitude is reflected by the general community with a destructive impact on the sufferers who find themselves stranded without sympathy, support or recourse to the law for compensation in the absence of medical testimony. Many sufferers live in limbo until they eventually discover a sympathetic practitioner.

Health practitioners generally find MCS difficult to define and diagnose. No single set of symptoms or single diagnostic test exists to identify MCS. A complete patient history, which includes environmental and occupational exposures, needs to be taken. The onset of MCS sees the individuals' health continually deteriorate. The case studies consistently indicate that improvement comes when the chemical sensitivity condition is understood and the individual can take appropriate action.

Sufferers indicate that a number of treatments help to improve their baseline health status. They seek relief through homoeopathy, naturopathy, acupuncture, massage, reflexology, etc provided by both alternative therapists and medical professionals. Presently there is no single 'cure' for MCS except avoidance. Avoiding the chemicals, which may trigger reactions, thus symptoms, is an essential part of managing MCS.

The case studies show that every aspect of life is affected. Individuals are forced to make

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dramatic changes in lifestyle at home. Many marriage and family relationships end from the stress of coping with this disabling condition. The majority are forced to leave their job and deal with the devastating loss of income and resultant poverty. Many are forced into social isolation. A few have committed suicide.

Sufferers of MCS need to create a 'sanctuary', relatively free of chemical exposures, within their homes and if possible immediate outside environment. If they can afford it they are forced to relocate. They spend as much time as possible within this environment due to the serious impact of an accidental, unavoidable exposure. They are denied adequate medical and hospital access. As a result they may experience intense isolation, loss of self-esteem and depression from not being able to have an active family, social and community life.

Some MCS sufferers are fortunate in that, with education and the efforts of their family, community and workplace, they are enabled to return to as normal a life as possible, some are able to undertake paid work, study etc. Unfortunately this is rare. There are a few lucky MCS children who have been able to return to school, with the help of the whole school community. However, this is also rare, with the majority of MCS children being forced into 'Distance Education' or Home Schooling.

Common comments made by MCS sufferers are:-

'I've suffered rejection by my church, employment, I've become a social outcast'

'Few people are prepared to understand and help you'.

'Improvement in my health came when we moved to an isolated area'

'I'm very reliant on my neighbours' attitude to maintain any quality of life'.

'I lead a lonely life, can't go anywhere, if I do I know I will be crook'

'Trying to find a doctor to listen to you was a problem. They didn't believe that such a thing can happen. A couple told me it was all in my head.'

'I had to leave work and am now on a s/s pension.'

'I'm housebound and trapped in a polluted area in public housing on a disability pension.'

'My husband couldn't accept lifestyle changes – we separated.'

'I can't go out to see friends: they don't respect my needs. My husband is of no support his attitude is 'if I don't see it- it won't hurt me.'

'It seems to me that all doctors can say is –"Stay away from chemicals and don't eat what upsets you'.

Multiple Chemical Sensitivity has a profound impact on the individual sufferer and their family. The impact on society is increasing as the number of farmers, nurses, computer consultants / technicians, teachers, academics, and other skilled workers, once productive members of society, can no longer support themselves or contribute to society. Their loss also translates to loss of money spent in the marketplace and in tax revenue.

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MCS Recognised Overseas

MCS is recognised in the USA, Canada, the UK, Sweden and in Germany. Multiple chemical sensitivity is also recognised under their ICD-10 (International Classification of diseases). Please refer to Appendix 2 for further information on the various agencies in the USA and Canada alone where MCS is recognised.

A letter to the then ACTA President Peter Harding in 1997 (refer Appendix 3), from the then Disability Discrimination Officer, Elizabeth Hastings, states ..*"The information available to me suggests that MCS is not a single condition but a range of conditions. It is possible that any one of these might fall within the definition of disability contained in the DDA and therefore MCS is a disability for the purposes of the Act"*... There has been little to no improvement to the plight of the individual with MCS over the years. It is still an unmet disability, with its sufferers being marginalised and suffering severe disadvantages in today's society.

With appropriate recognition, support and education, such discrimination could be alleviated in many circumstances. The quality of life of MCS sufferers is dependent upon the attitude of those around them.

Housing

Many individuals with MCS have difficulty in obtaining adequate housing. Very few have the financial resources to accommodate their needs. This involves living in as chemical-free an area as possible and building a 'chemical-free house' using materials to accommodate their sensitivities. Individuals reliant on public housing or rent face an insurmountable problem. Many approaches have been made by individuals to relevant government bodies regarding appropriate housing with zero to minimal success. Notable, however is the advocacy work by Dorothy Bowes, Co-ordinator of the Allergy Sensitivity & Environmental Health Association, Queensland, in her successful approaches to Disability Housing to accommodate 2 chemically sensitive individuals.

Public Places

Many MCS sufferers find it difficult to impossible to access public places such as shopping centres, meetings, halls, transport etc due to perfumes, pesticides etc. With education and compassion this situation has been addressed in a very few cases. This can be seen in the example of a town in Queensland who refrained from spraying 'its streets and open land' to aid a chemically sensitive individual (see appendix 4). Overseas examples include the Supreme Court of Canada which upheld a by-law passed by the town of Hudson, Quebec, that banned the cosmetic use of pesticides within municipal boundaries (see appendix 5). This no doubt assisted in improving the quality of life of many a MCS sufferer. Another example is where the town of Shutesbury, MA, in the USA 'recommended, and the town agreed, that the annual town meeting would be scent-free with a separate area for people who forgot'.... (see appendix 6) Halifax, Canada is another town where public places are perfume and pesticide free zones.

Hospital Protocols

Presently there are no hospital facilities or ambulance services in NSW that have protocols in place to ensure that an individual with MCS will be adequately catered for. Please refer to the speech presented in the NSW Parliament by the Hon Alan Corbett. (see Appendix 7). Upon

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request, ACTA provides a support letter to members facing hospitalisation, with zero to minimal degree of success in helping the individual (see Appendix 8). Generally the MCS individual faces a poor attitude toward their needs from hospital staff.

Children With MCS

The plight of children with MCS is particularly of great concern. The treatment by the medical profession, in general, of these children and their parents is short of criminal. It is difficult for parents of children with MCS to find a sympathetic medical or alternative health care practitioner. Frequently such children are admitted to certain children's hospitals. If the parents indicate their suspicions and/or observations that their child's condition may be aggravated by exposure to chemicals, they are dealt with contempt. An increasing practice by certain hospitals when faced with such parent concerns is to intimidate with inferences of them suffering Munchausen Syndrome by Proxy. (refer to Appendix 9) The result of this type of intimidation by doctors, who are not trained to recognise environmentally induced illness/sensitivity, is that quite often the child does not receive adequate medical treatment. Furthermore the tragic results of this approach is that it has been repeatedly observed.

Many case histories indicate that if a chemically sensitive child is allowed to grow up in as chemically free environment as possible then their sensitivities greatly improve, some quite dramatically, by the time they reach adulthood.

Education

The parents of MCS children face a continual battle to adequately educate their children. The NSW Education Department has been aware of the needs of these children since 1992. The 1995 Toxic Playground Conference highlighted the chemical dangers found in schools (see Appendix 10). In 1997 the National Children's Youth and Law Centre from the University of NSW presented a report to the NSW Education Department titled Disability Discrimination in Education in which Chemical sensitivity was included as a disability not being given adequate attention. (see Appendix 11). In March 2000 "The Toxic Playground" book by Jo Immig, was launched.

In 2002 the book "Safer Solutions" was launched by the then Minister for Education Mr John Watkins. This book dealt with reducing the use of pesticides in schools and childcare centres, the plight of the chemically sensitive being covered (see Appendix 12).

The integration of MCS children into the education system takes the form of many battles fought by individual parents in order to have the needs of their child met. To date no policy for the treatment of children with this disability exists within the Education Department. A few parents have achieved quite a high level of accommodation in the schools for their child whereas the majority have not, leaving many with the option of withdrawing their child and either enrolling them in Distance Education or Home Schooling their child.

If the child is being educated in school the parent and the child has to be ever-vigilant. Once an understanding with the school is in place the parent finds themselves constantly having to police it. This is as a result of non-existent direction from the department as to the accommodation of these children. As one mother stated, *"Our children need to be surrounded by compassionate individuals who can think laterally"*.

The needs of each child with MCS differ and each case needs to be treated on its own merit. However there are some general guidelines that will enable the integration of most MCS

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children. Some simple precautions include reverting to less toxic cleaning products or employing steam cleaning or fibre cleaning approaches: The use of water based: textas, whiteboard markers, liquid paper, etc instead of solvent based products; Not wearing perfumes and aftershave lotion in the presence of these children; Not applying spray-on deodorants, in the presence of such children or at least alerting the child so they can remove themselves from the vicinity; The provision of a toilet that has not been treated with air fresheners; If Integrated Pest Management controls fail and chemical application is required, prior notification of pesticide use in and around the school, is necessary so as the child/parent can take appropriate action (this may involve the removal of the child for a period of time); Ideally pesticide use at the beginning of the Christmas holidays to give the maximum time to out-gas.

Government Inaction

Unfortunately there appears to be a complete lack of political will to protect our children from chemical exposure. This was highlighted in the NSW Parliament when an amendment to the 1999 Pesticide Act was debated. The amendment “provides for substantial penalties for any person using a pesticide by any means so as to cause it to come into contact with a school or child care centre, a school bus or its passengers, or any persons awaiting a school bus”. (see Appendix 13), This amendment would have helped to protect not only chemically sensitive children in the schools but all children from unwanted chemical exposure.

Human Rights

Many individuals with Chemical Sensitivities have approached the Human Rights and Equal Opportunities Commission, as we have. In our case our sons' health was deteriorating as a result of spraying activities from a neighbouring property. Approaches to the individual concerned met with verbal aggression. The HREOC was approached on their rounds of “Bush Talks” (see Appendix 14). When the situation escalated we again approached HREOC for help, (see Appendix 15). On phone contact we were strongly counselled not to proceed as HREOC was a government funded institution and they could not/ would not go against government policy. They advised that in this case no law has been infringed by anyone.

Legal Rights

Currently in Australia a person, or child, with MCS does not have:

- any official recognition of their health condition by the medical system
- any official recognition of their health condition by the government
- any right to be protected from low-level exposure to chemicals used by other persons
- any right to be advised of the intended use of chemicals in their immediate vicinity
- any rights after being ‘assaulted’ by a chemical exposure caused by another individual after requesting that person pre-notify or delay its use.
- any rights to a safe learning environment for people with MCS in schools

Surely the Productivity Commission cannot sweep this growing disability under the carpet any longer!

In-anticipation
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