THE NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NSW

FORUM

September 2008

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New resource for parents

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. This information pack is the outcome of a fantastic project undertaken by MND Victoria and MND NSW in response to the needs of younger people when a family member has been diagnosed with MND.

Written for families making the difficult journey with MND, the pack includes booklets for parents, 8 to 12 year olds, teenagers, young friends, schools and health professionals who may be working with the family.

The booklets include suggestions from parents and children who wanted to share their experience of living with MND with other families. There are suggestions for ways of talking with your children following a diagnosis of MND, and ideas about how to keep communication strong as time goes by.

The development and publication of the information pack has been funded by a Department of Health and Ageing Local Palliative Care grant. The content was formed following consultation with families living with MND. Thank you to the parents and children who completed questionnaires and participated in telephone interviews and focus groups. Thank you also to the counsellors and health specialists, experienced in supporting people with a life-threatening disease, who provided their advice about content.

If you have children or teenagers and would like to receive a copy of the Talking with Young People information pack please contact your MND NSW regional advisor or our 'Info Line' on 1800 777 175.

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

Apparently spring is on the way but, as I write this, we are still in the grip of winter and the temperature is still in single digits across most of the State.

MND Victoria held an extremely successful national conference in late June with over 260 people attending. This was the fourth national conference and the attendance grows each year. The national conference for 2009 will be held in Sydney on 23 June. Details will follow early in the new year.

Professor John Hodges from Prince of Wales Medical Research Institute is conducting research into emotion and cognition in MND and is looking for participants. If you would like to take part in this important research see the back page of this edition of *Forum*. We will be sending out a letter inviting people to participate in the near future.

Petra Sammut, our Office Coordinator, has recently notched up ten years with MND NSW. Over those years Petra has been responsible for the seamless running of the office; the person operating behind the scenes who keeps the wheels in motion. Petra is often the first person to greet people when they come to the office. As I write this Petra is on a world tour taking a well-deserved break and will be back in October.

A Board and staff morning tea was held to acknowledge Petra Sammut, Office Coordinator, who has worked at MND NSW for a decade.

After nearly five years as an employee and prior to that seven years as a volunteer Roslyn Adams, Fundraising Coordinator, is leaving MND NSW. Changes within our fundraising program and a desire for personal change have led to her departure. We wish Ros well in her future endeavours.

By the time you read this we will have employed our new Information Line Advisor. This position has been identified as an important link between service providers, regional advisors and New South Wales health, disability and community services. It will also allow more time for our regional advisors (who have been responsible for Info Line to date) more time in the field.

Many of the additional services that have been included in the Association's programs recently have happened because of the wonderful support of donors (over 80 per cent of our recurrent funding) and also the state government. NSW Health and the Department of Ageing, Disability and Home Care have continually worked with us to identify systemic gaps in services. Kristina Keneally, the Minister for Disability Services, has written an article for us on page 4 of this edition of *Forum*.

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

Walk to D'Feet MND 2008

Sunday 9 November

See back page for more information

Farewell…
Roslyn Adams, Fundraising Coordinator

It is with regret that I say farewell to all the wonderful people with whom I have crossed paths during my time at MND NSW; I will be leaving on 9 September. A review of MND NSW fundraising activities has taken place and there is an increased need for a general assistant rather than an events coordinator within the department. As this does not hold the same level of interest for me I have chosen to move on.

I have been proud to be a part of MND NSW. My initial involvement began twelve years ago when, as a volunteer, I introduced the Entertainment Books as a fundraising opportunity for MND. Soon after this I was invited to join the Fundraising Committee and then five years ago I was employed as Fundraising Coordinator.

I have thoroughly enjoyed the contact I have had with each and every one of you in many varied capacities over the past twelve years. I wish you and your families the courage and strength required to live with MND. I have great admiration for you all.

With best wishes,
Roslyn

Join us for a fun day as we walk to d'Feet MND

10am Sunday 9 November

Homebush Bay

Adults $25 Children $10 (5-18yrs) Families $50

For registration and sponsorship details contact Kym ph. 8877 0912 or kymn@mndnsw.asn.au

Funds raised support research to find a cure for MND

Advocacy – it's everyone's role

In the last edition of Forum *you were encouraged to write to Canberra, to the federal government's* Inquiry into Better Support for Carers *to tell the government what is working for you as a carer, what is not and to let them know what needs to change. We included a template to guide your thoughts.*

Is what I am doing advocacy?

In this article we want to look at **that act** of **writing** a letter, **sending** in a submission or email, **making** a phone call, **talking** to people such as politicians or health bureaucrats; what we do when we speak out to raise awareness and improve the situation and lives of individuals or groups. We are often advocates without being aware of it or applying the name to ourselves.

Advocacy is a part of the work of the state MND Associations and a key focus of MND Australia and the International Alliance of ALS/MND Associations.

Are you having a problem accessing services? Let MND NSW know.

What is advocacy?

'Advocacy' is the deliberate process of influencing those who make policy decisions. In the health care sector advocacy is any activity that helps a consumer or organisation to get better health care that really meets their unique needs. It is also about influencing to change or improve policy decisions that can have negative impacts on the ill person, their family and carers. The two main forms of advocacy are individual and systems advocacy.

Individual advocacy

Individual advocacy focuses on changing the situation of one person. It can be about anything that affects the person. Individual advocacy includes:

- informal advocacy undertaken by individuals, their partner, relatives and friends. Many people with MND and their families engage in this informal advocacy.
- advocacy undertaken by voluntary, charitable and community-based organisations, such as MND associations, whose staff advocate for individuals.

Most state MND associations help people with MND and their families access vital health and community services in their local areas because access to these services can be very complex and hard to negotiate. Another advocacy role of MND associations is the education of a wide range of health and care providers about the needs of people with MND and their carers.

Systems advocacy

Systems advocacy works to change the situations of a whole group of people who share a similar problem or to change a service or system. Systems advocacy:

- strives to prevent problems
- encourages changes to the law, government and service provider policies and community attitudes.

Many state MND associations undertake systems advocacy at a local or state level. It is a key role of MND Australia and the International Alliance to undertake systems advocacy nationally and internationally.

Collaborative advocacy with others

The job of influencing is made even harder due to the relatively few people living with MND. But there is power in numbers! Organisations and groups who have similar or the same needs of people with MND such as disability and neurological groups, palliative care associations, carers' associations and chronic disease alliances can join together and engage in another form of advocacy - collaborative advocacy.

Small 'a' advocacy

There's another very informal advocacy that can be added - small 'a' advocacy: just talking to friends and neighbours about MND, in fact any one who will listen. It's about getting the word out. That's how change occurs.

Advocating for people with MND can:

- raise awareness about MND and the needs of families and carers
- promote research into MND
- help people with MND, their families and carers access more resources, get better health care and have more control over their lives
- promote changes to health structures and policy.

Advocacy - it's hard work

All advocacy is hard work and time consuming but systems advocacy is particularly so. It requires a sustained effort to make changes in service systems, policy or law. You have to know about those systems, how to advocate, be committed to doing more than the basics, be able to take and create opportunities when they arise, and be prepared to keep on going when nothing seems to be happening. Above all, it's about having a vision and passion to sustain the hard work and effort.

Advocacy - MND Australia

One of the key strategic objectives of MND Australia, the peak body for MND in this country, is to have an input into policy that impacts on people living with MND at national and international levels. The major area of influencing for MND Australia is to engage with the federal government on their policies.

Over the last two years MND Australia has made contact with key ministers and shadow cabinet ministers to promote MND care and research. There have also been a number of face-to-face meetings with key advisors and personnel within the Department of Health and Ageing in Canberra.

Advocacy on behalf of carers

The federal government's recent *Inquiry into Better Support for Carers*, mentioned at the beginning of this article, sought input from a huge range of people and organisations across Australia. The MND Australia submission is well worth a read at www.mndaust.asn.au.

(continued over)

Advocacy – it's everyone's role *(cont'd)*

Included with the submission is a very moving article written by past carer, Lisa Morgan, who told her story at the National MND Conference in Melbourne. Her paper called *Avalanche – our journey with motor neurone disease* highlighted many of the concerns outlined in the MND Australia submission.

Advocacy - MND NSW

At present MND NSW is talking to the NSW Department of Health about providing full funding for MND clinics. The clinics survive on money provided by MND NSW, fundraising by the clinics and on the good will of the staff.

FlexiRest, a flexible respite program was established by MND NSW, the Muscular Dystrophy Association of NSW and Multiple Sclerosis ACT/ NSW/Vic. It came about from the successful collective advocacy of the three organisations to the NSW Department of Ageing, Disability and Home Care. MND NSW is currently seeking money from the ACT government for funding for our ACT members. This is just one example.

Member advocacy

Before the launch of MND Week, MND NSW sends out the national *Call for Action* in the *Forum*. Each year there is a new theme. We ask you to write to your local member of parliament highlighting what is and is not working for you and what needs changing. If you don't have the time or energy you can delegate this task to a friend or family member. Get them to write or phone in on your behalf.

Advocacy – it's everyone's role

Many thanks to those of you who wrote to the federal government's *Inquiry into Better Support for Carers*.

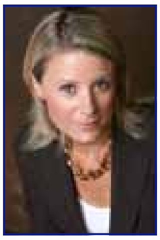
You don't have to wait for information from us or for the *Call to Action*. We can all have an advocacy role. It's not just for other people, something someone else can do. You can contact us at MND NSW and MND Australia any time you like or send your own submissions to government inquiries. We can help by providing template letters and talking through how to present your concerns.

Telling your personal stories make a real difference and ensures that you have a voice and that it will be heard.

Jane Barrett
Family Support Coordinator, MND NSW
Carol Birks
National Executive Director, MND Australia
Anita Richter
MND Australia volunteer and previously MND NSW

For more information about the Home Care Service see www.dadhc.nsw.gov.au

NSW Home Care Service Delivering



By Kristina Keneally
NSW Minister for Ageing

This year the Iemma Government has, for the first time, delivered a budget of more than $2 billion for services for the frail aged and people with disabilities. This is a significant investment which is translating to tangible improvements to services on the ground.

This increased funding will continue to provide improvements to the services available to people with MND. Over the last 12 months, through the Department of Ageing, Disability and Home Care, MND NSW has received funding to enhance its equipment loan pool and thus reduce waiting time for equipment; to develop flexible respite options through the FlexiRest program; and other funding to improve access to services for people with MND.

One of the services accessed by many people with MND is the Home Care Service of New South Wales, which assists frail older people, younger people with a disability and their carers to live in their own homes. The service provides people with help to perform personal and domestic tasks including cleaning, laundry, shopping and showering, as well as providing respite.

In a recent survey, the people who use the Home Care Service gave it a big tick - with a 96 per cent satisfaction rating. This great result was an increase of two per cent on the last survey two years ago. Of the people surveyed, 72 per cent said they were highly satisfied with the service, 24 per cent said they were satisfied and 2.7 per cent said they were dissatisfied (a drop of three per cent from the previous survey). Of course we will continue our work to keep service levels up and dissatisfaction levels down.

These great results are a big endorsement of the dedicated staff who work in the Home Care Service. They've achieved this level of satisfaction while providing more than 3.8 million hours of service to more than 54,300 people across the State last year.

The Home Care Service is funded through the Commonwealth / State Home and Community Care (HACC) program. It is delivering on its aims to reduce the risk of people prematurely or inappropriately going into residential and acute care; supporting people so they can remain in the community; supporting carers and enhancing people's quality of life. And it is doing so with the strong approval of the tens of thousands of people it is helping.

You can refer yourself or someone you know to the Home Care Service by phone, fax or email.

Statewide email: racentre@dadhc.nsw.gov.au
Sydney: ph.1800 350 792 or fax. 02 9891 6148
Regional and rural NSW:ph.1300 881 144 or
fax 1300 881 184

Family Support

Learn Now,
Live Well
17 and 24
November

MND NSW
Centre
Gladesville

4th National MND Conference, June 2008

On 24 June Family Support staff attended the 4th National MND Conference in Melbourne. They joined over 260 others to listen to keynote speakers Dr David Oliver (UK) and Lisa Morgan (wife of Richard Morgan), and to twelve other speakers from Western Australia, New South Wales and Victoria.

David Oliver opened with a very interesting presentation about the palliative care approach to MND. He talked about the time of uncertainty at diagnosis, planning for the future, the importance of communication from the start, trust, team work and how the palliative approach can benefit people living with MND.

Lisa Morgan’s presentation was very powerful and moving. She described how she and her family found themselves in a totally foreign world - the medical world and the world of disability. She further said that, *“ …MND is a journey of milestones, going in the wrong direction …”.* She stressed how important it is to break bad news in an honest and compassionate manner, and that health professionals need to avoid the jargon.

Jane Barrett, MND NSW Family Support Coordinator, presented a paper on our new respite initiative, FlexiRest, for people living with motor neurone disease, muscular dystrophy or multiple sclerosis. People from other states were very interested to hear about this new initiative as it provides an example of what services can achieve if they work together to meet the needs of their members.

It’s our turn next year to host the National MND Conference in Sydney. We are very excited to be involved in organising this national event and it will be held on 23 June 2009.

Visit to Sydney by Dr David Oliver

Following the Melbourne conference MND NSW was fortunate to host a visit to Sydney by Dr David Oliver. Dr Oliver is a consultant physician in Palliative Medicine from Wisdom Hospice in Rochester, UK. He works closely with people with MND and has spoken and written widely on care and control of symptoms. Dr Oliver's visit to Sydney was a great opportunity for our staff to meet with him. He provided us with valuable information about caring for people with MND and also about working with others who are involved in their care. It was interesting to hear that the experiences of people with MND in the UK are very similar to the experiences of those in NSW.

(l-r) Jo Fowler, Maree Hibbert, David Oliver, Caroline Gleig, Jenny Judd, Gina Svolos and Robyn Petersen at the MND NSW Centre, Gladesville.

While in Sydney, Dr Oliver also spoke at an event hosted by Sacred Heart Palliative Care Service. More than 60 health professionals attended to hear Dr Oliver's presentation, 'Palliative Care and Motor Neurone Disease – the Challenges'. This was a great response as it helps people with MND; the more professionals who are educated about MND, the more we raise the profile of MND in our community and so the better care our members receive from their treating health teams. As one health professional said to me after the talk, *"I realised from his talk that there are some things I just don’t think to ask my patients when they have MND, so this talk gave me some helpful ideas that will help me in my work with people with MND".*

Education programs

It was great to see many of you at our recent **Ask the Experts** day (see page 6). The feedback from those who attended was very positive. Comments included: *highly enlightening; enjoyed the day very much; it is certainly great to hear from the doctors and specialists*.

Our next education program will be a two day workshop called **Learn Now, Live Well** on 17 and 24 November at the MND NSW Centre at Gladesville and I encourage your attendance. It is a very informative program with presentations from an occupational therapist, physiotherapist, speech pathologist, dietitian and regional advisors. People with MND, their family and friends are welcome to attend. See further information on page 6.

New position – Information Line Advisor

Soon you will be hearing a new voice when you phone our Info Line. We have just recruited a new staff member to answer these calls. Up until now, the Sydney-based regional advisors have taken a turn each week to answer Info Line calls. This new position will release the regional advisors from Info Line calls so they have more time to work directly with their members. This new position will also assist when regional advisors are unavailable so that our members will always know who to contact if their regional advisor is away. More information about this in our next edition of *Forum*.

Gina Svolos
Manager, Family Support

walk to d'feet MND

Sunday 9 November
See page 2 for more information

Special Projects and Carers News

Care for Carers

The Care for Carers four-week program, run each year in Sydney, assists new and not-so-new carers to manage the complexities of caring for someone with MND and promotes the concept of self-care. Following the recent program held at Gladesville, one participant wrote, ‘it is good to hear it (caring for yourself) from someone else other than relatives’.

It’s so easy not to think about self-care – lack of time, no energy, a feeling that it’s an indulgence rather than a necessity, guilt about time away from caring or even that it’s not necessary. Caring and self-care go together. One depends on the other.

Self-care can mean almost anything from going off to the gym, talking to friends, delegating jobs, to taking regular breaks. It’s whatever gives the carer a break and time for themselves.

Ask the Experts

A mixture of MND information and research made *Ask the Experts* for 2008 a successful day with over 55 members, family and friends present. Professor Dominic Rowe’s session on MND provided an overview of the effects of MND and generated many questions. Ventilation and quality of life were explored by Patricia Reynolds from Respiratory Medicine at the Royal North Shore Hospital.

Les Bell and Janice Berg (above) and Louise and Philip Snelson (below) at Ask the Experts.

Professor Garth Nicholson of the Anzac Research Institute explained about the MND research developments associated with the TDP-43 protein. Lorel Adams, Manager of the MND DNA Bank spoke about how people can participate in research into MND through donating their blood and other samples. An international perspective was provided by Gina Svolos, MND NSW, and Carol Birks, MND Australia, during their overview of presentations from the 18th International Symposium on ALS/MND held last year in Toronto.

The MND DNA Bank team, Professor Roger Pamphlett, Lorel Adams and Daniela Baretto were there all day collecting blood and other samples for MND research from people with MND (11) and their relatives and friends (23). They were thrilled with your generous response. Thank you! If you haven’t given blood and want to, contact Lorel Adams on ph. 9036 5456 to make an appointment.

Meeting for bereaved carers

The first meeting for bereaved carers took place on 3 July. The general feeling was that people wanted to keep the group unstructured and informal. It was agreed that I will ring participants in September to arrange another meeting, possibly for the end of October. If you would like to be part of this group, please contact me on ph. 8877 0902. The group is for anyone who feels they would like support and time to talk after experiencing a bereavement from MND.

FlexiRest

The FlexiRest program has been running for nine months. It continues to provide money for respite, however the respite need is defined by the person with MND and their family/carer, for services that cannot be accessed through existing respite programs.

In a report by the FlexiRest Coordinator to the funding body, the Department of Ageing, Disability and Home Care, it is noted that MND NSW has been the biggest user of FlexiRest to date with 32 applications from a membership of 348 to June 2008. In the same period there were 28 applications from Multiple Sclerosis ACT/NSW/Vic membership of 5226 and 14 applications from Muscular Dystrophy Association of NSW membership of 450.

A key focus of the program is to maintain the care-giver relationship. In general people with MS tend to want to spend time apart. People living with MND often want time together away from the family home and/or time spent with other family members. It’s more mixed for people living with muscular dystrophy. Talk to your regional advisor about your respite options including FlexiRest.

Jane Barrett
Family Services Coordinator

Members Christmas Party

29 November
MND Centre
Gladesville.

Learn Now Live Well

An education and support workshop for people living with MND, their family and friends.

The program will cover various aspects of living well with MND. Workshops will be presented by healthcare professionals who have particular knowledge about MND.

It is preferable that you attend both days to get the most out of the program.

Monday 17 and Monday 24 November

10 am to 3 pm

MND NSW Centre
Gladesville

There is no charge for attendance. Lunch and refreshments are provided.

If you are interested in attending contact MND NSW on 8877 0999 or 1800 777 175 and register your name. A program will be sent to you. Assistance can be provided with transport cost if needed.

MND and Intimacy

Recently I had the opportunity to attend a forum on sexuality and disability at St Vincent's Hospital, Darlinghurst. I came back thinking that this is an area that can easily be overlooked or neglected by families affected by MND and also the health professionals involved in their care. I wondered who should first talk about the subject of sexuality: the person with MND; the husband, wife or partner who has noticed things are changing; the nurse involved in daily care; the MND NSW regional advisor; the local GP or maybe the neurologist? And I thought about how overwhelming it would be if everyone focused on this delicate topic.

I also found myself asking, why is it that we find it so hard to discuss sexuality and relationship issues when this is such a vital part of our lives and our well-being?

The reasons, of course, are many and varied. Sexual expression and intimacy have long been regarded as too sensitive or too delicate to talk about and can stir up 'old taboos'. It may feel easier to avoid the subject because it can be embarrassing to talk about the changes in function or body image that are taking place. It can be difficult discussing self-doubts and worries we may have. It can be hard talking about loss of self-esteem or feelings of inadequacy and rejection. People often feel they can't talk about sex and intimacy because they are mindful about introducing extra stresses into a stressed situation.

How we feel about ourselves can affect us physically and psychologically. Although MND may not directly cause sexual dysfunction, it does put pressure on relationships, including relationships with lovers or sexual partners. This pressure can create anxiety which in turn can affect libido (our sexual desires) and erectile function. There are also physical changes, such as a need to move from a 'double bed' to a hospital bed, or visits from carers and others, which can present challenges to a couple trying to maintain a sexual relationship.

When things are beginning to change or not working out, getting the right help or advice is important. And knowing where to get the best help is vital. If you feel comfortable talking to your regional advisor, neurologist or GP, you may like to mention that things are getting difficult and affecting your intimate relationship with your partner. While just talking about your situation can be helpful, there are also several centres of expertise where you can get advice on disability and sexuality and we can put you in touch with them. Contact your regional advisor if you would like further information.

Jo Fowler
Regional Advisor

14 October Information Evening
For people recently diagnosed with MND and their families and friends
MND NSW Centre Gladesville.

Equipment

Equipment repair or servicing is usually done at the MND NSW Centre at Gladesville by the Equipment Service staff when equipment is returned from loan. However sometimes an item may require a repair while it is being used by a member in their home. When this happens MND NSW Equipment staff need to be contacted so an appropriate repairer can be authorised to do the repair or replacement of equipment, if needed, can be arranged.

If a breakdown occurs on a piece of equipment that is critical for use during the time when MND NSW offices are closed, it is requested that the member contact either their occupational therapist, who may be able to arrange an urgent repair, or their doctor who will decide what short term changes in care may be needed . All repairs arranged by MND NSW are at no cost to the member but if a repair is done without notification and authorisation by MND NSW, the cost of the repair may become the member's responsibility.

There have been **239** pieces of equipment newly loaned to **100** members since 1 June 2008. New equipment to the value of $16,660 has been purchased during this time including new air mattress overlays, bathroom and transfer equipment.

Maree Hibbert
Equipment Services Coordinator

Family Support Calendar

14 Oct	**Information Evening** *For people recently diagnosed with MND and their families and friends. MND NSW Centre Gladesville.*
Oct (date to be advised)	**Bereaved Carers Group** *12-2pm at the MND NSW Centre at Gladesville. Lunch will be provided.*
17 and 24 Nov	**Learn Now Live Well** *An education and support workshop for people living with MND, their family and friends.. MND NSW Centre Gladesville.*
29 Nov	**Members Christmas Party** *A fun frolic for members and their families. At the MND NSW Centre Gladesville. Special guest: Santa. Watch your mailbox for your invitation.*

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.

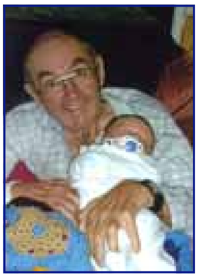
Mailbag

In Memory of Mr. Lawrence 'John' Fox

4 August 1939 -11 December 2007

Bev Fuller was the full time carer of John Fox, who had motor neurone disease for two and a half years before he died on 11 December 2007. What struck me first about Bev Fuller was that she was a woman full of life, dedicated to her caring role and dedicated to her friend. She asked me to write a memorial in honour of her dear friend John. I want to honour Bev for her preparedness to care where there was no duty to do so.

Bev and John had known each other most of their lives, growing up in towns that are about an hour's drive from each other. They grew up, they moved on, they both had their own marriages and children and led full lives. However, in November 2000 they bumped into each other again, both finding themselves widowed and in need of a friend, and John in need of a place to live. Bev suggested he park his caravan in the back paddock behind her house. He did so and repaid her hospitality by mowing her lawns and chopping the much-needed wood for the cold winter months.


John Fox with his great-grandson

Over time Bev noticed that John seemed to be having a bit of trouble getting around and the cold was harder to endure, so he gave up on the van and moved into one of the spare bedrooms of the house and rented it from Bev.

Then came their 'Black Friday' - 13 May 2005; the day they received the diagnosis that John had MND.

Over the years they became inseparable and part of each other's family. Bev cared for John beautifully during his illness and their friendship grew deeper as John’s health deteriorated.

Bev found love when she wasn’t looking for it, in the friendship and companionship of a very kind, warm man. John found an angel that he appreciated no end.

Thank you Bev and to all those like you who care, absolutely and tenderly.

Noelle Smith
Regional Advisor

My name is Pauline and I was told I have MND just nine months after my son Shaun died at the age of one month in May 1983. I was also told that I had three years to live. At the end of the three years I ended up in a wheelchair for three months and this frightened my husband to the point that he told me he could not stand by and watch me die, so he said he was so sorry and left. He passed away in February, two years ago.

My MND has been slowly progressive and through positive thinking and determination I am still here 26 years on. I must say that my MND has moved a lot in 26 years, but I am still able to drive my automatic power steering car, dress and shower and do my volunteer work at Shoal Bay. I have lost 27 per cent lung function and have a lot of trouble with my breathing and get very tired just doing things around the house. I use my wheelchair a lot now when I go out so that I can enjoy myself and not get so tired and out of breath. I could not do all this without my carer and now husband, Jim.

I met Jim on the internet four years ago. We got on really well and I felt that before anything went further I would have to tell him that I had MND. Well that did not matter and Jim then became my carer.

He left his house at Nelson Bay and moved into my home at Lemon Tree Passage in July 2005. You could not get a better carer; not only did he care for me, he painted the house and rebuilt the garden. He also modified the house so it is easier for me to get around.

I love to travel and in August 2007 I decided I would like to go on a holiday to Hong Kong. While we were there Jim surprised me and proposed to me on Hong Kong Harbour.

We married in April 2008 and then several days later flew to San Francisco before leaving on a cruise to Canada and Alaska. We had organised a wheelchair at the airports, hotels and on the ship so that I could enjoy myself without getting so out of breath and tired. I am hoping and praying that I will be able to travel again before my condition gets worse.

I am fighting to keep going so that I can enjoy being married to Jim and have a long life with him. I had been looking forward to getting married and having a beautiful honeymoon, so I fought hard for it to all happen, and it did.

Jim is 52 and I’m 55 and I hope that I have quite a few years ahead of me, but if not I know that I will miss Jim so much and will be looking down on him and being by his side until we met again. I’m not afraid of dying, but I worry about Jim and how he is going to manage without me. We have our lovely wedding photographs as memories, and all the great photos of our honeymoon in Alaska.

I’d like to say to everyone who has MND, don’t give up; fight this disease and let’s pray that one day they will come up with a cure to fix us all up so that we can all grow old together with our partners.

Pauline
Lemon Tree Passage

Email or write your letter to the editor of Forum

See back page for contact details

Support Groups

Central West

Our recent meeting in Orange was very well attended due to the interest everyone has in hearing about research into motor neurone disease. Lorel Adams, from the MND DNA Bank, and Carolyn Cecere, from the ANZAC Institute at Concord Hospital, spoke about the work being conducted by the researchers at their institutions. They also talked about the latest developments in MND research generally and there was great interest in the genetic studies currently being undertaken. Lots of people donated blood for research.

The next group, which will be over by the time you read this, will be in Dubbo. We will have learnt about what Carers NSW has to offer people with motor neurone disease who are being cared for at home.

If anyone has any suggestions for topics of interest for next year please contact me on 1800 777 175. The support group meetings are an opportunity for you to learn from and share with others who are living with motor neurone disease. They also provide me with an opportunity for me to catch up with you in person.

Jenny Judd
Regional Advisor

Don't forget to order your MND NSW Christmas Cards

Northern Sydney (Hornsby)

Our lunch time meeting continues bi-monthly and is attended by people with MND, their family members and carers. Also, we are lucky to have allied health workers attend from time to time.

As with any group, membership changes as new people are welcomed in and some of our regular members are no longer able to attend. Our thoughts are with those who have recently lost a loved one and those who are not well enough to attend the meetings.

We have enjoyed some talented speakers at our recent meetings. We felt privileged to hear from Lorel Adams, from the MND DNA Bank. In addition to talking about the latest research, Lorel told us about the Using our Brains program which collects, uses and stores brain and spinal cord tissue.

Betty Pettit and Joan Walker (above) and Henry Steeden with daughter Cheryl (below) at the Northern Sydney Support Group.

Kym Nielsen, our new Fundraising Manager was our August guest speaker.

We look forward to seeing you at our next meeting at Thornleigh Community Hall at midday on 9 October.

Jo Fowler
Regional Advisor

Gladesville

In spite of a rather chilly winter morning we had a good attendance at Gladesville at our last meeting.

Our guest speaker was Marion Mulholland, a registered nurse who works for the Home Enteral Nutrition service (HENS) provided by Nutricia. Her role is to support people at home who have recently had a feeding tube inserted. Marion spoke about how the PEG tube is inserted and gave advice on maintaining the site and on the dietary supplements available.

Hopefully the sun will be shining and it will be much warmer for our next meeting on 1 October. This will be the last support group for 2008 as we will have our Christmas event for members at the end of November.

Caroline Gleig
Regional Advisor

Support Group Contacts

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MND NSW Ph: 1800 777 175

Fundraising at the movies

Helen Kelmsley and a group of dedicated friends organised a fundraising movie night in Bowral in memory of Helen's husband James who died of MND in December 2007. James was a gifted artist and was responsible for the drawing of Ginger Meggs cartoons. The movie was the premiere of 'Sex in The City' and a great night was had by all.

www.dialbeforeyoudig.com.au
DIAL 1100
BEFORE YOU DIG

Ray Haddad's Golf Day at Oatlands – a winner

While the weather was not very kind the enthusiasm and high spirits were evident at Ray Haddad's Golf Day on Friday 25 July. Oatlands Golf Club provided a great challenge for the many golfers who signed up to support MND. The day started with a lovely BBQ brekkie to get everybody warm and ready for the blowy and rainy conditions out on the course. Major sponsor 'Dial Before You Dig' provided great looking polo shirts for everyone to wear. The day's golf was followed by a wonderful dinner and silent auction. Ray has decided to make this an annual event. Thanks Ray and all the wonderful sponsors and players who made this a great event for MND.

City 2 Surf

'Women with Issues'

To all those who participated in City 2 Surf 2008 we say congratulations! And to those who sponsored a willing participant, well done! It was an amazing fundraising effort. Your support in raising not only funds but awareness for MND is greatly appreciated. A special thank you to the ladies of 'Women with Issues' for a job well done in the City 2 Surf and their ongoing fundraising efforts for MND.

Balance Christmas in July Black Tie Ball

The Balance Christmas in July Black Tie Ball was held on Saturday 12 July 2008. It was a very successful night with over 300 guests dancing away to the entertainment provided by Saxonova. The night was dedicated to Elliot Jay, a beautiful 19 year old Balance learn-to-swim instructor, who died from MND in April 2008. All present joined together to celebrate his life. Many businesses from the Hunter donated prizes and we had a large tombola raffle on the night raising funds for MND NSW. A great night was had by all and the organisers hope their contribution helps in the research for finding a cure for MND.

(l-r) Rebecca Rosetti, Alix Doran, Ara-Jane Geddes and Kelly Stahlhut at the Balance Black Tie Ball

Making nutritional dinners for MND

Anne in the kitchen (above) and Lou, Jo, Margie and Anne making dinner (below)

Anne Darvodelsky, a trainee chef from Hornsby Shire recently held a fundraiser dinner at her home for ten friends. Everyone was asked to contribute towards the ingredients, bring a bottle of wine and be prepared to help in the kitchen. Anne's dinner guests, all close friends, were involved in preparing and eating a delicious four-course meal.

As they sipped chilled Chardonnay and munched on her mini Olive Palmiers Anne's friends learnt how to make handmade pasta for an entrée of salmon and scallop ravioli. Then for the main course they assisted in assembling and cooking a bacon wrapped breast fillet with herbs and mushrooms. Next they made individual apple pies with Chantilly cream. Finally they sat down to a delicious meal together. The friends had lots of fun, the food was marvellous, they all learnt some new cookery skills and they raised money for MND NSW. Thank you Anne for your wonderful effort.

Bowling over MND

Recently the ladies of RydeX Phoenix Women's Bowling Club held a fundraising bowls day to raise awareness and funds for MND NSW. One of their members Janice Berg has MND and, together with visiting bowlers from the Gladesville and Ryde City Bowling Clubs and some generous donations, the Club raised much needed funds for MND. Well done to all involved

Cocktail Party Fundraiser for RNSH MND Clinic

MND NSW Board Member Nick McLoughlin with wife Naomi McLoughlin at the Royal North Shore Hospital MND Clinic fundraiser

The 3rd annual MND Cocktail party hosted by Professor Dominic Rowe was held in July at the Royal Sydney Yacht Squadron at Kirribilli.

This event continues to grow and about 150 guests attended the party including our members with MND, their carers and their friends.

It was so good to see everyone enjoying the entertainment provided by MC Barry Lord and the Guy Strazz Band. It was great to see so many people venture out on a cold winters night to give their support to the Royal North Shore Hospital MND Clinic. Well done everyone!

Thank you for your continued support

Are you looking for a challenge? Walk the Kokoda Track for MND. 2 to 28 August 2009

We Need You!!

Why not hold an event to help us raise funds to provide vital services, equipment and support for research. It's as simple as organising a:

- high tea
- small raffle
- mufti day at your office
- trivia night
- sausage sizzle at Bunnings
- fashion parade
- bowls day
- golf day

Or maybe you would like to organise your own unique event. For further details contact Kym Nielsen, Fundraising Manager ph. 8877 0912 or 0419 480 195.

Community Social Club

At MND NSW we are offering you the opportunity to become a member of our Community Social Club. It's an innovative fundraising program that's designed to not only raise money but also give members a range of benefits including:

- big savings on thousands of retail items through the online retail store at www.communitysocialclubs.com.au
- Qantas Club business pricing.

Membership in the program is $24 per person annually and $5 from every membership purchased is donated to your nominated charity. Also, 15 per cent of every sale to you from the online store is donated your charity.

Your membership also includes a MyRewards membership valued at $99.This program includes a Members Directory with over 600 offers and coupons plus access to www.myrewards.com.au where you will find a further 25,000 offers and coupons valid throughout Australia.

To join contact Community Social Clubs on email info@communitysocialclubs.com.au or phone 1300 792 459.

2008 Christmas Card Photo Competition

Congratulations to Katie Lillyman, aged 17, of Tamworth, who is the winner of the 2008 MND NSW Australian Christmas card competition. Katie's photo of a kangaroo at Coffs Harbour will feature on the 2008 MND NSW Australian Christmas card. You will be able to order this card from the Christmas card order form enclosed in this edition of *Forum*.

Thank you to all who submitted photographs and congratulations to Katie!

Dates for the Diary

22 Sept	**Style is More Than Just Fashion** *Informative talk on image, lingerie and hair. 7pm at Boronia Grove, 49 Rawson Street, Epping. $30 includes drinks and nibbles. To book contact Elizabeth at Ms Elizabeth's Hair Studio on 9869 1003.*
25 and 26 Oct	**Ray McDougall and Margaret Burge Charity Weekend** *For the 8th year in a row, this weekend is being held in South West Rocks. Sat 25 October at 7.30 pm Sporting Memorabilia Auction at the Seabreeze Hotel. Sun 26 October at 7am 4 person Ambrose golf tournament at South West Rocks Country Club followed by a BBQ at the Seabreeze Hotel, $25 per player. There will also be a raffle on the Sunday. Contact Bruce McDougall on (02) 6566 5403.*
28 Oct	**Information Evening for the Kokoda Challenge for MND** *6pm, World Expeditions, Level 5, 71 York Street, Sydney. Chris Buykx of World Expeditions will be presenting on all aspects of the Kokoda Track based on his first hand experience.*
31 Oct	**The Hunter's MND Fundraiser** *Dinner at 7pm, Harbord Diggers, Freshwater. Organised by the Beacon Hill Youth Club. Contact Gail Bonnor if you would like to attend ph. 0415 561351 or gailbonnor@hotmail.com*
6 Nov	**Premium Wealth Management Charity Golf Day and Cocktail Party** *At Killara Golf Club. Contact Roz Kaye ph. 9279 0899 or roz@premiumwealth.com.au*
9 Nov	**Walk to D'Feet MND 2008** *This event is not just for Sydney-siders . We would love some of our country connections to walk on the same day in their home town. Contact Kym ph. 8877 0912.*
2009	
21 Feb	St Valentine's Day Ball, Dapto
Mar	Third MonStar Cup
11 Mar to 10 May	A Drive for A Cure in memory of Norman George Jones
2 and 3 May	Open Garden at 'Homeleigh', Pymble
2 to 28 Aug	Kokoda Challenge for MND

Noticeboard

Researchers seeking participants for new study about emotion and cognition in MND

Professor John Hodges and his team at Prince of Wales Medical Research Institute in collaboration with Professors Dominic Rowe and Matthew Kiernan and the Motor Neurone Disease Association of Australia are planning a research project focusing on cognition and emotion in MND. The primary aim is to identify the prevalence and pattern of cognitive and emotional changes in people with MND, and the potential impact on activities of daily living, decision-making and on carer burden.

The first part of this project is a postal survey, which consists of two sets of questionnaires for both people with MND and their carers. The questionnaires are designed to evaluate changes in aspects of cognition, especially judgement, problem solving and alterations in emotion.

Members of MND NSW will soon be sent more information about the research and an invitation to participate. Any information given by one family member will not be passed on to other family members. MND associations will not have access to the information provided by you for the purpose of this study.

Wanted: creative members with sewing or embroidery skills or knowledge

MND NSW would like to organise some tablecloths and runners with our MND NSW flower logo. These will be used on table displays for meetings, conferences, workshops and special interest groups. Possibilities could include: white or blue cloths with simple flower designs sewn on, embroidered, cross stitched, machine stitched or patch worked. If you have an interest in this area, can make patterns, have time to sew or any other creative ideas then please contact Iva Plessnitzer, MND NSW Regional Advisor 6286 9900 or Freecall 1800 777 175 to express your interest and Iva will return your call. Cloths and cottons will be supplied.

Legless in the Garden

"A story of how determination overcomes adversity, how liberating a disabling disease can be and how easy it is to be independent and happy in a shrinking domain". A book written by Zana Walker who was diagnosed with MND at the age of 46. For more information see www.lulu.com/content/1646698.

Carers NSW seeks carer representatives

Carers NSW provides carer representation at all levels of government and non government organisations. Carers have the opportunity to participate as carer representatives and engage in national and state policy planning and service decisions that affect them as individual carers, carers in general; people they care for; and their families.

Carers NSW are seeking people interested in being carer representatives who will reflect the diverse range of caring situations including:

- young carers
- older parent carers
- carers for people who are aging

One of the aims is to represent the range of cultural groups within NSW including:

- Aboriginal people
- Arabic, Cantonese, Greek, Italian and Vietnamese speaking communities
- South African, Sudanese, Indonesian, Iraqi and Lebanese cultural groups

If you are interested in being a carer representative contact Liz Dore at Carers NSW ph. 9280 4744 (Mon - Wed) or by email lizd@carersnsw.asn.au

source: TRI Community Exchange Inc

Support from United Petroleum for MND research

United Petroleum will give one cent per litre to the MND Research Institute every time you fill up your car at a United service station and present your United - MND Research Institute community card. To find out if there is a United Service Station near you, call United on 1300 383 587 or visit www.mndresearch.asn.au. Contact Janet Nash at the MND Research Institute of Australia ph 8877 0990 or email info@mndresearch.asn.au to ask for a United - MND Research Institute community card to be sent to you.

Low-cost computers

Low-cost refurbished computers can be purchased by holders of the Centrelink Health Care Card, Aged Pension Card, Disability Card or some other form of documentation relating to low-income or disadvantage from WorkVentures Connect. Prices start at $350 for a system with software and either a 56k modem or 10/100 network card installed - ready for the Internet. For more information see http://connectit.workventures.net.au

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

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Editor: *Penny Waterson*