

Spetember 2007

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Ask the Experts Forum

What part of the brain is affected by progressive bulbar palsy? Does MND have a connection to a previous illness? Has there been any research into the incidence of MND in different races? I wake up in the morning with a brown stain on my tongue and a strange taste in my mouth. Is this normal? Is the disease on the increase? Since my father was diagnosed there seems to be a lot more people with MND. These were some the questions put to the experts during the MND NSW Ask The Experts Forum on 23 July 2007 at Ryde.

Dr Dominic Rowe from Royal North Shore (RNS) Hospital started off the discussion giving an overview of MND, symptom management and multidisciplinary care. This was followed by Associate Professor Roger Pamphlett speaking about the work of the MND DNA Bank.

Associate Professor Pamphlett and Lorel Adams, Manager of the MND DNA Bank, were there for the whole day as many of those present gave blood, ten head hairs each and cells from the inside of the cheek taken via a swab to the Bank. Thank you so much for your generosity in participating in this project. It relies on you and requires a commitment to a future vision to find the causes of MND.

Multidisciplinary care was a key theme running through many presentations. Dr Helen Herz, a Palliative Care Specialist from Calvary Hospital explained what palliative care is, that it encompasses physical, psychological, social and spiritual aspects and involves a team approach to the care of the person with MND. Sandra Erjavec, Clinical Nurse

Consultant RNS Hospital, described the work of the MND Multidisciplinary Clinics at the RNS, Prince of Wales (POW) and St Joseph's Hospitals and the benefits of this approach to care.



Dominic Rowe, Peter Plunkett-Cole and Sue Johnston (above) and Maureen Halloway, Jean Robinson, Don Halloway and Rene D'Rosario (below) at the Ask The Experts Forum



MND NSW Regional Advisors and the Association are part of this spectrum of care. The regional advisor role is diverse as Caroline Gleig explained, and can include advocacy, education, support, referral and home visits. It is also broad with seven regional advisors covering different geographical regions across New South Wales.

Janet Nash let us know about the work of the MND Research Institute of Australia. Associate Professor Matthew Kiernan outlined the research being undertaken at POW Hospital including the role of exercise.

The feedback from the evaluations was overall very positive. Suggestions for another Forum included information about overseas research, exercise and equipment. If you felt shy about asking questions, next time, please pass your questions to someone else so they can ask for you!

I know people appreciated having the experts together. It is also a day to meet and get to know one another, put faces to names. Thank you for making it such a positive event.

Jane Barrett
Family Support Coordinator

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

June saw the successful staging of the 3rd National MND Conference. This year it was hosted by the MND Association of Western Australia in Fremantle. The Conference was attended by about 160 people from across Australia - all with a common interest in MND, from research through to care. MND WA is to be congratulated for their efforts and Gina Svolos, MND NSW Family Support Manager has more about the conference in her report in this edition of *Forum*.

Our Ask the Experts Forum held in July (see page 1) was well attended and as is always the case there were more questions than time. I would like to thank all of those who attended and particularly the MND NSW staff for being on hand and Dr Dominic Rowe, Associate Professor Roger Pamphlett, Associate Professor Matthew Kiernan, Dr Helen Herz, Janet Nash, Sandra Erjavec, Margie Zoning and Julie Labra for giving up so much of their time to be present on the day.

In the June edition of *Forum* I mentioned that MND NSW, Multiple Sclerosis NSW/Vic and Muscular Dystrophy NSW have formed a consortium to advocate for people with progressive neurological diseases. The group has initially focused on flexible respite care and I am pleased to announce that funding for our proposed model has been

received from New South Wales Department of Ageing Disability and Home Care. This has enabled the employment of a Flexible Respite Coordinator by Multiple Sclerosis NSW on behalf of the consortium. Julie Becke has commenced work and will be developing the systems to properly run the program over the next few months.

I know it's early but I would like to extend an invitation to all to attend our 2007 Christmas Party. This year it will be held at our Gladesville Centre and, as it gets a little hectic in December, we have moved it forward to Saturday November 24. See the box below for further information.

Our Annual General Meeting will be held in the afternoon on Tuesday 30 October at our Gladesville Centre. Full details will be mailed to all members in late September.

Due to the APEC meeting being held in Sydney, we had an unscheduled closure of the office, including the Info Line on Friday 7 September. I apologise if this caused you inconvenience.

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

MND NSW
Annual
General
Meeting

Tuesday 30
October 2007

Dr Dominic Rowe from the Multidisciplinary MND Clinic, Department of Neurology, Royal North Shore Hospital, Sydney suggests a **Four Question Test** for deciding whether or not to undertake a particular therapy or treatment:

What is the premise (or fact) behind the proposed therapy?	How is the therapy going to help me?
How might the therapy hurt me?	What has the person got to gain by offering the therapy to me?

Learn now Live well

Monday 12 and Monday 19 November
10am-3pm at Gladesville

Held over two Mondays, this is a program where people with MND plus family members and friends can come together and learn more about living with MND.

It will include information about exercise, managing difficulties and maintaining independence. There will be plenty of time to ask questions and learn from others living with MND.

Call MND NSW on 8877 0999 to register your interest and a brochure will be sent with more information.



**MND NSW
Members'
Christmas Party
Saturday
24 November 2007
MND NSW Centre
Gladesville**

Watch your mailbox for your invitation



Family Support

Since the last edition of *Forum* the Family Support team has held a number of events and it has been great to meet many of you during this time.

The Information Evening held in June was well attended by members, their families and friends. This evening provided an opportunity to learn more about MND and services available through MND NSW and the community. It is especially helpful for family and friends who don't often have other opportunities to learn about MND. So to our newer members I extend an invitation for you to invite your family and friends to our next Information Evening to be held on Tuesday 15 October at 6.30pm at the MND NSW Centre at Gladesville.

The Ask the Experts Forum in July was also very well attended and we had some excellent speakers talking about research and care for people with MND (see page 1).

As many of you would know we primarily have contact with our members through our Family Support Regional Advisors who provide support and information to our members either by phone or visits. We now have seven regional advisors covering all of New South Wales and while they may not be able to see everyone regularly due to the number of people they have in their region, they aim to be available when you really need it, especially during times of changes in your situation. So if you find that you need assistance with accessing services or getting information then give your Regional Advisor a call or phone our Info Line on 8877 0999 or 1800 777 175.

Member Survey

To help us to know what you think about how well we service our members a Member Survey will be sent out to members with MND **during September**. I would encourage you to complete this survey as honestly as possible as we use the results of this survey to help us plan and develop our services. We really want your feedback about how we are doing and also your suggestions on how we can improve services.

3rd National MND Conference

In June several of the Family Support team attended the 3rd National MND Conference in Fremantle, Western Australia. Paper presentations included the management of respiratory care, non-invasive ventilation, independent living, carers needs, and psychosocial and supportive care. There were many excellent speakers and I will highlight several who may be of interest.

Two speakers talked about current research in Western Australia. Professor **Grant Morahan** from

the Centre for Medical Research at University of Western Australia, spoke about a new field of study called systems genetics that is now being investigated. Professor **Nigel Laing** from the same medical research centre talked about research that was focusing on the SOD1 gene. It was exciting to hear that many different approaches are being taken by researchers to find the causes of MND.

The paper presented by **Mary Harney** from Fremantle Hospital was about Advance Care Planning (ACP). Mary explained that ACP is a process that gives the individual the opportunity to make their future health care wishes known so these can be acted on if they are no longer able to participate in decision making (see page 6 of this edition of *Forum* for further information on ACP).

MND NSW Equipment Services Coordinator, **Maree Hibbett**, presented a paper on the evolving equipment needs of people living with MND. She discussed the changes in equipment and technology and how technology has reduced some of the costs of equipment. While the right equipment can help a person with MND maintain family life it can also ensure occupational health and safety standards are maintained for family and other carers.

Jo Fowler and **Allison Pearson**, MND NSW Regional Advisors, also presented at the conference. Allison's paper was on the very successful MND NSW Link and Learn Program. Jo stepped in at short notice to present about MND multidisciplinary care. This was much appreciated by the attendees.

Robin Ray from La Trobe University has been researching carers needs. She found carers often covered up their reactions to preserve the feelings of the person for whom they are caring. Carers tend to hide the burden of caregiving and not disclose their feelings to people they didn't trust. Caregivers need to be able to ask questions and share the challenges of caregiving without losing face. She concluded that information should be tailored to the needs of the family and that caregivers may require assistance to identify a confidant and/or opportunities to use health and social care professionals as confidants.

On the Monday before the conference the Family Support team met with staff from MND Associations in Australia and New Zealand. This provided the opportunity to learn from each others experiences and to discuss ways to better support people living with MND. The next conference will be held in Melbourne in June 2008.

Gina Svolos
Manager Family Support



At the National Conference - Jo Fowler, MND NSW Regional Advisor presenting (above) and Amanda Baldwin, MND Victoria, with Anna Nicholas, MND Tasmania (below)



Information Evening - for people newly diagnosed with MND and their families and friends. MND NSW Centre Gladesville Tuesday 16 October at 6.30pm

Carers News

The label of 'carer' is one that many people simply do not apply to themselves. They care because they are a mother, father, friend, partner, wife, husband, son, daughter.

Caring for a person with motor neurone disease means acquiring new knowledge, skills and ways of coping with a changed world. It also involves being defined by governments, health, community and related services as a 'carer'.

The MND NSW Care for Carers Program which begins on Monday 3 September looks at what it means to be a carer. People will be able to talk with others in a similar situation, to share experiences and find ways through the complexities and stress of the role. There will be time to explore how people can look after themselves - the carer needs care too!

The program is run over four consecutive Mondays and includes information on how to access services and the physical care of a person with MND, plus more hands-on sessions such as getting to know the range of equipment available through the MND NSW equipment service.

I am looking forward to meeting new course participants - family and friends who are caring for people with MND, and hope they will get a lot out of this program. If you would like be interested in attending a future Care for Carers Program, contact me to register your interest.

Jane Barrett

Family Services Coordinator

Family Support Calendar

3, 10, 17, 24 Sept	Care for Carers Program <i>MND NSW Centre Gladesville</i>
28 Sep	Past Carers Meeting <i>MND NSW Centre, Gladesville</i>
16 Oct	Information Evening <i>For people newly diagnosed with MND and their families and friends</i> <i>MND NSW Centre Gladesville</i>
12 Nov	MND DNA Bank Canberra Visit <i>Take the opportunity to hear about the latest research on MND. Contact Allison Pearson, Regional Advisor MND NSW for more information ph. 6238 3769.</i>
12, 19 Nov	Learn Now Live Well <i>Information and Education program for people with MND their families and friends. One day per week for two weeks</i> <i>MND NSW Centre Gladesville</i>
24 Nov	MND NSW Christmas Party <i>MND NSW Centre Gladesville</i>

If you would like assistance with travel to attend any of the family support sessions or would like us to organise an MND information session in your region, please speak to your Regional Advisor.

Equipment

The MND NSW Equipment Service has been very busy over the last 12 months. The items of equipment loaned have enabled 254 individual members, in both regional and metropolitan areas of New South Wales, to be assisted in the areas of care, communication and the maintenance of independence. During this time, twenty eight electric Hi-lo medical beds were hired by the Association for members. Hiring most frequently occurs in regional areas because delivery costs of electric beds are very high. Currently seventeen beds are still on hire.

MND NSW also subsidises the cost to members for either the hire of a non-invasive positive pressure ventilator or the hire of a suction machine. This hire is authorised after discussion with the Manager of Family Support, Gina Svolos, after referral by an appropriate health professional. Seventeen members accessed this subsidy during the year. During the past year there has also been a gradual update of MND NSW owned electric beds and manual wheelchairs as demand for these items is always high.

There are presently 1246 items in the Equipment Pool. Items are available for loan to members after assessment by a health professional.

I would also like to introduce the new member of the Equipment Service Team, Matthew Fowler. Matthew will be working as the Association's second equipment assistant for one to two days each week. With Trevor Rakuraku, he will be arranging couriers, cleaning and repairing equipment. Welcome to the team, Matthew.

Maree Hibbert

Equipment Services Coordinator

Introducing...

Matthew Fowler
Equipment Assistant

I will be working part time, one to two days a week in the equipment room. In this role, I am looking forward to learning about the care and maintenance of the equipment, the workings of the courier system and how to best take phone calls.

I am a full time undergraduate student studying business marketing at the University of Western Sydney, at Parramatta. I enjoy cycling and in my spare time I am involved in the Army Reserve and the State Emergency Service.



Care for Carers Program

*MND NSW Centre, Gladesville
3, 10, 17 and 24 September*

Mailbag

From Pat Horne, Wollongong

The poem below was written by my sister - Monica Gleeson as she was flying home after attending my son's funeral on 12 April 2007.

My son - Clinton 'Clint' David Bourke was diagnosed with MND on 22 February 2006 - on this day our world and life's dreams all changed. Clint was only 35 years old and was a 'Mr Mum' to his four children - Jaimi, Jack, Ned and Grace prior to his diagnosis. Clint is my hero - the bravery and courage that he showed gives me pride and strength in my sad and lonely times.

Pat Horne

Wollongong

I kept my gaze on the sun as it set,
nestled gently on a soft bed of clouds.

The darkness closed in round the warm orange glow,
the last hint of our bright shining sun.

My spirits sink low as I blink through my tears,
but they rise up again as a bright light appears,
right above the last glimpse of the sun.

"Clint's Star" I declare - the first of the night,
I'm no longer alone while it shines so bright,
from this day on there will always be
a guiding light for us to see,
a heavenly reminder of my sisters' dear son.

"The light surrounding you" comes echoing through
as I gaze at that solitary spark
shining so brightly in a back drop of blue
There's no need for "Goodbyes", evermore a
"Hello"
A glimpse of our wish coming true.

Clint Bourke
1 September 1970 to 8 April 2007
'Forever Young'

From Therese Aoun, Sydney

As I was sitting at the airport, all I could think of was what was I thinking!?! I hadn't been overseas in years; let alone been away for this long with MND.

It all came about last year, before I was diagnosed, when my best friend Simy asked me to go with her to Brazil. I told her that I would, but that first I wanted to find out what was wrong with my hand. I got the news in June last year that I had MND. I was not expecting the news to be so devastating and I was certainly not expecting to go to Brazil now.

After a few months of doing tests and trying to come to terms with the news Simy brought up the subject of going to Brazil again. My immediate thought was I can't, but then I decided that I didn't want MND to restrict my life anymore than it already would.

So I said yes, asked my little sister if she wanted to come and then before I knew it March had come round and we were off to Brazil.

With plenty of pre-planning, making sure that airlines and hotels were aware that I required a wheelchair and with a full supply of documentation and medication to get me through the six weeks that we were away, we headed off. Apart from damaging my wheelchair, the airlines that we used were very helpful. They assisted with access to and from the terminal and planes and when fog resulted in us leaving Sydney hours later and missing all our connecting flights, they helped find a hotel in the stop-off city that had a disability friendly room.

When we finally reached Brazil, 26 hours later, I was very tired but really excited. It took me about a day to recover from the trip but once I was rejuvenated, nothing stopped me.

Brazil was amazing. We visited quite a number of cities and met people who lived with such a zest for life, focusing on the things that are most important - family and friends. We stayed with families whose ideas of fun were to have family members play an instrument, others sing and others dance. They lived in houses and had incomes that we would consider below the poverty line in Australia, but were happy.

Apart from visiting places that most tourists wouldn't go to, I also visited the most popular tourist spots - Eguaza Falls, Copacabana Beach and my favourite site - visiting Jesus.

The key to the holiday was planning and whilst it was not a very disability friendly country, the amount of support from the Brazilians was overwhelming. I would definitely go back there - the people are amazing - full of life!

I am so happy that I went. I felt more alive and energetic having gone than ever before.

Therese Aoun
Sydney



Therese Aoun with her sister Monda in front of the Jesus statue in Rio de Janeiro, Brazil (above) and Iguazu Falls (below)



Email or write your letter to The Editor of Forum.
See back page for contact details

Planning Ahead

Although there may be differences in how motor neurone disease progresses, it is not uncommon for people living with motor neurone disease to become concerned about what lies ahead and how decisions about their finances, health and lifestyle will be made.

Planning ahead can provide you with the opportunity to think about, discuss and set in place arrangements for financial, health and lifestyle decision-making. This can become particularly important if you have specific wishes regarding health care management and interventions or if you may expect to have future communication difficulties.

Most people find that living with thoughts and fears about what lies ahead is often harder than talking about and setting in place arrangements that can relieve these fears. These arrangements can be formal or informal, although some require specific documentation to be legally enforceable. Sometimes, setting in place your own arrangements will avoid the need for a Tribunal or Court to appoint someone to act on your behalf.

Planning ahead involves identifying what is important to you, communicating this to others and making arrangements to ensure that your wishes are carried out. Often, people find that their wishes change over time. Communicating with others about what is important to you is an ongoing process. Planning ahead reduces the possibility that your partner, family, friends or a court-appointed guardian will need to 'second-guess' what you would want to happen.

You can change your mind about your arrangements at any time as long as you still have the capacity to make decisions and you can communicate this to others.

Arrangements you make about decision-making on your behalf are only accessed if:

- you no longer have the capacity to make decisions, or
- you cannot communicate your decisions to others, or
- (in some instances) you have determined that they will take effect immediately.

Arrangements you might consider setting in place are:

- A **power of attorney** or an **enduring power of attorney** which allows you to give authority to someone you nominate, to make decisions regarding financial issues on your behalf
- **enduring guardianship** which allows you to give authority to someone you nominate, to make decisions regarding personal, health and lifestyle matters on your behalf; and
- An **advance health care directive**, which allows you to provide clear guidance to your doctors about your intentions for medical treatment in the future.

The New South Wales Department of Ageing, Disability and Home Care have produced an excellent free resource – the *Planning Ahead Kit*. The information on the following pages is an excerpt from this Kit. For more information about the Kit see *Further Information and References* on page 8 of this edition of *Forum*.

Person responsible – The role of the 'person responsible' is to make substitute decisions that consent to, or refuse consent to medical treatment. This person is required to have regard to the views of the patient but they are not bound to follow them. The 'person responsible' replaces the old term 'next of kin' as the person from whom consent for active treatment in the incompetent patient must be sought. The 'person responsible' is determined according to the hierarchy within the Guardianship Act 1987 (NSW) and in the following order:

- An appointed guardian (enduring guardian) with the function of consenting to medical and dental treatment. If there is no-one in this category:
- A spouse or de facto spouse who has a close and continuing relationship with the person. If there is no-one in this category:
- The carer or person who arranges care on a regular basis and is unpaid (the carer pension does not count as payment). If there is no-one in this category:
- The carer of the person before they went into residential care. If there is no-one in this category:
- A close friend or relative.

(NSW Health 2004)

*Past Carers
Meeting*

*MND NSW
Centre,
Gladesville,
28 September*

Planning Ahead *(cont'd)*

Power of Attorney or Enduring Power of Attorney – for financial issues

Power of attorney

A power of attorney is a document you can sign to appoint another person (called your attorney) to act for you in relation to financial affairs. The document states what the attorney is authorised to do. This can be quite narrow and specific, or as general as desired. Any lawful action taken by the attorney under the power of attorney is binding on you. It is therefore important to appoint someone you can trust.

When the power of attorney is signed, the document can be given to the attorney or you can hold onto it until the need arises. When it is provided to your attorney, it can be used to prove that he or she is authorised to act on your behalf. Even though you have appointed an attorney, you can still personally carry out any transactions, such as banking and the sale of property, while you retain the ability to do so.

A power of attorney is in effect as long as you want it, and can be cancelled at any time while you have the capacity to do so. It may also be set for a particular period of time, for example a period while you are ill or while you are overseas.

By law, *a power of attorney ceases to operate if you lose the ability to make decisions* or when you die.

Enduring power of attorney

If you want the power of attorney to continue, even if you lose the capacity to make your own decisions, you need to sign an enduring power of attorney. An enduring power of attorney differs from a power of attorney in that:

- The intention for the enduring power of attorney to continue is stated in the document;
- Your signature on the document is appropriately witnessed; and
- A certificate is attached to the document declaring that the witness explained the effect of the document to you before you signed and that you appeared to understand it.

Making an enduring power of attorney is a way for you to legally appoint a person of your choosing to manage your financial affairs even if you later lose the capacity to make these decisions for yourself.

An enduring power of attorney must be made when you are of sound mind. It is too late to make this appointment after you have lost the capacity to manage your own affairs. If there is a doubt, you should seek a medical opinion.

You can make enduring power of attorney arrangements, which come into effect immediately, or one that remains 'dormant' and only comes into effect in particular circumstances. For example, you could decide to complete an enduring power of attorney that becomes active only when you are unable to manage financial matters for yourself.

The person you appoint should be someone you trust. He or she must be 18 years or over. If you have no one like this or they are too busy or do not have the required skills, the Public Trustee NSW or private trustee companies can be appointed as your attorney. They will charge a fee for handling your affairs.

If you want your attorney to be able to sell or deal with real estate on your behalf, the power of attorney must be registered with the Department of Lands. If you want your attorney to be able to sell or deal with shares on your behalf, it is a good idea to register the power of attorney as outlined above, as some brokers or companies may require this, even though the law does not.

Enduring Guardianship - for personal, health and lifestyle issues

An enduring guardian is someone you appoint, at a time when you have capacity, to make personal, health or lifestyle decisions on your behalf should you lose the capacity to make them for yourself. The appointment of an enduring guardian takes effect only if you lose the capacity to make your own decisions. You can appoint more than one enduring guardian if you wish.

You might consider appointing an enduring guardian if you want to specify that a particular person, for example, a particular friend or relative, has authority to make decisions for you.

You choose which decision-making areas you want your enduring guardian to have. These are called functions. You can give your enduring guardian as many or as few functions as you like. For example, you can authorise your enduring guardian to decide such things as where you may need to live or what medical treatment you should receive.

You may give the enduring guardian directions about how to exercise the decision-making functions you give them. You cannot give your enduring guardian the authority to override your objection to medical treatment. Only the Guardianship Tribunal can do this.

Your enduring guardian must act within the principles of the Guardianship Act, in your best interests and within the law. You cannot give your guardian a function or a direction that would involve them in an unlawful act, such as euthanasia.

An enduring guardian cannot make a will for you, vote on your behalf, consent to marriage, manage your finances or override your objections, if any, to medical treatment. He/she cannot consent to treatments that are defined as "special" medical treatments, for example, treatments such as new or experimental treatments. Only the Guardianship Tribunal can consent to special medical treatments.

The person you appoint as your enduring guardian must be 18 years or over. He or she should be

Learn now
Live well

Monday 12
and Monday
19 November

See page 2 for
more
information

Planning Ahead (cont'd)

someone you trust to make decisions in your best interests should you not be able to make these decisions for yourself. While you are capable of making your own decisions, you can revoke the appointment of an enduring guardian. Only the Guardianship Tribunal can make changes to the appointment if you have lost the capacity to do this for yourself.

In deciding who to appoint, it is worth considering the willingness and availability of the person to take on the role, as well as their age and health.

Advance Care Directives - for clear guidance to your doctors about your intentions for medical treatment in the future.

An advance care directive (sometimes called a 'living will') is a way of recording your wishes or instructions for the future for doctors and health care workers. It is only used in situations when you are unable to communicate or have lost the ability to make decisions for yourself. It can provide a way of setting out exactly what you want done in particular circumstances or it could be used to provide a general description of how you would like to be treated.

Unlike enduring powers of attorney and enduring guardianship, there is no special form that you must use. However, the NSW Department of Health has published guidelines called *Using Advance Care Directives* on the best way to document an advance care directive (see Further Resources below).

These guidelines recommend that an advance care directive should follow these four principles:

1. It needs to be specific – it can include your preferences for treatment for a health condition you have now or one you may develop in the future. It is a good idea to talk to your doctor about your wishes.
2. It needs to be kept current – your wishes may change in the future, so it is important to review your advance care directive regularly or if there is a big change in your health. It is a good idea to note on it when you last reviewed it and whether or not you made any changes.
3. You must be mentally competent – you can only make an advance care directive while you still have the mental ability to understand the choices you are making.
4. It is good idea to have it witnessed. If you choose to make an advance care directive as part of appointing an enduring guardian, it will need to be witnessed by a solicitor, barrister or Registrar of the Local Court.

If you choose to make a 'stand alone' advance care directive, you can choose who you ask to witness it.

Does the doctor have to follow my wishes?

Yes. Although there is no special legislation in NSW which deals with advance care directives, the NSW Health Department's guidelines to doctors make it clear that if an advance care directive meets the four principles set out above, doctors are legally bound to follow it.

For example, you may say in your advance care directive that if you are unable to communicate with or recognise your family, and there is no possibility that you will ever improve or recover, you do not want CPR (Cardio Pulmonary Resuscitation) if your heart stops, but you only want to be kept comfortable and free from pain.

However, you cannot use your advance care directive to demand treatment that your doctors think would be futile (e.g. a heart transplant). Nor can you ask someone to actively and deliberately end your life. That would be euthanasia, which is illegal in all Australian states and territories, and has nothing to do with advance care directives.

Does everyone need an advance care directive?

No. It is up to you. Everyone is different, and you may not want to think about what may happen to your health in the future. You may prefer to leave such decisions to your partner, a person caring for you, or a relative or close friend who knows you well and you trust to make decisions for you. Talking over what you want will at least help them to know what you would have wanted if they ever have to make such decisions for you.

Further Information and References

- Your doctor
- Department of Ageing, Disability and Home Care's (DADHC) *Planning Ahead Kit: Resources for managing financial, health and lifestyle decisions into the future* (May 2006). Available at www.dadhc.nsw.gov.au or ph. 02 8270 2000 to request a copy be posted to you.
- NSW Department of Health. *Using advance care directives* (2004). Publication number (HEB) 040109 (NSW). Available at www.health.nsw.gov.au/pubs/2004/adcare_directives.html or Better Health Centre Publications Warehouse ph. 02 9816 0452 to request a copy be posted to you.
- The Benevolent Society. *Your Future Starts Now: A Guide for Over 50s* (March 2005). Available at www.bensoc.org.au or ph. 02 9339 8000 to request a copy be posted to you.
- Private Solicitor
- NSW Legal Aid ph. 1300 888 529
- Guardianship Tribunal. *Enduring Guardianship; Enduring Power of Attorney; Review of Enduring Powers of Attorney: Information for Parties*. Available at www.gt.nsw.gov.au or ph. 02 9555 8500 Freecall 1800 463 928 to request a copy be posted to you.

Contact a solicitor for advice that is specific to your circumstances

Support Group News

Southern Highlands/Monaro

The group is now in recess until February, 2008. It is natural for support groups to have a fluctuating membership and hopefully in the interim, current members will feel free to contact each other to continue friendships that have been formed. I will spend some time planning a new format for next year's meetings. It is envisaged that meetings will be held on a week day with an emphasis on guest speakers and time for refreshments and chat afterwards. I would welcome any suggestions you have regarding this.

There will, however, be an opportunity to get together with our MND community on Monday, 12 November when Lorel Adams from the MND DNA Bank visits Canberra in the hope of gaining your blood donation! The Bank has been set up by Assoc Prof. Roger Pamphlett, of the University of Sydney, to provide a resource for researchers undertaking studies into the causes of MND. Apart from taking blood samples, Lorel will give an update on current research with an emphasis on the work of the Bank. Blood samples from those with MND as well as their relatives and friends are sought. You are most welcome to attend even if you are not donating. For further information contact me on 6238 3769.

Allison Pearson
Regional Advisor

Gladesville

Attendance numbers have been increasing and I am seeing a real spirit of friendship and mutual support emerge amongst the group. For our August meeting we thought it might be interesting to look at family history and some of the group brought in photographs and talked about family origins or things they had done in the past. We also had time for general discussion and support. A case manager from Community Options also attended and outlined the role of case managers in the coordination of community care for people with MND. Everyone is welcome to visit the MND Centre at Gladesville and if it happens to be on a day when the support group is meeting, you are more than welcome to drop in and join the group. The next meeting on 3 October will be the last meeting for 2007 as we will have the MND Christmas Party in November. Please call me on 8877 0905 if you would like your name to be added to the invitation list so that you are kept informed of upcoming meetings in 2008.

Caroline Gleig
Regional Advisor

Northern Beaches

It has been a very satisfying year and we have had a variety of wonderful speakers. We have also had a number of new members joining our support group which meets at the Northern Beaches Palliative Care Cottage at Mona Vale.

In June, Margaret Erdmanis, a massage therapist spoiled each and every one of our members with

Support Group Contacts

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Central West

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Coffs Harbour

Lily Jenkins
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Illawarra

Cindy Cherry
Ph: 02 4223 8000

Gladesville

Caroline Gleig
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and

Northern Beaches (Mona Vale) and Northern Sydney (Hornsby)

Jo Fowler
josephinef@mndnsw.asn.au
and

Western Sydney

Jenny Judd
jennyj@mndnsw.asn.au

All Sydney metropolitan groups are coordinated through the MND Gladesville Centre.
Ph. 02 8877 0999 or Freecall 1800 777 175

New England

MND NSW
Ph: 1800 777 175

Newcastle & Hunter

MND NSW

Ph: 1800 777 175

Northern Rivers

Helen Gates
Ph: 02 6621 4018

Riverina & SW Slopes

Susan Chambers
Ph: 02 6942 3970

Southern Highlands/Monaro

Allison Pearson
Ph: 02 6238 3769
allisonp@mndnsw.asn.au

her gentle 'hands-on' therapies and her silky massage oils. Our August speaker was Trish Reynolds, Clinical Nurse Consultant, Royal North Shore Hospital, who discussed respiratory management.

The group meets every second month for morning tea from 11am to 1pm with the next meeting on 4 October. We encourage members to bring a partner or a friend along to the meetings and we would be pleased to welcome anyone interested in joining the group.

Jo Fowler
Regional Advisor



Makaylah, Jenny and Ken Winter at the Gosford Group (left) and Alec and Aviva Cohen at the Northern Sydney (Hornsby) Group (right)



The MND DNA Bank is visiting Canberra on Monday 12 November. For more information contact Allison Pearson, MND NSW Regional Advisor ph. 6238 3769

Annual garage sale - a big hit

Earlier this year Garry and Gai McKay, Jill Driscoll and their friends had their fifth garage sale in memory of Terry Driscoll who passed away from MND. To get the best result they send out flyers to friends and neighbours asking for a donation of saleable items. Over the years they have had a variety of bits and pieces to sell including a worm farm and kittens. Gai says, "Everyone is so supportive. One neighbour brings a cake for morning tea every year. Others get up at 5am to help me get everything out on the lawn. Our friend Fred, who also lost a friend to MND, makes the most amazing signs." Over the five years they have raised a wonderful \$7,000 for research into MND.



Jill Driscoll and Gai McKay

Charity trek

Nicholas Merry lost his father to MND and his mother to cancer. In memory of his parents, Nicholas trekked Kilimanjaro in June 2007 to raise funds for MND NSW and the Cancel Council; funds raised will be split 50/50 with the two charities. Congratulations Nicholas!



Nicholas Merry on top of Kilimanjaro

MND well supported at City to Surf '07

MND NSW was well represented by runners this year. A big 'thank you' goes to our champion runner Linda Draper who raised \$2,295 for the Association. The other representatives did extremely well too and we thank them for their effort. They were Debbie Brenner (\$100), Marianne Smith (\$505), Carol and Carly Skeffington (\$275 and \$110), Alison Nash (\$1050), Olimpia Pastega (\$615), Greg Smith (\$190), Charlie Bellemore (\$575), Jocelyn Ritchie (\$72) and Cameron Ritchie (\$147). This is an amazing total of \$5,934.



Linda Draper with her friends from Westpac at the 2007 City to Surf

Firemen do it again!

Once again the graduates of the Metropolitan Fire Brigade put on their uniforms, grabbed some buckets and headed off to Wynyard Station to collect money for MND NSW. Congratulations to Class 2/07 for a wonderful effort bringing in over \$7,000.



The MND fundraising lady of Bateman's Bay

Deidree Jones is known as the fundraising lady of Bateman's Bay because she can be found most days sitting in the Stocklands Mall selling MND merchandise and sometimes raffle tickets. Deidree lost her mother many years ago to MND but the memory of this devastating disease has not left her and she is determined to help those living with MND now, in any way she can.



Deidree Jones

Recently she organised for Judy Ford, Fundraising Manager MND NSW, to speak about MND to 60 women from Women in Business at the Catalina Golf Club. Deidree also organised for health professionals in the Bateman's Bay region to meet with MND NSW Regional Advisor, Allison Pearson, so they could find out more about ways to help people living with MND.

We are most appreciative of the wonderful support Deidree gives the Association.

Farewell to two good friends

Farewell to Ulladulla residents Di and Bruce Nicholls who are moving west to live closer to their children in Perth. Having been great supporters of the Association they decided to hold one last event to say goodbye to their friends and raise some funds for MND NSW.



Bruce and Di Nicholls

Held in July at the Uniting Church hall in Milton the morning started with Judy Ford, MND NSW Fundraising Manager, giving an informal presentation about MND and the effects of the disease to the 60 strong audience. Di followed with a short 'Blue' quiz where the answers or questions had something to do with the colour blue. After a yummy morning tea, Bruce spoke about his experiences as a MND carer. His humorous 'real-life' approach found a great connection with those present.

The proceeds from the gold coin entry and sales of merchandise were received gratefully and we thank Di and Bruce for putting on such a good gathering.

The 2007 Christmas Card range is now available from MND NSW. See the insert for more information

Thank you to volunteers

Those volunteers who were able to take time to visit Gladesville joined MND NSW staff for a lovely lunch at the Cornucopia Café in the grounds of the old Gladesville Hospital in July.

We really appreciate all the work our volunteers do for us and we are sorry not everyone can make it. Maybe next time!



Charity gala dinner

MND NSW was delighted to be the beneficiary of the Roseville Memorial Club's seventh Annual Charity Dinner on Saturday 23 June. The club raised a record amount of \$24,000 for MND NSW. Congratulations to the directors and staff of the club who organised the event and club members and the community for their support of the event; not only by attending but by way of donations of raffle and auction items. Special thanks must go to Elizabeth Newman, Charity Director who was the key coordinator and put together a wonderful event and also to our own volunteer Suzanne Ballinger for her contribution in the lead up to the evening and for obtaining raffle and auction items. Funds raised go to much-needed equipment and family support programs. It is through the hard work and dedication of organisations such as the club that we are able to maintain our support for people with MND, their families and carers.



Suzanne Ballinger, John Whitworth, Elizabeth Newman, Harry Wilkinson and Roslyn Adams at the Roseville Memorial Club's Annual Charity Dinner

And the winner is...

Sharon Morris from Scone won the beautiful quilt made by the Hunters Hill Quilters which was drawn on MND Global Day in June. Mae Hardaker won second prize and Judy Saladine won third prize. Congratulations to the winners and thank you to Hunters Hill Quilters and to those who sold and bought tickets.



Sharon Morris MND Global Day prize winner

To volunteer for MND NSW contact Roslyn Adams ph. 1800 777 175

Dates for the Diary

15 Sept	'Spring into Action' Fundraiser <i>Organised by Meg Tudehope, Sydney. Funds raised will go to purchasing a wheelchair.</i>
18 Sept	Sydney BarShow Bar Awards <i>Hilton Hotel Sydney.</i>
23 Sept	Singleton Bowling Club Bowls Day <i>50 Pitt Street, Singleton. Organised by Greg Cleary.</i>
6 Nov	Melbourne Cup Luncheon at Pymble Golf Club <i>Organised by Anne Brauer, Rosemary Hobbs and friends. MND is the chosen charity for the PGC in 2007.</i>
10 Nov	Tony Young Memorial Golf Day, Firemans Shield Competition <i>Cooma Golf Club. Organised by Valma Young.</i>

Volunteer – it's good for you!

Eat right, exercise – and volunteer. According to the American publication **The Health Benefits of Volunteering: A Review of Recent Research**, volunteers help themselves to better health while helping others. The study, released by the Corporation for National and Community Service in Washington D.C. found a significant connection between volunteering and good health. The report shows that volunteers have greater longevity, higher functional ability, lower rates of depression and less incidence of heart disease.

According to the report:

- A study of adults aged 65+ found that the positive effect of volunteering on physical and mental health is due to the personal sense of accomplishment an individual gains from his or her volunteer activities.
- Another study found that volunteering led to lower rates of depression in individuals 65 and older.
- A Duke University study found that individuals who volunteered after experiencing heart attacks reported reductions in despair and depression – two factors that have been linked to mortality in post-coronary artery disease patients.
- Two studies found that those who reached the volunteering threshold of about 100 hours per year, or about two hours a week, enjoyed significant health benefits, although there were no additional benefits beyond the 100-hour mark.

To volunteer for MND NSW contact Roslyn Adams ph. 1800 777 175 or email roslyna@mndnsw.asn.au

To read the report visit www.nationalservice.gov/about/role_impact/performance_research.asp#HBR

Noticeboard

Home Modifications and Maintenance Website

The NSW HMMS State Council is the peak body for the Home Modification and Maintenance Services industry in New South Wales. Their new website is now online at www.nswhmms.org. As part of the Home and Community Care (HACC) Program, Home Modification and Maintenance Services provide major and minor modifications and some maintenance work for the aged, adults and children with disabilities and their carers so they may live more independently in the community and remain living at home. The site contains lots of practical advice including how to apply for services, where to find the nearest service provider, the costs involved, and an overview of the client's rights and responsibilities. For further information see HMMS at www.nswhmms.org or contact Commonwealth Carelink Centre ph. 1800 052 222



Family Relationships Service for Carers

Supporting a person with disability can require families to make complex and difficult decisions. Achieving agreement between family members on outcomes that are in the interests of the whole family can be difficult.



A Family Relationships Service for carers, funded by Australian Government Department of Families, Community Services and Indigenous Affairs, has been established in each State and Territory to assist parents and other family members reach agreement on important issues.

If you have a Centrelink concession card the cost for an individual session is \$30, for others the cost is \$65 per session. For more information contact Interrelate Family Centres ph. 1300 736 966 or 9745 5544 or visit www.interrelate.org.au

Financial Assistance

Financial assistance and subsidies for people living with MND, including carers, may be available from Centrelink, Department of Veterans' Affairs and Telstra. The New South Wales Government also has several financial assistance programs including the Taxi Subsidy Scheme, Home and Community Care - Home Modifications Scheme, Program of Aids for Disabled People and the Isolated Patient Travel and Accommodation Assistance Scheme. Some of these assistive programs are income and asset tested. Contact your MND NSW Regional Advisor for more information.

Rilutek

Riluzone (Rilutek®) was previously only available for individuals with an amyotrophic lateral sclerosis (ALS) disease duration of two years or less. From 1 October 2007, the authority wording will change and the restriction will be for individuals with a disease duration of five years or less, provided that the person with amyotrophic lateral sclerosis meets other criteria. For more information see your neurologist.

Low Cost Internet Service for People with Disability

People with disability, veterans and frail aged throughout Australia can access a low cost Internet service thanks to a partnership arrangement between Technical Aid to the Disabled Australia and IPSOne, a Victorian based Internet service provider.



The partnership enables dial-up Internet access at the rate of \$5.50 a month with an establishment fee \$36. It offers unlimited downloads and flexible contract arrangements.

Technical Aid for the Disabled says that, normally, the cost of Internet access at \$30-\$40 a month is beyond the reach of many people with disability. This option is available to people receiving the Disability Support Pension, a DVA Entitlement Pension and an Aged Pension Card.

For more information, ph. 1300 735 439 or visit www.tadaustconnect.org.au.

Clinical Practice Guidelines for Communicating Prognosis

Doctors have been urged to approach discussions about the end of a patient's life with sensitivity and honesty, in new guidelines published in the June edition of the *Medical Journal of Australia*.



The new clinical practice guidelines for communicating prognosis and end-of-life issues were put together by a team from Australian and New Zealand of experts in palliative care, cancer, psychology, medical ethics, and geriatrics, among others. Information at end-of-life consultations should be tailored to the individual needs of patients and their families, said committee chair Dr Josephine Clayton, Head of the Department of Palliative Care, Royal North Shore Hospital, Sydney, and a senior lecturer and research fellow at the University of Sydney.

The guidelines can be viewed on the Medical Journal of Australia website at www.mja.com.au

Do you have a letter or ideas for Forum?

Contact The Editor, Forum, MND NSW, Locked Bag 5005, Gladesville NSW 1675

ACKNOWLEDGEMENT

We wish to thank Snap Printing, Artamon for their generous support.

DISCLAIMER All care has been taken in the preparation of this newsletter. The MND Association of New South Wales disclaims any liability for its content. The information contained within is of a general nature. For medical advice, consult your doctor.

Editor: Penny Waterson