

16 March 2012

The Select Committee on the Costs of Living
House of Assembly
HOBART TAS 7001

Attention: Shane Donnelly

Re Submission to Select Committee

The Multiple Sclerosis (MS) Society Tasmania is a not for profit organisation that is committed to reducing the impact of multiple sclerosis and other neurological diseases on individuals, families and carers/support people. The organisation is spearheading a campaign, known as *The Keeping Cool Campaign*, advocating for Tasmanians with neuromuscular conditions to receive energy concessions, based on medically required cooling, as their usage of air conditioning is of a higher rate than the average Tasmanian.

This campaign is being run in conjunction with the Neuro Muscular Alliance of Tasmania (NMAT), members of which include MS Tasmania, Huntington's Association of Tasmania, Muscular Dystrophy Tasmania, Motor Neurone Disease Tasmania, Parkinson's Tasmania, Spina Bifida Tasmania and the Alzheimer's Association. The campaign is being run by MS and NMAT as *The Tasmanian Keeping Cool Alliance*, which also advocates for these purposes on behalf for people with conditions such as cerebral palsy, epilepsy, lupus, polio, spinal cord injuries, brain injuries, lymphoedema and scleroderma.

Pursuant to that campaign the Keeping Cool Alliance lodged a budgetary submission concerning electricity concessions as part of the Community Consultation process. We enclose a copy of that submission and ask that you take that into account, when assessing the terms of reference regarding the Cost of Living.

We have had the benefit of considering the comprehensive submission lodged by TasCOSS. We support the contents and recommendations of that submission, "particularly concerning terms of reference (b) dealing with bundling concessions through a smart card system.

We thus endorse Recommendation(b): That the Tasmanian Government investigate options for delivery of concessions that give concession holders greater flexibility and choice in accessing entitlements but also that ensure that individuals retain the ability to access the total basket of concessions with no reduction in or forcible reallocation of existing concessions.

The Alliance further submits that the basis for such a card should be open and transparent and that funding should be regarded as a whole of government issue

Michael Bowman
Keeping Cool Campaign Officer

20 January 2012

The Secretary
Department of Treasury and Finance
GPO Box 147
HOBART TAS 7001

Attention: Emma Sward

**Re Community Consultation: 2012/2013 State Budget
Medical Cooling Electricity Concession**

The Multiple Sclerosis (MS) Society Tasmania is a not for profit organisation that is committed to reducing the impact of multiple sclerosis and other neurological diseases on individuals, families and carers/support people. The organisation is spearheading a campaign, known as *The Keeping Cool Campaign*, advocating for Tasmanians with neuromuscular conditions to receive energy concessions, based on medically required cooling, as their usage of air conditioning is of a higher rate than the average Tasmanian.

This campaign is being run in conjunction with the Neuro Muscular Alliance of Tasmania (NMAT), members of which include MS Tasmania, Huntington's Association of Tasmania, Muscular Dystrophy Tasmania, Motor Neurone Disease Tasmania, Parkinson's Tasmania, Spina Bifida Tasmania and the Alzheimer's Association. The campaign is being run by MS and NMAT as *The Tasmanian Keeping Cool Alliance*, which also advocates for these purposes on behalf for people with conditions such as cerebral palsy, epilepsy, lupus, polio, spinal cord injuries, brain injuries, lymphoedema and scleroderma.

In support of this budgetary submission on behalf of *The Tasmanian Keeping Cool Alliance*, we attach the following information:

1. Discussion Paper for a Tasmanian Medical Cooling Electricity Concession
2. MS Australia Keeping Cool Survey 2009
3. Bureau of Meteorology statistics.

We provide the following information sought by the budgetary submission guidelines:

1. Executive Summary

There is an urgent and vital need for the Tasmanian Government to implement a Medical Cooling Concession to assist those on low incomes with a medical need to keep cool on hot days and nights.

With rapidly rising electricity costs it is increasingly difficult for them to afford the costs of keeping cool.

It is proposed that the minimum appropriate level of funding for Medical Cooling Concession should be between \$135 and \$165 (approximately one – third the costs of keeping cool for these house holds).

Approximately 850 people would be eligible based on their medical need to keep cool. The low income criteria is the same as the existing Electricity Concession. It is expected that doctors would need to sign-off on the medical need for cooling.

Heat Intolerance is a major issue for most people with MS (90%) and also for some people with a wide range of other conditions including: Parkinson's disease, Huntington's disease, motor neuron disease, post-polio syndrome, muscular dystrophy, poliomyelitis, chronic fatigue syndrome, lupus, lymphoedema, scleroderma, cerebral palsy, spinal cord injury, and some people with acquired brain injuries.

Costs to Government would be relatively low in the first few years of the concession as uptake will increase gradually. With an initial uptake of 215 people in 2011- 2012 costs to Government would be about \$29,000 - \$35,000, and would eventually level to \$145, 000 to \$175, 000 by 2015-2016 as uptake is maximised. These figures are based on indexation to an average CPI increase of 3% annually, although ideally the concession should be indexed to actual residential electricity prices to ensure its value does not erode over time.

Administratively the simplest approach would be to structure this concession similarly to the existing Electricity Concession – a flat annual rate. A percentage-based scheme would be more equitable however, and also support incentives for increased energy efficiency of air conditioners and homes.

All other states in Australia have concession programs for people with a medical need cool (and most also include assistance for those who with a medical need to keep warm) in recognition of the critical importance of their need to keep cool and the increasing difficulty they have in doing this because of rapidly rising electricity costs.

We urge the Tasmanian Government to address this issue in the next State Budget for 2012-2013.

2. The environment in which the organisation currently operates.

Multiple Sclerosis (MS) Society of Tasmania (a Company Limited by Guarantee) is a Not for Profit organisation which has been operating for the past 52 years. It delivers quality services to our clients, families and key supporters. This support encompasses clinical case management, specialised nursing, counselling and project work. In addition to this MS Tasmania delivers a host of client focused programs and forums as well as facilitated support groups around the State. Examples of focused programs conducted are Information is Power, Seminar Series, Research, Aids and Equipment forums, GP Education, MS and Employment Forum and a Couples Program.

In addition, MS Tasmania has a dedicated Clinical Research Nurse Co-ordinator who is working within the Royal Hobart Hospital which supports MS clinical drug trials. The Menzies Research Institute is a key supporter of the research efforts that are made by the MS Society. Significant research breakthroughs were achieved in 2010/11 via collaborative efforts which included other parts of Australia, the United Kingdom and Canada. Ongoing research is occurring with the focus on utilising the findings to date to provide a direction in our quest to find the cure.

The services that are provided by MS Tasmania funding via a number of sources namely Government Funding (22.3 %), Pharmaceutical companies (0.01 %) and Fund Raising, Investments and Bequests (77.69 %).

3. Identification of instances where Government goods and services could be delivered more effectively. That is, in a better way or more successfully.

The research that has been undertaken by Dr. Michael Summers clearly draws the link between a rise in body heat of 0.5 degrees when the temperature gets to at least 25 degrees which causes some patients to be significantly affected. The only way to get them back to a normal operating regime is for the surrounding area to be below 25 degrees. If the person has a heat pump installed this means that the matter can be managed by the individual concerned.

This research is supported by Doctor Bruce Taylor, Associate Professor at the Menzies Research Institute and Consultant Neurologist, who says that heat intolerance is a significant problem that affects people with neuromuscular conditions. "In the case of MS 90% of people with that condition are heat intolerant and as little as 0.5C increase in core body temperature can significantly

increase MS symptoms. People with these heat intolerant conditions do not have a choice about turning on their air conditioners” said Doctor Taylor.

By encouraging the installation of heat pumps by reducing the effective energy charge via a specific rebate, then unless there are other major complicating factors, the services of an Ambulance and/or the Emergency Department of a Hospital would not be required.

Based on the experience of other state jurisdictions, the rebate provided, ranges from \$158 to \$502 per annum.

This is an insignificant amount when compared to the cost of a single event associated with the need to use an Ambulance and or an Emergency Department at a Hospital.

The eligibility criteria for being able to access the rebate as outlined in the business case will be strict and include the need to obtain at the least a General Practitioner's support, but most likely this support will come from the consulting Neurologist.

4. Identification of instances where Government goods and services could be delivered more efficiently. That is, more cheaply, or in a more timely manner.

The statement made above focuses on the direct financial benefits to Government but what also needs to be taken into account is the impact on clients, their families and friends. The access to an air conditioner at a cost effective running cost means they are encouraged to use it and as a result places the ability to address their individual issues immediately within a family setting without highlighting to the broader community that they are having some medical issues.

The approach therefore what is being advocated is the provision of an electricity rebate addresses both the effective and efficient delivery of services to this particular group of individuals. Additionally, the Government would be viewed as being humane and concerned for the issues associated with a specific group of people.

5. Identification of services that the Tasmanian Keeping Cool Alliance considers should be a higher priority to Government.

- (a) The Alliance is of the view that current public policy that exists in other States of Australia, such as electricity concessions, are a useful and effective means of assisting people with heat intolerance. The Discussion

Paper that is attached sets out the medical energy concessions (also referred to as rebates) that exist in all other States in addition to general pensioner concessions. We refer to the list attached of maximum temperatures for Hobart this month.

The Alliance argues that there is no reason why Tasmanians should be deprived in this manner. If it is argued that this concession is not applicable due to Tasmania's climate, the evidence is to the contrary. Enquiries of the Bureau of Meteorology indicate that between 1991 and 2011 an average of 20 days per year had a maximum temperature of 26 degrees or above in Hobart at a sample weather station. The evidence is clear that Tasmanians suffering from heat intolerance are affected in this State as in any other. There is also anecdotal evidence indicating that there is a significant number of people with neuromuscular conditions that are detrimentally affected by cool weather and need to use heating.

- (b) The Alliance submits that Government needs to recognise that maximising the efficiency of cooling (and in some cases heating) for households containing people with neuromuscular conditions can minimise the economic and environmental costs to the community.

Page 3 of the Discussion Paper states: "These overall economic costs make it more likely that people on low incomes with MS (and any other heat intolerant condition) will struggle to cover the additional costs of keeping cool on hot days and nights. One consequence is not using air conditioners as much as they ideally should, resulting in increased health problems. This in turn can lead to increased costs through greater use of medications, visits to GP's and hospitalisation which all have a significant impact on the quality of life."

Another significant effect on the community is in relation to employment. In the case of people with MS although 87% of such people are of working age, and most people with MS are employed when first diagnosed, 80% are not employed 10 years after diagnosis. The combination of the resultant low incomes and the high economic cost of neuromuscular conditions means that energy concessions are often a critical factor in their lives and thus the community as a whole. Thus the Alliance argues that the Government is compelled to instigate these concessions for people with neuromuscular conditions suffering from heat intolerance.

Supporting Information

In further support of this submission we enclose a sample of extracts of letters provided to us from people suffering from a heat intolerant condition or supporting someone who is.

(a) Beth Muller - former MS client advocate:

"I am 72 years old and have lived with MS for the greater part of my life. My husband and I moved from Brisbane to Tasmania in 2001, leaving all our family and friends behind, because of my severe heat intolerance reactions, as I could no longer live in the hot humid Queensland climate. Because of the heat I could only go out of our air-conditioned home in our air-conditioned car to air-conditioned premises always using my wheelchair. A very restricted life!

Because MS is a neuromuscular condition, a rise of as little as .05C in my body's core temperature, causes very uncomfortable and debilitating changes in my body. When the ambient temperature rises to 23C, severe heat intolerance reactions instantly begin and because of MS my body does not have the natural cooling ability to sweat and I require other cooling devices.

My quickest way to relief is:

- Air-conditioned space
- An Ice Vest
- Ice cubes in pouches placed on/in my clothes
- Cold drinks, water or tonic water which helps to relieve the muscle cramps

My Heat Intolerance Symptoms:

- Pounding headache
- Increasing loss of cognitive ability
- Blurred vision
- Difficulty in recall
- Severe Muscle pain and cramping particularly in my shins and feet
- Bladder problems increased frequency (every 15minutes or so)
- Total fatigue
- Heart pounding
- Difficulty in walking
- Balance problems resulting in falls
- Difficulty in talking
- Often slight hand tremors

Anyone who has had suffered from Heat Stroke, or has run in a Fun Run and seen or experienced the wobbly collapse of runners, will recognise

some or all of the symptoms that I suffer every time the temperature rises above 23C. As my MS condition worsens I am finding that I am experiencing the above symptoms at lower temperatures and also when minor temperature fluctuations occur. Air-conditioning is a vital for my essential living necessities and although it is expensive I cannot live without it."

(b) Andrew Potter, an MS client advocate:

"I was formally diagnosed with Multiple Sclerosis during September 1989.....I was 23 years old, just married and just started paying off a house mortgage....interest rates back then just happened to be for us , 18.5 %!!!

Within a couple of months my range of symptoms increased dramatically and these pretty much continued to develop, start and stop, start again and stop etc over the next ten years.

I continued to be gainfully employed.....fulltime...and then part-time as my physical and sensory health allowed.

2001 I was unable to maintain my employment given my MS and my wife then returned to work when our two daughters were 6 & 3 years old respectively. At this time I was having a 2 year course of Chemotherapy..... with the concerted attempt and vision this may well push some of my progressive MS symptoms into abeyance.

Fortunately for me now some 11 years later, following the course of Chemotherapy & a huge range of symptoms variance & also buckets of different medications during this time I am currently managing OK with living alongside with MS.

One of the many symptoms I live with each and every day, however is heat induced fatigue levels.....

I am now employed part time and only during the peak holiday season as a Council Inspector..... to achieve success in this capacity I have been able to negotiate my times of work being early morning & late afternoon.... This is primarily for me to avoid the heat of the middle part of the day in Spring & Summer....Pretty much a vital component for me as most of my work is conducted outside.

As I mentioned to you only this morning, yesterday was not a good day as I experienced severe levels of fatigue post my work shift.....purely and

simply due to the challenges I experience in relation to fatigue levels that are exacerbated when it is hot!

I was fortunately able to utilise whilst at my place of work a Vehicle with Air-conditioning.... this keeps me going!!

It goes without saying our private residence has a substantial Electricity A/C each ¼.....most particularly given I use substantially more electricity to keep cool than would be usual for the generic community given my predominance of being very much fatigued....due to the temperature levels during our Spring and Summer period....."

(c) Ruth Noye, an MS client's mother:

"I am writing on behalf of my son, Rodney, who suffers from Multiple Sclerosis (MS).

I am soon to turn eighty years old and I am Rodney's primary carer.

MS sufferers are affected by heat more so than any other condition. Rodney has an air conditioner (a.c.) which he runs 24 hours a day for heating in winter and in particular cooling in summer.

When Rodney gets hot his whole body "collapses" and we refer to it as the "Jelly fish syndrome". He cannot even hold his head up which has its own inherent problems with breathing etc.

Whilst the pensioner rebate for electricity which we receive at the moment is appreciated, Rodney is finding it extremely difficult to make ends meet financially when it comes to the increasing cost of his Aurora electricity supply, not to mention continence aids, rent, food, mobility aids, pharmaceuticals etc.

Rodney finds it an absolute necessity to run the air conditioning 24 hours a day in summer and of course cooling uses more power than heating..."

(d) Judith Pfundt, MS client:

"I am a 56- year old woman, recently diagnosed with Multiple Sclerosis (MS).

MS is an incurable neuromuscular condition in which the body's immune system attacks itself.

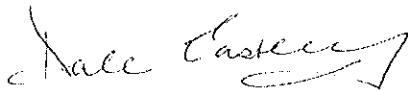
One of the most troubling symptoms of MS is heat intolerance, a symptom I experience frequently, and common to those suffering from the disease (about 90%). Warmer weather affects my central nervous system causing fatigue and discomfort, impacting upon my ability to participate in daily life. As temperatures increase I tend to hibernate in my air conditioned home, although I still experience frequent 'hot flushes' in the middle of winter. This is gradually causing me to become socially isolated, even affecting my ability to travel interstate to visit my daughters.

Obviously air conditioning is a necessity to my health albeit an expensive one. A medical cooling energy concession (which is in place in all other States in Australia) would make a significant difference to my quality of life and assist me financially to meet my increasing electricity bills..."

Recommendation

That the Tasmanian Government implement a minimum Medical Cooling Electricity Concession of between \$135 and \$165 for people who:

- (a) Have a Centrelink or DVA pensioner concession card or Centrelink health care card and
- (b) Have medical evidence supporting the need for the concession.



Dale Eastley
Chief Executive Officer