

MARCH 2009

New Premises	1
News from Executive Director	2
Client Support News	3
Research	4
Fundraising/Supporter News	5
Articles from Members	6-7
March of Faces Banner	7
Diary Dates	7

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NEW OFFICES

After 13 years at King William Road Unley, the MND Association together with 8 other charities have relocated to new premises at 302 South Road Hilton.

For the past 18 months, the groups were looking for modern and improved premises that would provide a more welcoming and acceptable working environment. The search for new premises was coordinated by Ms Sandy Puddy, Disability Information Resource Centre, who spent many hours searching and inspecting buildings throughout Adelaide. The groups are most appreciative of Sandy's tireless efforts.



[Peter & Ricki at work in our new office](#)

Please note that our **OFFICE HOURS** are

Monday to Thursday
8.30 am - 5.00 pm

If you phone out of these hours, please leave a message and we will return your call as soon as possible.

TENANTS	SUITE
Attention Disorders Association of SA Inc	7
Huntington's Disease Association (SA & NT) Inc	3
Motor Neurone Disease Association of SA Inc	1
Narcolepsy & Overwhelming Daytime Sleep Society of SA Inc	9
Neurofibromatosis Association of SA Inc	8
Physical Disability Council of SA Inc	6
SA Council on Intellectual Disability Inc	5
Stroke SA Inc	4
Talkback Association for Aphasia Inc	2

[Tenants at 302 South Road Hilton](#)

The move and outfit of the new premises were made possible by a one-off funding grant the groups received from the Office for Disability and Client Services, Department for Families and Communities.

The groups receive an annual grant from the Office for Disability and Client Services that covers the cost of rent, utility charges, some insurance charges and other items associated with renting the premises. Without this grant it is most unlikely that the groups would be able to maintain offices from which to operate.

While the MND Association is most appreciative of the building grant given to the groups, the Association will continue to press the Government to provide funding to support our client service activities.



[A view of our premises travelling south along South Road. Our premises are on the western side of South Road](#)

NEWS FROM THE EXECUTIVE DIRECTOR

Awareness Week 2009

MND Awareness Week will be held throughout Australia from 3 – 9 May. The State Associations will be undertaking various activities to raise public awareness of MND and to raise much needed funds for Association activities and to fund MND research projects.

In South Australia, the MND Association will have displays in shopping centres at Burnside Village, Westfield West Lakes and Westfield Tea Tree Plaza. There will also be merchandise for sale at selected businesses and medical centres that will be supporting the MND Association during Awareness Week. The annual Service of Remembrance will be held on Sunday 17 May.

For the first time MND Australia and the State Associations have engaged a national media company to coordinate all media during Awareness Week. This includes community service announcements on Channels 7, 10 and Foxtel. In addition, Channel 9 Adelaide are producing an advertisement for MND SA as part of our joining the Channel 9 Telethon. This advertisement is aimed at increasing public awareness of MND.

MND Australia has again asked the State Associations to undertake a **Call to Action: Living Better for Longer** to address national issues facing all people living with MND in Australia.

*The **Living Better for Longer** campaign continues this year to highlight to governments and the community that we need them to **CARE** about MND to ensure that all people living with MND and their families receive the **CARE** they need at, during and following a diagnosis of MND.*

The Key asks include:

- C**oordinated care based on the needs of the individual and their family
- A**ccess to timely information
- R**espite and research to find the causes, an effective treatment and a cure
- E**arly diagnosis and equipment

MND Australia and the State MND Associations are calling on all members around Australia to get active in telling their community and governments about the **CARE** they need to help them **live better for longer**.

You can get involved in this campaign *by using the letter template enclosed with the Newsletter to write to, or email, your government representatives to tell them about your needs*. You might also like to seek a meeting with them to tell them about the impact of MND on you and your family.

Please insert the information into the letter that is appropriate for you, adjust the text as you see fit and send or email to your Federal and State MPs and Senators, the health, family services and disability ministers and also the Prime Minister to let them know about your care needs. Let them know about the gaps in services provided to you but also let them know what is working well for you!

Electronic versions of the letter are available for emailing or downloading at the MND Australia website www.mndaust.asn.au

Contact details for your Federal MP and Ministers:

<http://www.aph.gov.au/house/members/index.htm#contact>

Contact details of Senators:

<http://www.aph.gov.au/Senate/senators/index.htm>

Contact details for your State MP:

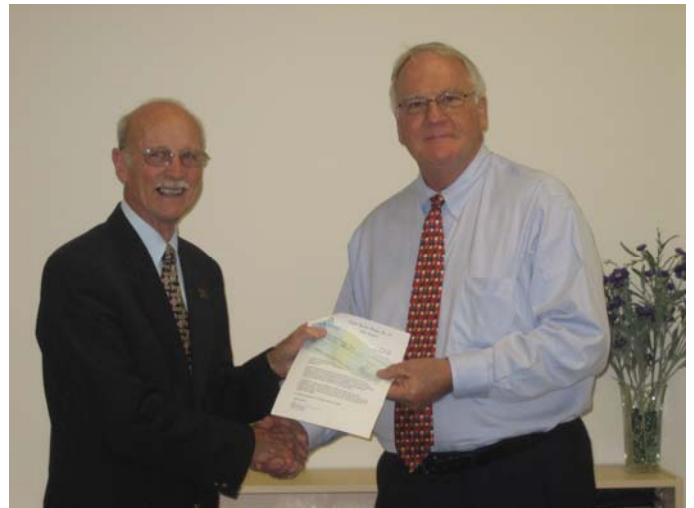
Each state MND association to insert link here

If you need advice about where or to whom you should direct your particular concerns, or if you need assistance in writing your letter, please contact the MND Association.

Donation from Freemasons Charity Fund

The MND Association was delighted to receive a donation from the United Service Lodge No 37 with a matching donation from the Freemasons Foundation. The Lodge will be supporting the Association for three years.

The Lodge was established in 1887 and its membership is from members and families of Australia's Armed Services.



The Lodge's Worshipful Master, Barrie Newman is pictured presenting a cheque for \$1,000 to MND Association Executive Director, Peter Whitehouse

Peter Whitehouse
Executive Director

CLIENT SUPPORT NEWS

Hi everyone

It seems not so long ago that I wished you all a Merry Xmas; here we are with Easter rapidly approaching. Scary!!

As I write this, the move and the inevitable logistical problems that accompany relocating have been addressed, and we are well settled into our new and considerably nicer premises on South Road. Please take the opportunity to visit at anytime – the kettle is never far off the boil.

We have been joined at the Association by an Adelaide University counselling student, [Jane](#), who joined us on Monday March 23 for an initial period of 10 weeks. In all likelihood this will be extended by a further similar period of time. I have had preliminary discussions with Jane regarding her objectives during her time with the Association and I am optimistic that once the fine details are finalized both Jane's objectives, and those of the Association, will be well served during her time with us. I will keep you informed of how this evolves.

Carer's Meetings

I have raised the issue of Carer's Meetings in previous issues of the Newsletter. Response to requests for feedback on this activity has led me to believe that for a number of reasons, carers are either uninterested in the activity or the various logistics associated with attending meetings are insurmountable. I am reluctant however to 'give up' on this initiative, therefore you will find in this edition of the newsletter a further attempt to clarify this issue. **Please take the time to send back your response in the reply paid envelope.** I realise that sometimes the logistics associated with organizing this type of activity poses its own difficulties. For this reason I have left out everything other than asking the question of whether you would attend carer meetings if you were able to. Addressing the logistical challenges can be tackled once the desire for the meetings is determined.

Networking

We have also discussed the idea of identifying individuals, both clients with MND and their respective spouses/partners who would be prepared to register their contact details with the Association and who would allow us to pass their contact details onto other clients/spouses/partners wanting to speak with individuals similarly affected. If this is something you would be interested in discussing further please contact me anytime.

I will be away from the Association for a couple of months for medical reasons beginning mid April (having some new body parts installed). I will still be available to be contacted if necessary on my mobile 0422 182 896.



Cheers
John Gilligan
Client Support Coordinator

RESEARCH

Another new MND gene discovery (FUS) implicates a common mechanism underlying MND

Two reports published simultaneously in the journal *Science* on 27 February 2009 describe mutations that have been identified in the gene encoding fused in sarcoma (FUS).

One study describes FUS mutations found in Australian and UK MND families; the other reports FUS mutations in North American MND families.

FUS mutations account for between 3% and 5% of MND families. As such, FUS is the second most common known cause of MND after SOD1. However, a substantial significance of this discovery lies in the functional similarity of the FUS protein with TDP-43, a protein previously shown to be abnormal in MND. Abnormal TDP-43 pathology is thought to be present in over 90% of all MND cases (sporadic and familial MND combined). In contrast, SOD1 pathology only accounts for about 2% of all MND cases. Until now, the known MND genes (including SOD1, TDP-43 and ANG) had diverse and seemingly unrelated functions.

It has been difficult to identify a common defective mechanism underlying motor neurone degeneration. With the discovery of abnormal FUS in MND, a common defective mechanism has been identified. Both FUS and TDP-43 are RNA binding proteins that are thought to process and transport RNA. They both normally reside in the nucleus of the cell. In the affected motor neurones of most MND patients, TDP-43 is shuttled out of the nucleus to the cytoplasm where it forms aggregates. This same process has been found to occur with FUS in MND patients who carry a FUS mutation. Research efforts can now focus on this common defective mechanism to better understand the disease biology and ultimately give insights into new therapies that target that defective process. Development of cell and animal models based upon mutant FUS should help accelerate the search for therapies.

This work was made possible by the dedicated cooperation of families with inherited MND. In Australia, the work was supported by the National Health & Medical Research Council and the Peter Stearne Grant for Familial MND from the MND Research Institute of Australia.

Dr Ian P Blair and Professor Garth Nicholson
ANZAC Research Institute & University of Sydney.

RESEARCH

SPORADIC MND, IS IT ALL IN THE GENES?

Worlds largest genome-wide screen for genes linked to sporadic MND finds nothing... Yet!

The hunt is on all over the world for variations in people's genetic makeup that may increase risk of sporadic motor neurone disease. So far these ambitious scientists are mostly coming back empty-handed. This is likely due to the fact that, like snowflakes, each case of MND presents differently. This is the conclusion the authors of the largest genome-wide (a genome is a person's complete set of genes) association study to date; "A two-stage genome-wide association study of sporadic amyotrophic lateral sclerosis (also known as MND)", published in *Human Molecular Genetics*.

It appears that the variability present in MND, both clinically and genetically, means that researchers have their work cut out for them. But researchers have not given up hope, the International Consortium on Amyotrophic Lateral Sclerosis Genetics, sponsored by the ALS Association (ALSA; USA), is working to collect thousands of subjects by archiving and analysing genetic data in one large repository.

Researchers uncover gene thought to be associated with sporadic MND

Dr. Robert Brown and his group at the University of Massachusetts have teamed up with researchers in London and Belgium to identify a gene whose normally occurring variations appear to determine the susceptibility to sporadic (non-familial) MND.

The gene, elongation protein 3 (ELP3), is a gene that influences RNA metabolism. RNA is the messenger molecule communicating the coded blueprint hidden in DNA and aids in the production of functional proteins.

Dr Brown's group are excited by the findings, and are busy testing the effects of this gene on different cell types and in mice. "In the longer term, our goal as always is to determine how we can use this information to develop treatments for MND" says Dr Brown. The findings have been published in *Human Molecular Genetics* in an article titled "Variants of the elongator protein 3 (ELP3) gene are associated with motor neuron degeneration".

DIET AND MND

Fruit and vegetables join the fight against MND.

To date there have not been many researchers tackling the question of whether there is a link between diet and MND. However, a team of researchers in Japan have attempted to do just that. Their work was published on February 11 2009 in the journal *Neuroepidemiology*. "We investigated the relationship between dietary intake of vegetables, fruit, and antioxidants and the risk of MND in Japan" reports Dr Okamoto and co-workers.

RESEARCH (Cont)

153 MND patients and 306 age and gender-matched controls were asked about their diet. The researchers found that "a higher consumption of all fruits and vegetables was associated with a statistically significantly reduced risk of MND".

This led the researchers to suggest that higher intake of fruit and vegetables gives protection against the onset of MND. This research must be viewed with caution, since there are many other lifestyle choices that may be associated with the level of fruit and vegetable intake. For example, people who eat more fruit and vegetables may also be more likely to participate in regular exercise and other healthy activities and thus, in general, be in better health.

AWARENESS WEEK

3 – 9 May 2009

During this week, Community Access sites have been booked at the following shopping centres to display MND information and merchandise.

Friday, 1 May	Burnside Village
Wednesday, 6 May	Tea Tree Plaza
Friday 8 May	West Lakes Shopping Centre

Thank you to everyone who has volunteered to assist at the above shopping centres. You will receive a written confirmation of your time shortly.

We still require volunteers to assist at West Lakes Shopping Centre on Friday 8 May.

If you have an hour or two to spare and would like to assist at West Lakes, please phone our office on 8234 8448.

We are hoping to target as many people as we can during this week. Linda Kluske, one of our tireless volunteers has been busy in the past weeks contacting various medical clinics and other businesses to see if they would be interested in having MND merchandise during Awareness Week. She has been extremely successful. Thank you Linda.

Do you know of any friends or businesses who may be interested in collecting for MND, or take merchandise for sale?

Please contact us if you do.

Thank you

Lions Xmas Raffle 2008 Winners

- 1st Prize - Andrew Holmes, Woodcroft - ticket number 8125
- 2nd Prize - Patrick Catareanti, Lockleys - ticket number 2819
- 3rd Prize - Manuel Cruz, Ingle Farm—ticket number 2931

FUNDRAISING & SUPPORTER NEWS

Walk to D-Feet MND

REGISTER NOW!

Sunday, 26 April 2009 Start 11.00 am

Adelaide Sailing Club Barcoo Road

Bring your family ... Bring your friends

Bring your dog ... Organise a group of friends!

4km walk with optional 1.8km extension loop to Henley Sailing Club.

Wheelchair / stroller friendly. Free Sausage Sizzle at end of walk. Water and fruit supplied. BYO chairs, rug or table. Coffee, tea and drinks available for purchase from the Adelaide Sailing Club.

Have you received your registration form? If not please contact our office on 8234 8448 or download from our website www.mndasa.com.au

Adults \$25.00 ... Children \$10 (5-18 yrs) ... Families \$55.00

Start collecting sponsors now. Prize for top adult and child fundraiser.



Channel 9 Telethon

"Take 9 Movie Card"

Save \$130.00!



Purchase a "Take 9 Movie Card" for **\$15.00** and you will receive:

- 2 FREE tickets
- 2 people attend x 9 times @ only **\$9 per visit** (each pay \$9.00)
- For concession card holders, students and children there will be a further discounted price of only \$8.00 for any movie
- Plus a bag of fruchocs on use of card first visit (not on use of free tickets)
- Tickets available from early March 2009 and valid for use until 28 February 2010
- Available at all sessions every day (unless session is sold out)

Phone our office on 8234 8448 to purchase your card.



Bayer



Australian Central

Thank you to all of our supporters who have purchased tickets and/or helped us to sell tickets in the 2009 Australian Central Community Lottery.

We are well on the way to reaching our goal of selling 200 books of tickets. Our aim is to raise \$4000.00 for MNDASA.

We currently have 47 books of tickets left to sell.

If you can help us to sell our remaining tickets, we would be grateful for your assistance. Tickets sell for \$2.00 each and the full amount from each MNDASA ticket sold will be donated to MNDASA.

Please call the office on 08 8234 8448 if you can help us to sell our final supply of tickets.

Raffle

We will be holding a raffle on the day of the walk and have currently received donations from the following

Adelaide Shores Holiday Village - two nights accommodation for two adults \$400.00

Haigh's Gift Basket \$80.00

Charlesworth Nuts "Feastful of Flavour Basket"

Jurlique Gift Packs

Family Pass to *Adelaide Zoo*

Entertainment Book \$65.00

Cos Restaurant \$50 meal voucher

Sky City 2 x \$50 food and beverage vouchers

2009-2010 ENTERTAINMENT BOOKS ON SALE NOW

Thank you to our supporters who regularly buy their Entertainment Books from MNDASA. MNDASA receives \$13 per sale.

Now is the perfect time to purchase the 2009/2010 edition. The books are available from our office at 302 South Road Hilton or phone us on 8234 8448

Entertainment Books cost \$65.00 each (plus \$7.50 for postage and handling) and they offer great discounts at many of SA's excellent restaurants, leisure operators and casual dining outlets.



CAN YOU HELP?

Volunteers required to assist with Walk preparation

If you can spare an hour or two on **Wednesday 22 April** or **Thursday 23 April** to assist with processing of registrations and other last minute tasks, please contact us on 8234 8448.

YOUR STORIES

From **Patricia McAuley**

In 2007 when no-one knew what was wrong with me, I decided to enter the Masters Games that year. I started walking regularly both on flat surfaces and those with hills. I had no idea that one had to walk in the same fashion as the Olympic athletes.

Fortunately, luck was with me! A kindly Olympic judge showed me how to walk heel, toe, keeping leading leg absolutely straight and unbent. I listened carefully and after a few practises had mastered this awkward step.

I had entered in the 1500m walk, the 5km walk and the 10km walk. I won a bronze medal in the 1500m and silver in the 5km. I did not walk in the 10km event as the day was hot with a hot northerly wind. Discretion is the better part of valour!

When an invite to the Masters in Geelong appeared on my computer I decided to attend and enter the same three events, hoping the weather would not be too hot. You will remember those very hot days we had, so for a week not too much training unless the night had been cool. Then it was possible to walk 12km before it became too hot. Starting at 0500 hours it was possible to do the walk and be home before 0700 hours. Though I had now been diagnosed with MND, only my voice was affected, so I went to the games with the blessings of my neurologist and my doctor of Chinese Medicine. I had been having acupuncture for some months and found it helped me greatly.

I left home on February 18 in my car and headed for Clunes where I could stay with friends for a couple of days. The roads have improved so much that it was a surprisingly quick trip. I had not seen these friends for eight years so there was much catching up to do over the next couple of days. On the Friday they lead me into Ballarat and set me on the road for Geelong. A friend had booked accommodation for me that was handy both to Geelong Football Club Grounds and the John Landy Track and Field. Walking distance to both in fact.

On registering I discovered that the 10km race walk was scheduled for 8 am on the Saturday. The instructions for the starting point were none to clear, but I finally found someone who knew and made my way to the track. Just under two hours later I had my first Gold medal. Quite a thrill to stand on the podium and be presented with the medal.

No rest for the wicked! The 1500m was scheduled for the following day at 3.05 pm. It was quite a warm day and I was annoyed to find no water was made available for the competitors. I had told the organisers when I registered that I was also diabetic and diabetics need to drink at least every second lap. I was attempting a personal best, but by the time I finished I was borderline dehydrated. A kindly woman shared her water bottle with me and I soon obtained two more drinks. Thankfully I had managed a "personal best" in this event. I did not wait for the presentation as I needed to get back to the motel and have a refreshing shower.

On the Monday I headed for Portlinton as I was not required to be at the track that day. It was refreshingly cool down there and a nice safe beach to do some swimming—no hungry sharks! Later that day I walked back to the main town a round trip of 5km and bought some salad to have with salmon for dinner. I had been suggested that I try the local mussels but upon enquiring was warned that they were very "fishy" and "fishy" is something I try to avoid.

On Tuesday I was up and away early and heading back to Geelong. I got a park at the Landy field and waited none too patiently for the 5km which was scheduled to start at 12.30 pm. I had a high car breakfast along with some protein and had plenty to drink. Water was available on the track and again I set out to do a personal best. I remember overtaking someone in a younger age group and hearing her ask, "How can you walk so fast at the end of the race?" When we had all finished I told her I always tried to walk the final lap a little faster.

After the medal presentation— yes, another Gold Medal and a Personal Best. I was also presented with my Gold medal for the 1500m event. Free massages were available so I decided to have one before I returned to Clunes. It was very relaxing. I was so fortunate, no lactic acid build up after any of the events. So I bid new found friends farewell and headed back for Clunes, arriving in time for a lovely fresh salad for dinner.

Wednesday morning I packed up and bid my friends farewell. An easy drive home though crossing the ferry at Wellington is a little hazardous with the river so very low. Very steep drive down to the ferry and getting off an equally steep climb.

A woman I met at Geelong lives in Hackham, so we are both in training for the World Masters Games in October. I am hopeful of maintaining my fitness and am looking forward to meeting athletes of all ages from all over the world. A friend, a very sweet Thai girl has offered me a bed. She lives on the right side of town for easy access to the Olympic track. We will share the driving and take a couple of days to get to Sydney. I am hopeful of setting new Personal Best times for all events. I have mastered the correct gait for walking and the judges around the track have told me so. Sydney should not be too hot in October and anyway one can always take a dip in the pool in the afternoon when the swimming competition has ended. If Adelaide has as many enclosed heated pools as Melbourne I would also compete in the swimming—this was my preferred sport as a teenager. But my nearest heated pool is in North Adelaide so swimming is out!

By the time I train and compete in these games I might need a couple of new knees!



A proud Patricia with her 3 gold medals!

We welcome articles, stories, poems etc from all of our MNDASA members and friends. If you would like to send us an item for the next MND Newsletter please send us an email at: admin@mndasa.com.au or post your information to PO Box 2087 Hilton Plaza SA 5033.

YOUR STORIES (Cont)

Fundraising for MND Research



Jean jumping from the plane

Elizabeth North great-grandmother [Jean Atkins](#) really jumped to great heights in memory of her daughter Tina, 2400m to be exact.

Jean's daughter Tina died on 21 November 2008, three years after being diagnosed with MND. Jean hoped the fundraiser would draw attention to the disease and raise money to find a cure.

On Friday 28 February just before her 80th birthday, Jean jumped out a plane to raise money for Motor Neurone Disease research. She was joined by her son Tony, grandchildren Jason and Che and friends. Fifty family and friends gathered below to watch this special event.

Jean and her husband Jim have been overwhelmed by the response. \$2,841.50 has been raised.

Well done Jean!



Jean getting more confidence as she heads towards the ground!

DIARY DATES

Walk to D-Feet MND

☺ *Sunday 26 April 2009*

Registration forms now available



Awareness Week 2009

☺ *Monday, 3rd May - Friday, 9th May*

Planning Committee busy preparing for this very important week.

Service of Remembrance

☺ *Sunday 17 May 2009*

2.00 pm - Disability SA Chapel
Fisher Street Fullarton

Professor Roger Pamphlet DNA Blood Bank

☺ *Tuesday, 26th May*

11.00 am - 3.00 pm at Fullarton Centre

Information will be forwarded to clients and their families shortly

ACCU Raffle tickets

☺ *Friday, 29th May*

Please return all raffle books by this date

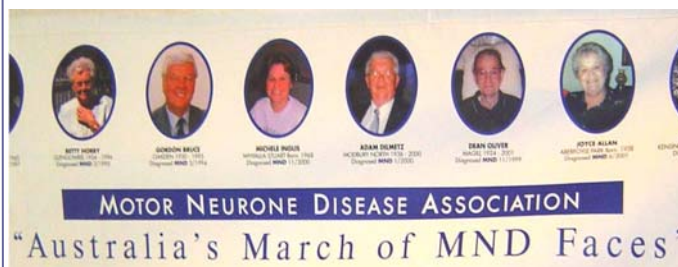
MARCH OF FACES BANNER

The March of Faces banner features a photographic display of people with MND.

MNDASA has produced two banners and we aim to produce a third banner as soon as we have 20 new faces. *At the present time we have eight new faces.*

If you have MND you can be included in the banner once you have completed a permission form and submitted a photograph of yourself. You are welcome to include family or caregivers in the photo if you wish.

Family members are also able to submit a photograph in remembrance of a person who has died from MND. If you would like further information, please contact us on (08) 8357 0245 or email us at: admin@mndasa.com.au



Do you have an item for sale that may be of benefit to MND clients? If you would like to advertise an item in our next Newsletter, please send us an email at: admin@mndasa.com.au ... or you can post your information to PO Box 2087 Hilton Plaza SA 5033.



If undelivered, please return to:

The Motor Neurone Disease
Association of SA Inc

PO Box 359

Unley SA 5061

MND Newsletter

Print Post Approved

PP 544876/00014

PRINT
POST
PP 544876/00014

POSTAGE
PAID
AUSTRALIA

Families and Friends are invited to attend
the
Annual Service of Remembrance

to be held on

Sunday 17 MAY 2009

at 2.00 pm

in the

Disability SA Chapel
103 Fisher St, Fullarton
(enter via gate 2 or 3)

Afternoon tea will be provided

MND Service of Remembrance

If you will be attending, please complete this slip *in the reply paid envelope*
by Monday 11 May 2009.

I / we will be attending the Service of Remembrance on 17th May 2009

Name /s _____

Name of person/s to be remembered _____



Your Name
Your Address
Your Telephone no. and/or Email

Politician's Name and Address
Date

Dear

Re: Living Better for Longer MND Week 2009 (3-9 May)

I am one of about 1,300 people living in Australia today who has motor neurone disease (MND), *or I am a carer of a person with MND*. MND is a rapidly progressive neurological disease, with an average life expectancy of only 2-3 years from diagnosis. Each day in Australia at least one person dies of this cruel disease and another is diagnosed.

I am writing this letter/email to you because we need you to **CARE** about MND to help us to get the care and support we need to **live better for longer**.

The Key asks of MND Australia include:

Coordinated care based on the needs of the individual and their family

Access to timely information

Respite and research to find the causes, an effective treatment and a cure

Early diagnosis and equipment

My needs are:

INSERT YOUR NEEDS HERE

Federal and State governments are now working more closely together to address the needs of people with disability and chronic and complex conditions. We seek your support to ensure that all people in Australia living with MND now, and in the future, are able to access care and support based on our needs to help us **live better for longer**.

Please feel free to contact me either by telephone, email or at the above address.

I am looking forward to your response.

Yours sincerely,

Your signature



Write your name and address here.



Write what is appropriate for you - suggestions include:

The types of respite you might need, personal care for an hour or two a day to help with showering etc, access to a multidisciplinary clinic, aids and equipment, equipment to help with breathing, a package of care, case management, palliative care, counselling etc etc



Your signature and a note if you are signing on behalf of a Support Group