



FORUM

June 2002

Motor neurone disease is known as amyotrophic lateral sclerosis (ALS) or Lou Gehrig's disease in some countries.

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Governor of New South Wales

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MND in the News

RILUTEK (RILUZOLE) – REGISTERED.

Rilutek has been registered for use in Australia by the Therapeutic Goods Authority and should be available by prescription after August 2002. The outcome of request for listing on the Pharmaceutical Benefits Scheme (PBS) will be known about mid July 2002. If Rilutek is not listed for the PBS, although available in Australia, it will be expensive. As soon as more information is available, we will inform all members with MND.

Riluzole remains the only medication proven in large trials to prolong survival in MND.

BUDGET 2002 - FUNDING FOR PALLIATIVE CARE IS TO BE

BOOSTED. Regional Australia will benefit significantly from \$55 million over four years towards palliative care. The funding will improve capacity in the primary care workforce; enhance, coordinate and support health and other support systems; develop better reporting and information systems; build evidence on funding and service delivery; improve access to medications and raise awareness in the wider community.

There are also to be an extra 6000 community aged-care packages over four years to help frail older people stay in their own homes.

MND AND EUTHANASIA have been highlighted in recent media reports.

This is very confronting for others who are living with MND but allows people the opportunity to look at their own approach to living and dying. Many people, after coming to terms with their diagnosis, are able to reach a stage of heightened appreciation of treasured relationships, the joy of a new day - in fact - a more positive approach to living. These attitudes are reported in several compilations of stories from people with a positive attitude to living with MND, including those published in *Cornflower Blues* (available from MND NSW).

End stages of MND are frequently short and palliative care teams are able to provide expert symptom management to relieve any physical distress, ensuring that the person with MND will be made as comfortable as possible. They will also provide emotional support through the final stages for the person with MND and their family.

Research around the world continues to provide hope that an effective treatment will be found.

Misdiagnosis in MND is unusual, but occasionally a similar, treatable condition can account for the symptoms.

MND/ALS GLOBAL DAY Friday 21 June 2002 INTERNET CHAT

Global Awareness Day takes place each year on 21 June. This date, the Solstice, was chosen by the International Alliance of ALS/MND Associations as a symbolic turning point or time of change.

The MND Associations of Australia will celebrate Global Day by holding an Internet Chat. This is a way to acknowledge Global Awareness, and secondly to encourage people affected by MND to participate. In previous years this has proved to be a successful and enjoyable link with health professionals with an interest in MND and a way for people to chat to others with MND or their family members.

(Continued on page 5)

From the President's Desk

The MND Association of NSW has grown from strength to strength, with constant emphasis on providing quality care to people with MND.

Corporate Governance. The Board of Management has made significant progress in the way it has directed and controlled the affairs of the Association. Two more people living with MND have been recruited to serve on the Board from 2 May 2002.

The Board comprises people with diverse experience and expertise including neurology, general medicine, nursing, law, company management, accountancy, management consultancy, strategic research, information technology, and administration. Additionally, the personal experiences of three board members living with MND will maximise the potential to provide the greatest benefit to members.

Four board sub-committees support the Board: Care Support and Research, Audit, Staff/Volunteers, and Fundraising.

Board of Management accepted a new policy paper recently which clearly defines board role, principles for board effectiveness, code of ethics and conflict of interest.

Business Plan. The current business plan runs to 30/6/03. Board of Management has appointed a sub-committee to conduct a review in consultation with the members. The four-member committee has a person with MND, a management consultant, a chartered accountant and an information technology manager. The authors of the two previous business plans (1995-2003) were people with MND.

MND Research Institute of Australia (MNDRIA). MNDRIA NSW has donated \$50,000 to the MNDRIA to support MND research projects in Australia. A further sum of about \$16,000 will be given to the MNDRIA before the end of this financial year. Board of Management has appointed a sub-committee consisting of Phil Bower, Dr Paul Brock, Paula Trigg and myself to review the existing policy relating to MND research and funding issues.

The Family Support Service has enhanced its service with a part-time equipment officer and an equipment storeman. There are nine people in the team headed by the manager of the Family Support Service.

Stem Cell Research. MNDRIA NSW has joined the Coalition for the Advancement of Medical Research Australia (CAMRA) whose goal is to advance stem cell research with the aim of developing therapies with the potential to help hundreds of thousands of Australians. CAMRA believes a rigid ban on the production of new stem cells would hinder both research and the clinical application of stem cell technology.

As your President and a person living with MND, I am in the office two to three days a week and give whatever support I can. Please feel free to contact me in the office if you have any concerns or just to share your thoughts with me.

Our thoughts are with all those who have lost loved ones. My best wishes to you all.

Kevin Langdon

Many thanks to all who contributed to the most successful MND Awareness Week ever. The week concluded with a special service of thanksgiving at St Andrews Cathedral in Sydney.

MNDA EQUIPMENT HOUSE

The MND Equipment Service has expanded exponentially over the last few years and storage has been a major problem. Although ideally we would like all our aids to be out on loan, unless we have excess in storage we would not have anything available to meet urgent needs. Unfortunately we were not able to find additional storage space at Concord Hospital but we have leased a building in Victoria Avenue, Concord West.

The MNDA Equipment House is on the western side of Concord West Railway Station and storage racks and shelving are now being finalised.

All requests for equipment loans, which are available at no cost, require a written prescription from an occupational therapist (physio/speech pathologist etc), so please try to plan well ahead for your needs. It is a good idea to have an OT assessment early so the therapist can explain the use of the particular aids that will make your daily living easier.



Linda Hager, MNDA Equipment Officer, and Joe Leone make preparations for moving the equipment store to Concord West.

Family Support

MND Awareness week was once again a wonderful, if hectic, time for the family support team. We all enjoyed the Launch particularly listening to Dr Perry Bartlett's interesting and hopeful talk on future stem cell research and, of course, catching up with many of you.

The Annual Conference for Health Care Professionals focusing on **Health Promoting Palliative Care** was held on Tuesday 19 March in MND Awareness Week. Professor Alan Kellahear from La Trobe University was the

keynote speaker and gave an inspiring presentation on his concept of Health Promoting Palliative Care.

The main objectives are to enhance a sense of control and support for those living with a serious life threatening illness. Information should be given on a range of topics such as financial management, services available and how to manage symptoms of the disease to enable people to be in control of their lives and to make informed choices and decisions about their care. It is also about providing adequate social

supports through the education of the community, health care providers and governments to ensure adequate and relevant care and support for all people with life threatening illnesses. Professor Kellahear advocates 'Health Promoting Palliative Care through popular writing' and has been writing about death and dying in the press for a number of years in an attempt to demystify death, and to encourage others to write similar articles. He, like all of us, believes that death is part of life and that communities need to be educated about death in order for them to be able to support others living with a life threatening disease. Much of what the MND Association does actually encompasses many aspects of this model of care, but Professor Kellahear's talk highlighted areas that we could focus on more in the future.

Music Therapy can be particularly beneficial to people with MND. Kirsten Robertson Gillam is a music therapist and lecturer whose presentation on music therapy and its potential to help people to express their thoughts and feeling, even in the absence of speech, was most moving. For information on Music Therapy and its availability in your area, please talk to your MNDA family support worker.

Other conference speakers included Dr Helen Herz, Palliative Care Physician at Calvary Hospital, and the team from Port Kembla Hospital who presented a case study on a person living with MND. The conference was truly a team effort – Anita Richter spoke about the

Care for Carers Pilot Program, Janet Nash discussed familial MND, Ruth Quaken introduced the case study, I talked about the role of the MNDA family support team whilst Caroline Gleig and Linda Hager organised registrations! It was a most successful day with approximately 110 health care providers from a variety of settings and from a wide geographic area in attendance.

Another **Care for Carers** Program, organised by Anita Richter, has just finished. The small group participated fully, making the program very worthwhile from everyone's point of view. The Carers' Manual is being edited by Cilla Barrand and reviewed by the relevant health care disciplines and should be completed soon. We look forward to launching this comprehensive resource soon.

We are developing **Living Well with MND** workshops to be held later in the year. There will be two full day workshops two weeks apart for people living with MND, their families and friends. The workshops will address topics such as physiotherapy, small aids and equipment, diet, financial planning etc. Details should be ready for distribution with the next *Forum*.

The MND Equipment Expo will not be held this year, as we have been unable to access our usual venue due to building works at Concord.

Respite Care/ Holiday Respite. There have been a number of initiatives in some areas of NSW, which enable carers and/or the person they are caring for to have short breaks through respite care funding. We are occasionally asked to find people who would like to access these services at quite short notice. If you feel you may like to take a short break in the future, please ring the office so we can ensure that you can take advantage of any such holidays that come along. Also contact the Carer Respite Centre on 1800 059 059 if you need a break of any description, to see what is available, or if you require emergency respite assistance.

Accessing personal care and assistance can be particularly difficult. The Physical Disability Council (PDC) is lobbying the Government and has written to the Hon Mrs Faye Lo Po, Minister for Disability Services, requesting an immediate response. MNDA NSW will continue to feed through to the PDC any problems people living with MND encounter in accessing adequate care and support. Please let us know about any problems you currently have. This will lend strength to our lobbying efforts. Writing to your local member of parliament will also help to ensure that the Government is aware of this issue and its effect on people living with MND.

Carol Birks

If you have any light-hearted (interesting/funny) anecdotes on caring that can be shared with others by inclusion in our MND Carers' Manual, please let us know.

Fundraising and awareness

MND Awareness Week

In 2001, you raised over \$70,000. In 2002, you raised much, much more despite conflicting with children's charities like 'Bandaged Bears'. At the moment, it is looking as though we will meet the Fundraising Committee's target of \$100,000. Again, the Shopping Centres made a substantive difference raising over \$13,000 with Bass Hill Plaza accounting for an impressive \$3,011 thanks largely to the help they get from Bass Hill Girls High School. Warringah Mall had support from St Augustine's College and Tamworth would not be so successful without the help it receives from Calrossy Girls School!

An innovation was the street collections in Sydney and we have to thank Megan Paton for putting the whole family to work at Circular Quay. And Sydney Girls High and St Andrew's Cathedral schools ensured the Town Hall area was true blue on Blue Day. Judith Durham also made a timely visit to Sydney and collections were made after two concerts at Taronga Zoo just before Awareness Week. The collections added another \$3,337 to the coffers!

Newcastle's report outlines the fantastic achievements in that area. Their success is due to wonderful team work of the Support Group led by Alistair and Christine Fyfe, Don and Audrey McKenzie and their very active fundraiser, Neta Cassidy. Both the Northern Region and the Central Coast also worked hard and were extremely successful.

Sydneysiders were also busy with media coverage. Andrew and Sue Paxton were instrumental in getting the excellent coverage on Channel 9's Today program, while the countryside had Prime TV who interviewed Dr Perry Bartlett after he spoke at Government House, and Graham and Janet Chalker as well. Radio interviewees were MNDA President, Kevin Langdon, Dr Paul Brock, Bill Hoey and Carol Birks. Radio 2GB's Alan Jones and Ray Hadley gave MNDA substantial support throughout their programs on Blue Day and there were interviews on seven other stations during the week.

Journalist, Deborah Hope put together a substantial feature in The Australian to help launch Awareness Week on 13 March. In fact, this year's launch was rated the 'best ever' and the Association was delighted that Minister of Education and Training, John Watkins, was able to attend as our Guest of Honour – keeping alive the memory of his uncle, the late John Watkins.

Generally, it was felt that there was a higher level of awareness about Motor Neurone Disease – which is what it is all about. However, a review is now being undertaken so that next year is going to be both bigger and better.

Support for MND continues beyond Awareness Week

The St Paul's & Women's Colleges Charity Ball was held on 1 June at St Paul's College in the presence of Her Excellency, Prof Marie Bashir, Governor of New South Wales (*and MNDA Patron*) to support the MNDA. The Ball was wonderfully planned and organised by the student Ball Committee led by Nicole Hall, Matthew Gibbs and India Hardy.

Wayne King memorial concert was held at Taronga Zoo in May with Wayne King's music arranged by Peter Casey. Many of the pieces received their world premiere and there was a standing ovation for pianist Evgeny Ukhanov's sensitive interpretation of the works. The concert was attended by many of Wayne King's friends and a message from his friend, Danny la Rue, was received with warm applause by the audience. The Benefit Concert, arranged by Catherine Casey and Robyn Spencer of Harmony Events, was in aid of both AIDS and MND.

City to Surf 2002

Last year, the runners in City to Surf raised over \$5,000 from friends and supporters for MND. Now the challenge is to raise even more money in 2002. Look out for the entry form. The first appeared in the *Sun Herald* on 2 June together with the training guide for the 14 km trudge up Heartbreak Hill then downhill all the way to the beach.

This is a great tradition that has been going for 31 years. The 32nd City to Surf takes place on 11 August. It is a 10.00 am start. Entry forms will be available for ten weeks, but if you need any further information, call 1800 555 514.

Granted

The MNDA has received \$23,000 from the Sylvia & Charles Viertel Charitable Foundation for the purchase of equipment. This is a wonderful gift and the money is already being put to good use. Another \$5,000 was received from the Annie Danks Trust and substantial funds have also been given by the Magistrates' Institute of NSW, the Lions Clubs of Toronto and Jervis Bay and the Rotary Club of Toronto (who held a very successful ball on 23 March), Mallesons Stephens Jaques, the Mollymook Golf Club and Miss Elsie Pelling.

A special thanks must also go to the pupils of St Paul's Grammar School who raised over \$2,000 for the MND Association and also to all our wonderful Support Groups.

Elizabeth Herbert

**HELPING
THROUGH YOUR
WILL**
Your Will can be a
convenient vehicle for
making a charitable
gift of lasting value.
Please consider the
MND Association as a
living memorial for a
loved one.
Many people support
the work of MNDA
NSW through

MND/ALS Global Awareness Day Friday 21 June

INTERNET CHAT

As in previous years the format is informal and friendly, and everyone is welcome to join in. MNDAA is grateful to the health professionals who have given their time to share this day, by offering advice and answering questions.

The details to join in at the relevant times are as follows:

Go to www.enable.net.au and you will see the words Motor Neurone Chat Forum at the bottom of the page. Click on this once and you will go straight to the forum.

While visiting EnableNet for the forum please feel free to explore the Disability Information section which offers links to more than 2,700 disability related websites including a range of information on MND.

10.00am – 11.00am	Sandy Lowe	Speech Pathologist
11.00am – 12.00 noon	Special time to chat to other people living with MND/ALS	
1.00pm – 2.00pm	Adam Kennedy	President MNDAA
2.00pm – 3.00pm	Special time to chat to other people living with MND/ALS	
3.00pm – 4.00pm	Helen Stanley	Registered Nurse
7.00pm – 8.00pm	Karen Glaetzer	Palliative Care

Congratulations to Fundraising Committee and Board Members Suzanne Ballinger, Pamela Hennessy and Paula Trigg who received a Rotary Club of Wahroonga Community Service Award on 13 March for their fundraising achievements for MND over the past two years.

SAILAWAY

'Sailors with DISabilities' have offered another day's sailing on Friday 21st June (MND/ALS Global Day).

Phone 9743 5872 if you would like a couple of hours all at sea. There is room for sixteen people and space for wheelchairs too.

Dear Editor

It is almost 7 years since my mother died from MND and at last I would like to share with other readers my mother's story.

The inscription reads "Lindy Lukey, Author, Mother". This epigraph to our mother who loved people, reading and writing, is engraved on a brick outside Manly Library under a shady tree.

Writing was Lindy's life. Her first journalistic article was published at 17, later working on publications such as The Radio Times, The Launceston Examiner, Australasian Post, The Herald and Weekly Times. Writing radio stories, and pieces on jazz, a Penelope column, and stories for Women's Weekly and Ita; she was a busy Australian mother with a love of her country and an eye for the things which made life "magic".

A collection of her stories embracing Australia from the 19th to the 21st century was due to be launched in 1994. In that same year she was diagnosed with MND, and by the end of the year she could not walk, eat, write or talk. She was a mother and grandmother with still so much to say, and whilst her mind and passion remained untouched, a little known disease took her away in 1995 at the age of 67. Her collection was never completed.

My family and I help almost every year to raise funds at Warringah Mall during MND Awareness Week. We donate more than we make, so this year with the Association's permission we held a stall at The Corso, Manly, and also sold second hand goods which were sold out by 09.30. It was a wonderful day meeting many people who had unfortunately met MND devastation. An idea to share with other volunteers for next year.

Sally Gibbs, Balgowlah North



ASPECT was spectacular on Sydney Harbour as she sailed from the CYC at Rushcutters Bay on Saturday 9 March.

FRIENDS OF MND

We all need 'Friends' and Motor Neurone Disease could do with more. This is a very special group of people who regularly donate funds to keep the Association at work. They are led by our No 1 friend, Melinda Gainsford-Taylor and there will be a party for our 'Friends' in the evening - at the Royal Sydney Yacht Squadron - on MND/ALS Global Day (21 June).

Interested in joining?

If we have not mailed you or if you have friends who may be interested in becoming 'Friends', call Elizabeth Herbert on 9743 5872.

Regional News

SUPPORT GROUP CONTACTS

Central Coast

Audree Dash
Phone: 02 4384 2907

Coffs Harbour

Lily Jenkins
Phone: 02 6652 2571

Illawarra

Nick Guggisberg
Phone: 02 4223 8238

Newcastle & Hunter

Don Mackenzie
Phone: 02 4920 8760

New England

Robyn Barton
Phone: 02 6766 6065

Northern NSW

Phil Bower
Phone: 02 6743 4218

Northern Rivers

Noelene Kidd
Phone: 02 6624 4684

Penrith/Blue Mountains

Judy Stringer
Phone: 02 4736 3346

Panania

(Caroline Gleig & Ruth Quaken)

and

Hornsby

(Anita Richter)
are coordinated through the MNDA office.
Phone: 02 9743 5872

Wagga Wagga

Wes Russell
Phone: 0408 692 127

Northern NSW

We are very pleased to introduce the **new family support worker for Northern NSW** to you.

Christina Jason joined the team in April. Christina has a Bachelor of Social Sciences degree and experience with people with Huntington's Disease and recently has been supporting people with intellectual and physical disabilities and mental illness in the Hunter Region.

Following an intensive orientation period, Christina is now contacting all the members in the Northern NSW region. There are around 70 people with MND in the region so it may take some time for Christina to contact everyone. If you would like to speak to Christina she may be contacted on Mon, Tues or Weds on 4933 1002. Christina plans to visit the Mid North Coast in the next couple of months.

Carol Birks

Coffs Harbour support group had another successful Awareness Week raising over \$2,500. As coordinator of the group, I wish to thank all the helpers for their wonderful support during the week.

Lily Jenkins

Newcastle & Hunter

If you are living with MND and have **young children or teenagers** you may feel particularly isolated and alone at times. Maybe you feel that you face quite different issues to other families living with MND, most of whom have older children, and the established support groups may not be meeting your needs.

If you would like to get together or establish contact with other families please phone Carol Birks at the office to discuss.

Awareness Week was well supported in our region. The week was introduced with a well attended church service and there was good support from the media (radio, TV & newspapers) throughout the week). Friends and families responded well to the call for help at the shopping centres.

Thank you to all who gave their stories, their time and their smiles. Well done everyone.

Audrey Mackenzie

Theatre Night

Thurs 18 July.
The Elanora Players will perform 'A Murder is Announced' at the **Elanora Community Centre**. Proceeds from the performance and raffle will go to the MNDA.

For bookings and enquiries phone Vanessa MacArthur on 9948 5574.

Are you the IT man?

Urgently sought.
The MNDA needs someone to consult on B-pay and other electronic financial systems.
If you have the expertise, your Association needs YOU!

Jobseekers

Various unpaid, positions available.
Bored?
Looking to pass the time away with a friendly team?
Opportunities unlimited for photocopying, filing and working on the database.
Tea and coffee thrown in.
Phone 9743 5872 for details and ask for Elizabeth.

Golfers

should note that fundraising days will be held at
Lismore on 7 July,
Manly Golf Club on
3 October and
the Ray McDougall & Margaret Burge Memorial
Days will be at
South West Rocks on 12th
& 13th October.

FOR INTERNET USERS

OZPALS is a group of people in Australia and New Zealand with an interest in MND who keep in touch by email. To subscribe go to <http://ozpals.8m.com>.

Internet Chat - Living with MND

Every Wednesday & Sunday at 8pm EST. Go to www.mnd.asn.au/ then click on the chat room link.

Also try <http://neuro-mancer.mgh.harvard.edu/brainchat/classic.shtml> or www.alschat.com for chat rooms which are open 24 hours per day.

Visit the MNDA NSW website at www.mndansw.asn.au for links to many useful and interesting sites.

Research

Dr Perry Bartlett from the Walter & Eliza Hall Institute in Melbourne was the keynote speaker at the launch of MND Awareness Week at NSW Government House on 13 March.

The article below gives a brief description of Dr Bartlett's exciting research work with neural stem cells.

Finding the nerve stem cell – possibility of replacing motor neurons lost in MND.

Discoveries by scientists at The Walter and Eliza Hall Institute of Medical Research may

hold the key to the regeneration of damaged nerve cells in the brain. The scientific team, headed by Dr Perry Bartlett, has succeeded in isolating a stem cell from the adult brain which continues to give rise to new nerve cells under normal conditions.

Some nine years earlier, the same team had shown that the adult brain contains very small quantities of neural stem cells. However, because these cells could not be specifically identified or isolated, their properties and location within the brain have

remained a mystery. As a result of work primarily carried out by Rodney Rietze, who was a PhD student at the time, a new process has been developed which now allows the routine identification and purification of these cells. This discovery has revealed the location of these cells in the brain, and confirmed that they give rise to new nerve cells under normal physiological conditions.

Now, for the first time, these neural stem cells can be purified from the vast population of cells in the brain, and investigated to determine how they can be stimulated to generate new nerve cells following injury or disease. Potentially, the discoveries mean that a person with motor neurone disease may be able repair their brain or spinal cord by stimulating their own stem cells to produce large numbers of new nerve cells.

The first step of this work is now underway, as the team is investigating how to instruct purified stem cells to produce greater numbers of neurons in the culture dish. Ultimately, this should lead to the development of drugs which can stimulate the brain stem cell to produce new neurons, and overcome the medical and ethical drawbacks associated with other potential therapies such as the transplantation of embryonic stem cells.

The research by Dr Bartlett and Dr Rietze was published in the prestigious scientific journal *Nature*.

PERCUTANEOUS ENDOSCOPIC GASTROSTOMY (PEG)

If eating and swallowing become difficult, alternative methods of feeding may be discussed and recommended by health care providers. It is advisable to think about these forms of feeding fairly early on if swallowing starts to become a problem. The current trend is to recommend a PEG fairly early to help reduce debilitation and weight loss. Research suggests that insertion of a PEG may help to extend survival and improve comfort. Not all people with swallowing difficulties choose to have a PEG – it is an individual decision to make. Indicators for considering a PEG and discussing this procedure with your speech pathologist, dietician and doctor are:

- aspirating or inhaling food
- anxiety associated with eating
- fear of choking
- inadequate food or fluid intake
- increasing length of time taken over meals
- weight loss
- fatigue from eating.

The most common form of alternative methods of feeding is the use of a PEG tube. Under local anaesthetic or a light general anaesthetic, a small feeding tube is inserted directly into the stomach through a small hole in the skin and left in place. This involves a short stay in hospital. This is a relatively safe procedure that is best carried out before breathing problems are experienced. There are some risks, however, that should be discussed with your doctor.

The PEG tube has a disc or dome on the inside of the stomach for support and a disc or cross bar on the outside against the skin. These discs prevent the tube from moving. The small disc on the outside of the body has a stopper that is closed when not in use. The feeding tube is then attached at mealtimes to administer the formula feed.

Special formula food and fluids are then given via the tube. The hospital will usually provide the tubing and equipment required depending on the methods of feeding recommended. Different methods of feeding include:

- bolus method using a syringe
- gravity feeding – a bag of food hangs from a stand and drips through the tube into the PEG
- pump method – a pump known as a Kangaroo Pump delivers a measured quantity over a number of hours.

The hospital will teach you the most suitable method. Many hospitals are also able to provide the formula food at a reduced cost. Speak to the nurse or dietician involved in caring for your person with MND. The complete diet may be given this way. However, if it is safe to do so the person may continue to take some food and fluid by mouth for pleasure and use the PEG to supplement the diet as required.

Research is the basis of hope for the future. Research in Australia and around the world is contributing to the possibility of realistic hope for understanding the cause and development of a treatment for MND.

MAILBAG

Dear Editor

Life Can Still Be Fun.

Like most MND families it is the long diagnosis time that is so distressing. Then once the 'bombshell' has finally landed, it's 'what do we do next'? Having had nearly 40 years of life in the Applied Sciences, I crave knowledge and, thanks to the internet, I was able to gain some in-depth information and thus assuage some of those fears of what MND meant to my loved one and me.

I was not amused by my newly gained knowledge. My most perplexing question was – 'what can we do to make the best possible life together without worrying about the inevitable timetable'? We both like people and enjoy socialisation and have worked for charities most of our lives. We agreed that we were not going to change the things in our life that we enjoyed doing so much. If anything, we have increased our social times and the giving of ourselves to community activities and, although mobility becomes more difficult, we cope with what ever comes along ... making a joke and laughing where we could be crying in self pity. Giving more of yourself toward others has a remarkable re-bound effect – you feel good for the things you do and less about what impost there is upon you.

We have found that there is support infrastructure from the MND Association and from community health agencies, the goal always being to be able to remain in your own home. But travel isn't out of the question. We recently attended the Rotary District Convention in Dubbo. The Carers Respite Centre arranged for wheelchair friendly accommodation in Dubbo which had a hoist, kitchen/living room and a user-friendly ablution area. The Carers Respite Centre also arranged for a nurse to come in each morning to help with bathing and dressing and getting ready to go out for the day. On one day the nurse accompanied us to the Dubbo Zoo where her invaluable assistance and additional care permitted a most joyous outing to be had by both patient and carer. We have to be thankful that such facilities are available. We would highly recommend using any of the 54 Respite Centres around NSW.

We know time is getting shorter, but we are not letting that dampen our spirits for giving more than we receive. We truly are aware that this provides much satisfaction and better outcomes for everyone.

*Lee Furlong, MND Carer
Westleigh*

Dear Editor

Some people might want access to their superannuation to assist in meeting the costs of living with MND.

Generally, superannuation is only paid when people retire from the workforce after reaching age 55, or because of permanent disability. Under some circumstances people can apply to the Australian Prudential Regulation Authority (APRA) to have their superannuation benefits released before they reach retirement age. There are only very limited circumstances where benefits may be released early. These are defined in regulations and cover expenses in respect of:

- **medical treatment** for you or your dependant where the treatment is necessary to treat a life threatening illness or injury, or to alleviate acute or chronic pain, or acute or chronic mental disturbance, and where such treatment is not readily available through the public health system;
- **medical transport** for you or your dependant to access treatment necessary to treat a life threatening illness or injury, or to alleviate acute or chronic pain, or acute or chronic mental disturbance;
- **modifications to the family home and/or vehicle** to accommodate special needs arising from the severe disability of you or your dependant;
- **palliative care** for you or a dependant who is dying, or expenses associated with your dependant's death, funeral or burial.

In addition, it is possible to have an amount approved for release to prevent foreclosure of a mortgage, or exercise of a power of sale over the member's principal place of residence.

Not all superannuation fund rules allow a release on these specific grounds, even with an approval from APRA, so it is recommended you contact your fund first.

For more information, phone APRA on 1300 131 060, or access their website www.apra.gov.au.

It is also worth checking your life insurance policy to see if it includes terminal illness cover. If an adult insured person is diagnosed as having less than 12 months to live, insurers may make an early payment of some or all of the death cover.

Accessing a life policy may be more tax effective than accessing superannuation but this would obviously depend on each person's circumstances and advice should be sought in this regard.

*Bill Gole (MND member with MND)
APRA*

We welcome your ideas - Forum is your voice - so if you would like to contribute to the next issue, please write to the Editor.

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DISCLAIMER

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