THE NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NSW

mnd New South Wales

FORUM

March 2009

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Shave for MND

Sally Johnston, a university student with a passion for wanting to do something for the Association, decided to raise much needed funds for MND NSW by novel means.

Sally's grandmother died of motor neurone disease a year ago. Sally, together with a friend from work, Simon McKenzie-Smith, decided to Shave for MND.

Supported by her mum, Anne, Sally held a 'Shave for MND' drinks party on one of the hottest recorded February days. Invitations were sent to family and friends and, on the day, cousins, parents and friends snipped away. Sally's and Simon's hair dropped to the ground as their friends dropped donations into the collection buckets. What a success!

MND NSW would like to thank Sally and Anne Johnston of the ACT and their wide network of supporters for organising a great way for a bunch of people to get together, have fun, relax and raise funds. Thanks also to Simon for participating in this event.

(clockwise from top) Sally, ready to start, with her mum, Anne; an eager supporter assisting the cause; Sally 'shaved for MND' ; Sally and a friend relieving Simon of his locks.

Handmade with Love

Julie Nichols, founder of Canberra's Handmade markets has said she was overwhelmed by the response to the Handmade with Love market day held on 7 February. There were around 3000 visitors and all stallholders remarked on the wonderful atmosphere that filled Albert Hall. Julie coordinated the sale of MND NSW merchandise at the markets and also ran a raffle on the day with proceeds going to the Association. Thanks Julie.

The market will be on again from 10am to 4pm on 23 May, at Albert Hall, Canberra. There will be more than 70 stalls, featuring the work of talented artists, gourmets, craftspeople and designers; and of course, MND NSW merchandise and raffles. For more information visit www.handmademarket.com.au

Getting ready to Trek

Some of our Kokoda Trek participants have started their fundraising in earnest. Justine Wallis from the Illawarra recently held a barbeque at Bunnings, Wollongong, with lots of help from her family and friends. This is one of the many events that Justine is holding to help raise the funds for Kokoda Trek. We do have some spots still available on the Trek or alternatively you can visit www.everdayhero.com.au to sponsor one of the participants.

Justine Wallis, with her grandfather, Ron Wallis at the barbeque.

Tuesdays with Morrie

The special MND NSW fundraising event, Tuesdays with Morrie, on Monday 16 February, resulted in a full house at the lovely Ensemble Theatre. The stage adaptation of Mitch Albom's book was beautifully directed with moving performances by Glen Hazeltine as Mitch, and Daniel Mitchell as Morrie. A great evening was had by all attending. Thank you to the cast, crew and management of the Ensemble Theatre for supporting MND NSW and for providing our supporters with the opportunity to attend.

Motor neurone disease is known as amyotrophic lateral sclerosis (ALS) or Lou Gehrig's disease in some countries. The Blue Cornflower has been adopted in most countries as the symbol of hope for people living with motor neurone disease.

A Message from the CEO

The new year has begun and while the Association is coping well, we are starting to feel the effects of the current economic climate.

The tragic events caused by bushfires in Victoria and floods in northern Queensland bring home the plight of others and make us realise that we are, in fact, a small part of a larger society. We can help in small ways and by doing so, as a wider society, make a huge difference.

Eighty per cent of our recurrent funding depends on the generosity of our supporters. We appreciate that even though everyone is feeling the effects of the changing economic outlook, individuals and communities as a whole have been able to get together to support MND NSW.

Highlighted on the front page of this edition of *Forum* are just some of the events that individuals, community groups and corporations have pulled together to support people with motor neurone disease. If you would like to know more about supporting MND care, our equipment programs and MND research please call either me, ph. 8877 0914, or Kym Nielsen, Fundraising Manager, ph. 8877 0912.

Services are increasing and, in partnership with another non-profit association, we are in discussion with the New South Wales Government about communication device assessment and provision. After an initial meeting with the Department of Ageing, Disability and Home Care (DADHC), the partnership has been asked to provide some more information, particularly around training packages for assistive devices and the use of video conferencing for assessment. More information will be provided in upcoming issues of *Forum*.

The Association's calendar is full for the first half of 2009. Upcoming events include our regular information evenings for people recently diagnosed with motor neurone disease, a Care for Carers program and the hosting of the 2009 National MND Conference in June. This will be the fifth national motor neurone disease conference, and we expect it to bring together nearly 200 healthcare and disability professionals from across Australia and New Zealand, to discuss the latest developments in motor neurone disease care, advocacy and research.

To all those who have lost loved ones and friends to MND I extend, on behalf of the Board and Staff, our deepest sympathy.

Graham Opie
Chief Executive Officer

Join us in raising community awareness of motor neurone disease during MND Week 2009

Introducing…

Suzanne Rymer
Information Line Advisor

As Information Line Advisor at MND NSW I'll be answering telephone queries and providing information to members, carers and health professionals. My background is working as an occupational therapist, in the United Kingdom and Australia.

I have a passion for travel and enjoy the theatre, art and cooking. I'm looking forward to meeting you either in person or by phone over the coming months.

MND Week 2009

3-9 May

You can help create awareness about motor neurone disease during MND Week

We are looking for lots of volunteers to sell merchandise for MND Week.
You can choose the time and place. In the past we have sold at shopping centres, railway stations, hospitals and lots of local rural stalls.

Are you a member of a golf club, tennis club or gym? Maybe you could sell our wonderful socks or puppies at your local school. You could even ask one of your local stores if you could place a box of merchandise in their business for a week.

Get creative - there are lots of opportunities for you
to help raise awareness about motor neurone disease.

Contact Ayse today at MND NSW ph. 8877 0908 or email aysed@mndnsw.asn.au

Family Support

Field trip to Orange

In February, I spent the day in the Orange and Lithgow districts with Jenny Judd, MND NSW Regional Advisor, who was making a field trip.

It was a great opportunity for me to meet some of our members in their homes and also the members, carers and others attending the local support group. Thank you to the members in the Orange-Lithgow area for your hospitality.

My trip was also a reminder as to just how hard our regional advisors work on these field trips; fitting in as many visits and contacts as they can. Our seven regional advisors all work part-time and cover a particular geographical area of NSW or ACT. They are often away from their Sydney, Newcastle or Canberra offices for several days at a time; meeting with members, providing MND educational sessions to health professionals and attending case conferences, MND clinics and services.

Our regional advisors try to meet every member living in their geographical area as soon as possible after they join the Association so that when you talk to them on the phone you can put a face to their name. For people in regional areas this is usually on the regional advisor's next field trip to your area.

The MND Info Line operates from 9am to 4.30pm (EST) Monday to Friday, for people located in NSW, ACT and NT ph. 1800 777 175

Information evening

We had 22 people attend our information evening in February. This meeting provides the opportunity for those recently diagnosed with MND, together with their family and friends, to find out more about MND and meet others in similar situations.

These evenings are held every few months and our next information evening will be held at 6.30pm on Tuesday 13 May. During the evening we provide an overview of MND, discuss issues surrounding diagnosis, talk about the impact of this on people and provide information on support services available from MND NSW and within the community. Please contact the MND NSW Centre at Gladesville ph. 1800 777 175 if you would like more information.

Welcome

I would like to welcome Suzanne Rymer, our new Information Line Advisor, who commenced in this role in December. Suzanne is now taking most of the calls that come in on the MND Info Line. This telephone service provides a point of contact within the Association for people with MND, their family and friends; and a point of contact for health and community care professionals wanting information about MND and related topics.

As Information Line Advisor, Suzanne is also a substitute contact person for members when they are unable to contact their regional advisor. The Info Line operates from 9am to 4.30pm (EST) Monday to Friday, for people located in NSW, ACT and NT ph. 1800 777 175.

National MND Conference 2009 in Sydney

The national conference will be held in Sydney on 23 June and the Family Support team is very busy with preparations. We are currently developing the program of presentations around the theme of **MND** **C**are **A**dvocacy **R**esearch and **E**xcellence. Attendance is primarily for health and community care professionals from across Australia who work with people with MND. The conference provides an opportunity to educate those attending about MND so that the quality of care for people with MND continues to improve.

Economic impact of neurological illness on well-being

Last year, some of our members participated in a research study conducted by Deakin University and the University of Melbourne. The research was looking at the impact of economic pressure and psychosocial factors on the general well-being of people with chronic neurological illnesses and their families. The researchers used questionnaires to gain this information over a twelve-month period.

The first aim of the study was to examine whether economic factors contribute to a prediction of quality of life over a twelve-month period for the person with the illness and their partner/carer. Previous research in this area shows that people living with a progressive neurological illness are faced with significant increases in costs, such as illness-related expenses, as well as a reduced income. What has not been clear is how these factors contribute to the experience of economic pressure.

The second aim of the study was to examine the impact of psychosocial variables over time, on both the quality of life of the person with the illness and their partner/carer. There has been little research undertaken to date that has examined the importance of psychosocial variables such as mood, interpersonal factors and social supports on the quality of life of people with a progressive neurological illness, and even fewer studies that have investigated these factors with regard to partners/carers.

The background to this is that a person’s mood and level of satisfaction with interpersonal relationships and social supports can significantly impact quality of life. For people living with a neurological illness, opportunities to socialise and pursue personal interests can become limited. They may also have an increased reliance on supportive social networks. For their partners/carers, the strain and responsibility of the carer role can be extremely demanding and socially isolating, increasing the partners/carers need for reliable social supports.

The final report from this research was released recently and I just wanted to provide a very brief summary of the findings*:

(Continued on page 4)

Family Support *(continued)*

(Continued from page 3)

A total of 257 people living with a neurological illness and 192 partners/carers completed the research questionnaires twice over a twelve month period.

Of people living with a neurological illness, there were 52 people living with motor neurone disease (MND), 26 people living with Huntington's disease (HD), 79 people living with multiple sclerosis (MS), and 100 people living with Parkinson's disease. Of partners and carers, there were 49 MND, 43 HD, 40 MS, and 60 Parkinson's participants.

Some of the findings included:

From an economic perspective

- *People living with MND, MS and Parkinson's demonstrated a substantial increase in spending cutbacks over a twelve month period.*
- *Among people living with a neurological illness, cutbacks in spending predicted economic pressure for all illness groups and was a stronger predictor of economic pressure than income or illness-related expenses.*

From a quality of life perspective

- *For people with MND, a combination of economic factors (income, illness-related expenses, spending cutbacks and economic pressure) significantly predicted low quality of life.*
- *The severity of symptoms was a significant predictor of low quality of life for people with MND, HD and MS.*
- *Having a negative mood significantly predicted low quality of life for people with MND and Parkinson's.*

For partners/carers

- *Mood significantly predicted quality of life for partners/carers of all illness groups.*
- *Psychosocial variables were significant predictors of quality of life for three out of four partner/carer groups (MND, HD and MS).*
- *For partners/carers of people with MND, marital relationship satisfaction significantly predicted quality of life.*

Thank you to all who participated and to the researchers for investigating these important issues. Findings from studies such as this one are used by the MND Association when advocating for services, talking about MND in the community, planning educational sessions, developing our own services and undertaking projects with other organisations.

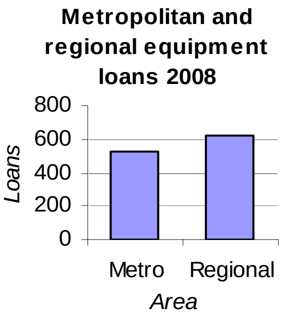
Gina Svolos
Manager, Family Support

**McCabe M, Firth L, O'Connor E, Kiehne M. 2008. Economic impact of neurological illness on well-being, Deakin University and the University of Melbourne.*

All equipment items are loaned, delivered and maintained free of charge to members. Increasing fuel prices have unfortunately also increased MND NSW transport costs .

Equipment

There is always a demand for equipment and during 2008 there were **1143** items loaned to members in NSW and ACT. Just under **1000** items were retrieved during the same period.



There has been a slight geographical swing in the demand for equipment: **54%** of loans were to members in regional areas.

The **top ten** items loaned during 2008 (below) shows a significant increase in the demand for Lightwriters, cushions and raiser-recliner armchairs.

Equipment top ten	Items loaned
cushion	102
manual wheelchair	98
armchair - raiser recliner	76
mattress overlay	69
shower commode	69
bed - electric medical	54
Lightwriters - communication	49
powered wheelchair	46
hoist	44
sling	44

The demand for electric beds, hoists and electric wheelchairs has remained steady with a total of 54 beds, 44 hoists and 46 electric wheelchairs loaned. Manual wheelchairs are always in high demand and 98 manual wheelchairs were loaned during 2008.

Just over $200,000 was spent during 2008 on purchasing new equipment. Beds, for example, are about $2000 each and we purchased ten new beds to help meet demand. Some electric medical beds are also hired by MND NSW for members in regional or hard-to-access areas. During 2008 we hired 21 beds for loan to members in these areas.

When purchasing equipment items, we can get a reduced price if we make bulk purchases, for example during 2008, bulk purchases of manual wheelchairs, Lightwriters and electric wheelchairs were necessary to help meet the demand.

Tracking the trends in our equipment loans helps us plan future purchases, organise storage and budget for transport costs. The equipment loan service is highly valued by our members - thank you to our donors for their continued support of the equipment loan pool during 2008. Thank you also to the NSW Department of Ageing, Disability and Home Care for their continued support, which helps to fill gaps and decrease waiting lists for equipment items.

Maree Hibbert
Equipment Services Coordinator

Special Projects and Carers News

MND Week
3-9 May
2009

FlexiRest

According to a report commissioned by Carers Australia, the cost for the government to provide the services that carers currently provide in the home, would be $30.5 billion! It's a staggering figure.

We also know that the monetary figure says nothing about the many other costs associated with caring – social, financial, emotional, relational, some would even say spiritual. People care because they are a partner, husband, wife, parent, brother, sister, friend. Often, they do not even consider themselves a carer. It's just what they do because someone they love is ill.

We need to care for our carers. We know the value of the work you do. One way to do this is to help give you a break. The term that's used is 'respite'. Commonwealth Respite Centres provide a range of respite options such as in-home or centre-based care and emergency respite. However this often does not suit what many people with MND and their families want.

In 2007 the New South Wales Department of Ageing, Disability and Home Care (DADHC) was approached by MND NSW, the Muscular Dystrophy Association of NSW and MS Limited about respite needs. A four-year flexible respite program, which became known as *FlexiRest*, was established from July that year to provide money for respite that cannot be provided by other services. It's a fantastic program offering real choices about how you and the person you are caring for, choose 'to take a break'.

There are often mixed feeling about taking time out. Some people feel they do not deserve to use FlexiRest – 'there are more needy people than me'. Others feel it's just too hard to arrange or feel guilty about wanting time away.

However, 70 or so MND NSW members and their carers have used FlexiRest to visit relatives, go fishing, stay in a holiday chalet, take a harbour cruise, have a massage: whatever lifts the spirits, recharges tired batteries or gives a new perspective to life. Carers are valuable people. A nationwide strike would cause absolute chaos! We need to support the job you are doing. Talk to your regional advisor about respite and FlexiRest.

Bereavement Group

A lunch was held in February for those experiencing bereavement during the past 12 months. It was attended by 14 people; some travelling from the south and north coast and western Sydney to attend. One of our volunteers, Pamela, who has also cared for someone with motor neurone disease, was at the meeting and was able to share her experiences. Thank you to all for making it a valuable day for those attending.

Care for Carers

The MND NSW **Care for Carers Program is starting in May**. If you are new to caring for someone with MND or have been caring for a while and want some extra information and support, then come along and join us.

Health professionals will talk on a range of subjects such as aids and equipment, preparation of the home, how to eat well with MND, getting to grips with all the services, how to manage swallowing and communication problems and the emotional challenges of caring. Information is very valuable but from our experience, being with others in a similar situation, sharing experiences and ideas, is one of the program's great strengths.

This program runs over four consecutive Tuesdays starting 5 May from 10am to 3.30pm at the MND NSW Centre in Gladesville and you will need to register to attend. To find out more ring Gina Svolos on 8877 0999 or speak to your regional advisor.

Jane Barrett
Family Services Coordinator

Join us during MND Week 2009 at the MND NSW

Day of Hope and Remembrance

Wednesday 6 May 2009
1.30 to 4pm

Soka Gakkai International Centre
3 Parkview Drive
Sydney Olympic Park

We will have guest speakers, a vocalist, candle-lighting ceremony
and of course afternoon tea with good company.

Close to public transport and parking is available.
Contact MND NSW to register if you are planning to attend ph. 8877 0999 or 1800 777 175.

Mailbag

Dear MND NSW,

I thought I would pass on this priceless photo of my two daughters, Brianna (L) and Kiara (R) with their amazing grandparents, Gordon and Denise Druitt.

In the midst of dressing the Christmas tree this year, they thought it would be fun to dress Grandma and Grandad up as Mr and Mrs Claus! Being the people they are, they didn't mind being draped in tinsel and baubles and whatever else took the girls' fancy!

You might also notice that Mum (Denise) also proudly sports the Never Give Up wristband and is holding her plush puppy, Scooter, for the photo. Both are never far from her side.

Santa will be hard pressed to find a better gift that these two wonderful people for my kids this year!

Thanks to everyone there at MND NSW for the fantastic work you do for people like Mum and for all of us.

Nicole Papasidero

I Didn't Choose

I didn't choose:
To be incapable of moving;
Spending my days Foxtel watching.

I didn't choose:
To need to be fed;
Or be hoisted into bed.

I didn't choose to need constant help just to get through.
I didn't choose to be a burden on you.

BUT

I did choose:
To appreciate life;
To get into mischief and strife.

I did choose:
To view each day with delight;
And never give up the fight.

I chose to show love and devotion.

I chose to be an inspiration.

by Linda
2 January 2008

This Broken Body

I remember when I used to kick a ball
Hit the stumps, I wouldn't fall
I'd walk the greens, I wet a line
To have this back would be divine

But this broken body won't let me play
The motor neurone took it away
No longer can I kick a goal
Hit a six or make that hole
This broken body frustrates me so
How I wish that it would go

I miss driving a car and riding a bike
Going out drinking on a Friday night
Cuddling the kids and making love to my wife
This no longer feels like it's my life

But this broken body won't do as I say
Motor neurone took it all away
Now I sit in my chair from morning till night
Thinking about what's to come
Will it be a scary sight?
Heaven or hell, just a hole in the ground
What will happen when I'm not around?

Will I be remembered as a failure or success?
Will they all miss me when they lay me to rest?
Will the girls grow up to be successful and strong?
Will my wife love again, long after I'm gone?

I guess it hurts so much 'cause I've had a wonderful life
A loving family, a beautiful wife
Two healthy kids, good friends by my side
A career I enjoyed, I've had honour and pride

I'm not ready to go there's so much to do
Travel the world, trek in Peru
Teach my daughters to drive a car
Screen their new boyfriends, watch from afar
Escort them down the aisle
Wipe their tears; take joy in their smiles
Bear witness to grandchildren, see generations to come
Grow old with my wife and bath in the sun

But this broken body won't let me stay
Motor neurone will take that away
So farewell my loved ones have a good life
And remember me fondly as you go on with your life
Think of me and smile, keep me in your heart
Make the most of each day, and play a great part.

by Karen
23 December 2008

Email or write your letter to the editor of Forum

See back page for contact details

Support Groups

Canberra

On 13 December our support group members and families enjoyed a Christmas brunch barbeque. The weather in Canberra during the week had been a little bleak with cooler temperatures and some much needed rainfall: one member had 71mm in the previous 24 hours in their backyard! However six families and I enjoyed the morning in spite of the slightly gusty winds.

Much food and Christmas spirit was had by all. The Pearce Community Centre has a lovely covered barbeque area and wheelchair accessible facilities in the adjacent building, so it was an ideal venue. It was, however, missing a power outlet so a few trips were made inside to boil the kettle for tea and coffee. One of the people attending stepped up to the barbeque challenge and cooked our steak sandwiches and bacon and egg rolls with obvious skill. Many thanks to families that brought something to contribute to the brunch - including a home-made apple pie, fruit mince tarts and a jelly bean salad. Planning is underway for our 2009 meetings, If you would like more information please contact me.

Iva Plessnitzer
Regional Advisor

Kokoda Charity Challenge for MND NSW 8-21 August 2009

Gosford

Welcome back everyone! It was wonderful to catch up with so many of our members again after the Christmas holiday. Thanks also to those dedicated people who put so much effort into selling tickets in the annual Rotary raffle. It was once again a successful drive and part of the proceeds from this raffle go to the MND Association. Well done everyone!

Seven meetings have been scheduled for this year and we have invited some interesting speakers along to increase our knowledge about motor neurone disease and to learn new ways to help ourselves, our families and our friends. For information about the Gosford group and dates for future meetings call me at the MND NSW Centre at Gladesville.

Jo Fowler
Regional Advisor

Kingswood

There was a great turn-out for our first get-together of the year in January at the Neighbourhood Centre in Kingswood. Carers and people living with motor neurone disease shared stories about the challenges facing them in both the past and the present. This provided us with a great opportunity to strengthen ties and to learn how to support each other at difficult times.

It was lovely to see some children at the group – they are always an inspiration and a lovely distraction! There were many ideas for speakers for this year and these will be arranged as the year progresses. In March, I am working on the possibility of a cruise on the paddlewheeler, the Nepean Belle. This may involve changing the date for one of our regular meetings. If we are able to go ahead with the cruise, I will send details out to regular group members.

Our meetings are usually on the fourth Tuesday of alternate months from 1pm until 3pm. Call me at the MND NSW Centre at Gladesville if you would like to receive regular information about upcoming meetings, and you do not receive this already.

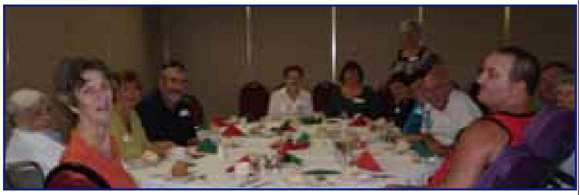
Jenny Judd
Regional Advisor

Northern Sydney (Hornsby)

Another year is well under way and we were fortunate to start up our support group again in February with two informative guest speakers. Trish Reynolds, Clinical Nurse Consultant, from the Royal North Shore hospital, spoke about the management of respiratory difficulties and non-invasive ventilation. Christina Dodds introduced us to the Home Hospice service and spoke about their new programs and growing relationship with MND NSW.

Our next meeting is on 9 April and we will be focusing on healthy eating, managing weight loss and PEG tubes. If you missed out on getting the list of our meeting dates for 2009 call me at the MND NSW Centre at Gladesville and I will organise for the list to be sent to you.

Jo Fowler
Regional Advisor



The Orange support group Christmas lunch in December was very well attended. There were members, their families, past carers and health care workers present and everyone enjoyed convivial company and great food from the Orange Ex-Services Club.

Australian MND DNA Bank Newcastle donor drive - a great success

Thank you to the members and their families in the Newcastle area who participated in the recent Australian MND DNA Bank donor drive, and gave DNA samples to contribute towards research. As part of the day, Lorel Adams, Manager of the Bank, gave a very informative presentation on the latest research into motor neurone disease. The day also provided us with a great opportunity to catch up with members from our area.

Eileen O'Loghlen and Noelle Smith
Regional Advisors - MND NSW Newcastle office

Volunteers and You

Hello again everyone. Since December I have attended an MND information evening, visited several support groups and met several volunteers (hello Audree and Sheila up on the Central Coast). I have also had some people contact me wanting to volunteer and I am chasing up a few leads about groups of people who may offer their time for our members. This is where you come in.

If you would like some assistance in any way, be it lawn mowing, gardening, spending some time chatting to help get rid of that feeling of being alone during the day when others may be at work or at school – I would like to hear from you. I am beginning to put together a list of members who would like a volunteer to give them a bit of a hand. We don't want to take away your independence; in fact we want to help you maintain it for as long as you can and a volunteer can help you do that. Perhaps you would like to tell your story and have it written down for your family. I can find a volunteer to do that.

I would rather start with a list of roles that we need volunteers for, rather than a stack of volunteers who we need to find roles for…if you follow what I mean. Our pilot project, which ran in the Hunter area a few years ago, found that when a volunteer was matched with a member early in the MND 'journey', it worked out a whole lot better. Relationships were able to be built over time, making it easier for the member and their volunteer to get to know each other. I'd love to hear from you if you'd like to chat about how volunteers can help you. I'd also like to hear from you if you'd like to volunteer with us.

Greg Colby
Family Support Volunteer Program Coordinator

Emotion and cognition in Motor Neurone Disease

Professor John Hodges and his team at Prince of Wales Medical Research Institute would like to thank all the people who have responded to the survey on emotion and cognition in motor neurone disease. This survey is designed to look at possible changes that may have occurred in thinking and emotion in people with MND.

So far 100 families have been included. Without their willingness to respond, this survey would not have been possible.

At this stage, further responses are still being sought. If you have not yet responded, but would like to participate in this survey, please do not hesitate to contact Dr. Patricia Lillo ph. 9399 1036 or email at p.lillo@powmri.edu.au. Prince of Wales Medical Research Institute. Barker St cnr Easy St, Randwick NSW 2031.

Care for Carers

A course providing education and support for carers enabling them to better care for the person with MND at home.

This program runs over four consecutive Tuesdays in May 2009 from 10am to 3.30pm at the MND NSW Centre in Gladesville.

5, 12, 19 and 26 May

Aids and equipment
Preparation of the home
Eating well with motor neurone disease
Accessing services
Challenges of caring

To find out more
contact Gina Svolos, ph. 8877 0999 or
speak to your regional advisor.
There is no charge, but you will need to
register to attend.

Support Group Contacts

METROPOLITAN

Ph: MND NSW 1800 777 175

Gladesville
Caroline Gleig - carolineg@mndnsw.asn.au

Northern Beaches (Mona Vale) and Northern Sydney (Hornsby)
Jo Fowler - josephinef@mndnsw.asn.au

Western Sydney
Jenny Judd - jennyj@mndnsw.asn.au

REGIONAL AND RURAL

ACT and Southern NSW
Iva Plessnitzer Ph. 6286 9900
ivap@mndnsw.asn.au

Broken Hill
Jamie Mitchell Ph. 08 8088 7123 (bh)
or 08 8088 1333 (ah)

Central Coast
Audree Dash Ph. 4384 2907
Sheila Holmes Ph. 4392 5513

Central West
Jenny Judd Ph. 1800 777 175
jennyj@mndnsw.asn.au

Illawarra
Cindy Cleary Ph. 4223 8000

Newcastle and Hunter
Noelle Smith or Eileen O'Loghlen Ph. 4921 4157
noelles@mndnsw.asn.au
eileeno@mndnsw.asn.au

Northern Rivers
MND NSW Ph: 1800 777 175

Interested in knowing more about the Family Support Volunteer Program?
Contact
Greg Colby,
MND NSW
ph. 8877 0999

Morphine and other opioid medicines

This information is based on *Morphine in palliative care* (Calvary Health Care Bethlehem) *and Facts about morphine and other opioid medicines in palliative care* (Palliative Care Australia).
Extract from *MND News*, the newsletter of MND Victoria, Nov-Dec 2008.

> *"The best source for more information about morphine is your doctor and care team."*

What is morphine?

Morphine is a natural product which has been used for centuries as a pain relieving medication. It is recognised around the world as one of the most effective medications to relieve cancer pain, and is also used to treat pain in other conditions. Morphine comes in a wide range of forms and the best form for you should be decided with your own doctor.

In MND, morphine can be used to reduce the cough reflex, help relieve shortness of breath in people with breathing difficulties, control pain and help to reduce fear and anxiety.

Morphine and other opioid medicines are for improving life - not hastening death

Some people fear that being prescribed opioid medicines means that they are closer to the end. The aim of morphine treatment is to improve your comfort and so enhance your quality of life, enabling you to do the things which are not possible if pain is unrelieved. Morphine will not shorten your life expectancy when used appropriately to control pain. Many people live for years taking morphine.

All medicines can have side effects - the side effects of opioid medicines are manageable.

Sometimes people worry that the side effects of their opioid medicines will be worse than their pain. However, not everybody experiences side effects, and your doctor may be able to alleviate them by changing the dose or the medicine.

Opioid medicines are not addictive

When your doctor chooses the right dose of opioids for your pain, you will not become addicted. Addiction only occurs when people have no pain and they abuse opioid medicines. It is often easier to relieve pain in its early stages. Some people only tell their doctor about their pain when it gets bad. However, it is usually easier to manage pain in its early stages, so the sooner you share information about your pain, the more manageable it is likely to be later.

Will I need more morphine over time?

The experience of pain is different for each individual. People often remain on the same dose of morphine for long periods of time. Over time, your body may become used to an opioid medicine. This is called 'tolerance'. Some people find that their morphine dose needs to be adjusted on a regular basis to control their symptoms. If your morphine dose needs to be increased it does not always mean that your disease is worse.

Managing pain can improve your life

Some people worry that using opioid medicines will limit their lifestyle. However, it is the pain, not the medicines that limit your enjoyment of life. Without pain, you will probably feel better, have more energy, have a better appetite, and be more independent.

The best source for more information about morphine is your doctor and care team.

Family Support Calendar

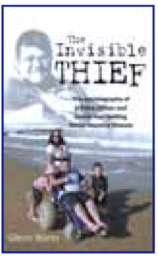
5, 12, 19 and 26 May	**Care for Carers** *A four-day course providing education and support for carers enabling them to better care for the person with MND at home.* *MND NSW Centre Gladesville.*
6 May	**Day of Hope and Remembrance** *Sydney Olympic Park.* *(see page 5 for more information)*
13 May	**Information Evening** *For people newly diagnosed with MND, their families and carers.* *MND NSW Centre Gladesville.*
17 August	**Ask the Experts** *An information day for people with MND, carers and friends.* *Sydney metropolitan area.*

For more information contact
MND NSW Info Line 1800 777 175

If you would like assistance with travel to attend family support sessions or would like us to organise an MND information session in your region, please speak to your regional advisor.

Book Review

The Invisible Thief
by Glenn Watts



An autobiography of a police officer and family man living with motor neurone disease. Glenn reflects on his experiences before his diagnosis with motor neurone disease; growing up at Picnic Point, training at the New South Wales Police Academy, Goulburn, and his postings at Lakemba and Campsie.

Always a bit of a larrikin, Glenn recalls many pranks played on colleagues during this time. This same larrikin spirit flavours his experience of living with a life-limiting disease. At times scattered with colourful language, Glenn's book is engaging and easy to read.

Caroline Gleig
Regional advisor

The Invisible Thief is $25 plus $5 post and packaging. To order your copy contact vicki_watts@aapt.net.au
$5 from every copy sold will be donated to MND NSW.

Noticeboard

Companion Card

If you have a significant, lifelong disability and require attendant care for the rest of your life, a Companion Card will allow you to participate in community activities and events without discrimination. This means you will no longer be required to pay two admission or booking fees in order to take your attendant carer with you to participating venues and events.

How does it work?

You can present your Companion Card when booking or purchasing a ticket at a participating event or venue, provided you require attendant care support to participate in that particular activity. The venue issues you with a second ticket for your companion at no charge.

Who can apply for a card?

The Companion Card is for people with a profound disability who always require an attendant carer to support their participation in community activities and venues. Companion Cards will not be issued in the name of a companion or carer - a card will only be issued in the name of the person who has a lifelong disability. A Companion Card will be issued to people who are assessed as meeting all of the following eligibility criteria -

- you are a resident of NSW
- you have a severe or profound disability
- you are unable to participate in most community-based activities without significant assistance with mobility, communication, self care, planning and the use of aids and other technology does not meet those needs
- your level of support is lifelong.

How do you apply?

First, you need to request an application form by contacting Companion Card ph. 1800 893 044.

The application form requires information about you and the condition you have that causes your need for a companion at events. You will need to get a health professional (doctor, nurse, physiotherapist, psychologist, occupational therapist, social worker or speech pathologist) to sign the form and may also need to get a funding agency manager's signature if you receive attendant care funding, high level residential aged care package, community aged care package, high needs pool funding or extended aged care in the home package.

You will also need to submit two passport photos of yourself, initialled on the back by a health professional.

If you need assistance completing the form, contact your MND NSW regional advisor. For more information see www.companioncard.com.au


The Mortgage Stress Handbook

Mortgage Stress Handbook

Published by Legal Aid NSW, this handbook is about what you can do if you are having problems with your mortgage, or you can see problems arising in the future.

It will help you by:

- explaining the range of options available to you
- providing sample documents for you to use
- telling you where you can go for further assistance

The Mortgage Stress Handbook is intended as a guide to the law, and is not a substitute for legal advice. Contact Legal Aid NSW Publications Unit ph. 9219 5028 to ask for a free copy to be posted to you or download free online at www.legalaid.nsw.gov.au.


"I've Got Nothing to Lose by Trying It"

I've got nothing to lose by trying it - weighing up claims about cures and treatments for long-term conditions

The last ten years has seen a rise in use of the internet and patient chat-rooms and forums for people with chronic diseases. These offer valuable support, but have also brought masses of advertising, surreptitious promotion and misleading stories. Today patient charities, doctors and scientists are warning people with long-term incurable conditions about the emotional and financial costs of over-hyped treatment claims that sell false hope.

Online adverts and chat-room conversations testify to the 'incredible' benefits of new medicines and treatments selling the empty promise of curing the incurable. But the evidence for many treatment claims is unreliable and patients' yearning for improvement is being exploited. Whilst people must be left to make up their own minds about what treatments to use, doctors and scientists are critical of those who aggressively market - with misleading claims, optimistic testimonials and even pseudo science - to people who are desperate for some source of hope. Leaving them unsure about what to try and uncertain where to draw the line.

The guide, published by Sense About Science with the Multiple Sclerosis Society, Motor Neurone Disease Association, Alzheimer's Society and Parkinson's Disease Society (all in the UK), explains how to tell the beneficial from the bogus in the face of the miracle cure stories, new wonder-drugs and breakthrough therapies that are increasingly promoted.

This guide is available free online at www.senseaboutscience.org.uk/index.php/site/project/267/ or contact your MND NSW regional advisor for more information.

Open Garden at 'Homeleigh'
17 Linden Avenue, Pymble
2-3 May
10am-4.30pm

Noticeboard *(continued)*

Talking with Young People about MND

A new Australian information pack for parents, *Talking with Young People about MND,* is now available from MND NSW.

If you have children or teenagers and would like to receive a print copy of the *Talking with Young People* information pack please contact your MND NSW regional advisor or the MND Info Line on 1800 777 175. For others, the publication can be accessed free online at www.mndaust.asn.au

Services for members selling accessible motor vehicles

MND NSW will publish a small five-line text only advertisement free of charge in *Forum* for members selling accessible motor vehicles, space permitting. Contact the editor of *Forum* for more information.

Paraquad NSW offer a web-based classified service. For $20 you can advertise up to five items. For more information see www.paraquad.org.au/Classifieds.aspx

SBS radio 2008 Homereach series

The SBS radio 2008 Homereach series provides practical information for people with a disability, their carers, the frail and the aged. The eleven episodes, each about six minutes long, cover issues such as preparing wills, home maintenance, respite care and accessing services in NSW.

If you missed them on the radio between November 2008 and January 2009, you can listen to them online or download for later listening from www.sbs.com.au/radio/article/559/Homereach

Each episode has been produced in **Arabic, Croatian, Dari, English, Italian, Khmer, Mandarin, Spanish** and **Vietnamese**.

If you would like to listen to Homereach but are unable to download the series, contact your MND NSW regional advisor.

Episode 1 - Home and Community Care

- summary of services available
- costs

Episode 2 - Home Care and Domestic Assistance

- using Home Care and Domestic Assistance
- frequency of service
- personal care tasks performed by Home Care
- eligibility
- costs

Episode 3 - Meals

- shopping assistance to purchase groceries
- centre-based meals
- home-delivered meals
- special dietary requirements
- costs

Episode 4 - Prevention of falls

- mobility problems
- identifying risks
- home modifications
- risk factors
- fatigue
- side-effects of medicines
- inappropriate footwear
- hazards in the home

Episode 5 - Home Modifications and Maintenance Service

- using Home Modifications and Maintenance Service
- types of maintenance services available
- types of modifications
- how modifications impact lives of clients
- costs and procedure

Episode 6 - Wills

- the importance of making a will
- who can help you
- formal requirements
- dying without will
- incapacity before a will is drawn up
- preparing documents
- power of attorney
- guardianship

Episode 7 - Carers Part 1

- what is a carer
- carer issues and needs
- Carers NSW
- carer support kit available in many languages
- referral service

Episode 8 - Carers Part 2

- who is a carer
- what is respite care
- types of respite
- use of community transport
- ethnic specificity
- costs

Episode 9 - Aged care

- what is an aged care assessment team
- services available to people over 65
- assistance to remain in own home
- assistance to access nursing home and hostel accommodation

Episode 10 - Advocacy services

- protecting and securing your rights
- the Multicultural Disability Advocacy Association

Episode 11 - Recap

- recapping the Home and Community Care Program (HACC)

Dates for the Diary

24 March	**Third MonStar Cup** *Pennant Hills Golf Club, Pennant Hills. Sponsor a hole or register now to be part of this event. Email admin@monstarcup.com.au or see www.monstarcup.com*
30 March	**Food Services Golf Day** *Carnarvon Golf Club, Lidcombe.*
2 - 3 May	**Open Garden at 'Homeleigh'** *17 Linden Avenue, Pymble, the home of Suzanne and Bob Ballinger in Pymble through the Open Garden Scheme. 10am-4.30pm. $5 admission to OGS. Lunch, morning and afternoon tea available. Plant, MND merchandise and Mother's Day stalls.*
3 - 9 May	**MND Week 2009** *Volunteers are needed on Sydney's streets - and elsewhere. The prime time is between 7-9am at one of your local train stations. So, why not join a team or organise to sell some merchandise at your office? No previous experience needed - just a big heart. To volunteer or for further details contact Ayse Dalkic at MND NSW ph. 8877 0908 or email aysed@mndnsw.asn.au*
6 May	**Day of Hope and Remembrance** *Sydney Olympic Park.* *(see page 5 for more information)*
23 May	**Canberra Handmade Market** *Albert Hall, Commonwealth Ave, Canberra. This is an on-going event. Entry is free. For further information see www.handmademarket.com.au*
21 June	**MND Global Day-Walk To D'Feet MND** *Inaugural Canberra Walk beside Lake Burley Griffin. We are currently looking for volunteers to help out with this event. Why not walk yourself or sponsor a walker to help raise funds. For further information contact Jamie Whiley on jamiewhiley@hotmail.com*
4 August - 3 October	**A Drive for A Cure in memory of Norman George Jones** *61 days .....34 Cities......16000 Kilometres... 1 Goal Drive around Australia in 8 weeks promoting awareness and raising monies to help find a cure. The drive will incorporate all major capital cities and various regional stops. For more information see www.driveforacure.com.au*
8 - 21 August	**Kokoda Challenge for MND** *If you would like to find out more contact Kym at MND NSW on 8877 0912 or kymn@mndnsw.asn.au or World Expeditions www.worldexpeditions.com.au*
22 November	**Raising Hell on the Mountain Top for MND** *Penny Leemhuis from Ballarat, Victoria, will be walking with close friends and personal trainers to the summit of Mount Kosciusko located at Thredbo. All monies raised will be donated to MND NSW in memory of David Tatnell.*

It's on again

Looking for a relaxing day of golf at a great course? Then tee-off with us at around 12.30pm for the 2009 **MonStar** Cup on Tuesday 24 March at the picturesque Pennant Hills Golf Course. For further details and to register for the event see www.monstarcup.com.

New MND polo shirts now in stock

New MND polo shirts in royal blue and white made from Biz Cool 100% breathable polyester cool dry fabric are now available. The polo has a soft silky finish and a flattering semi-fit cut. They feature a knit collar with contrast piping and a contrast stripe from shoulder to sleeve. The new ladies shirts have an open v-placket collar with two press-studs.

These shirts are lovely to wear and very smart. Order yours today.

Volunteer ID
Is yours up to date for 2009?

Anyone selling merchandise or asking for donations on our behalf must, in keeping with the Office of Charities requirements, wear ID issued by MND NSW. If you need a new badge contact Ayse ph. 8877 0908 or email aysed@mndnsw.asn.au.

kokoda Charity Challenge.

The Motor Neurone Disease Association of NSW and World Expeditions are excited to offer the MND Association Kokoda Challenge.

8-21 August 2009

$6500 fundraising target

This trip is limited to the first twenty people registered. **For further information contact Kym Nielsen at MND NSW ph. 8877 0912.**

You can write to the Editor, Forum, MND NSW, Locked Bag 5005, Gladesville NSW 1675

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Editor: *Penny Waterson*