

March 2007

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MND Week 2007

6-12 May

Come and have some fun for a good cause!

Railway Stations

We will be selling Glow in the Dark bag tags (for use on luggage, lap tops, musical instruments and school bags just to name a few), pens, wrist bands, enamel badges, cornflowers and other merchandise around

metropolitan railway stations on **Friday 11 May** from 7 to 9am. It is a great way to spend a couple of hours volunteering for MND. Permission has been granted for us to collect at the following stations so please nominate which one you would like to collect at: Wynyard, Martin Place, Town Hall, St James, Circular Quay, St Leonards, Edgecliff, Emu Plains, Penrith, Epping, Hornsby, Seven Hills, Wahroonga, Warrawee, Turramurra and Roseville. If there is a station close to you that has not been mentioned please contact Roslyn Adams ph. 8877 0908 and we will seek the required permits.



New MND Glow in the Dark bag tags

Shopping Centres

Do you have a shopping centre near home at which you could sell merchandise and collect donations? You wouldn't have to spend all MND Week there, just one day would be great, for example, **Cornflower Blue Day on Friday 11 May**. Permission would need to be sought from the shopping centre management and we would be happy to assist with this.

Other Activities

Are you a member of a tennis, squash, gym or golf club? Are you involved with a **local school**? You could sell our wonderful MND socks through your **club** or our 'Never Give Up' wristbands or Glow in the Dark bag tags through schools. You could ask your local pharmacist, doctor, newsagent, delicatessen or hairdresser if you could place a **box of merchandise** in their business for a week to promote MND Week.



Cotton cap sporting the new MND logo

**We would love to have your support.
Contact Judy Ford or Roslyn Adams
at MNDA NSW on 8877 0999**

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

A Message from the CEO

The MNDA NSW 2006 Christmas party, held at Dedes restaurant at the Sydney Rowing Club Abbotsford late last year was once again an event enjoyed by all. With spectacular views of the harbour in the background, MNDA NSW members, Directors and staff were wonderfully entertained by 'Tu-Lips' – Laura and Teighe Purnell, who travelled to Sydney from Canberra for the event. The special guest visit by Santa, organised by Peter Ford, added to the festivities. It was a great opportunity for everyone to chat, reflect on the year and relax.

The Annual General Meeting (AGM) of the Association was also held in December. At the meeting Katrina Horman and Paul Brock AM retired from the Board. Katrina, an occupational therapist, joined the Board in 2003 and has been a constant presence at Board meetings, providing great insight into issues discussed. Paul joined the Board in 2002 and it is in a large part due to Paul's tireless efforts that MND has received such wide publicity and political attention both in New South Wales and nationally over the past few years. Thank you to both Katrina and Paul for their contributions.

Also at the AGM, the Board was delighted to welcome Gary Jacobson and Alex Green who were appointed as Directors of the Association. Gary has returned to this role after a twelve months hiatus, while Alex comes to us with a strong fundraising background and a great commitment to furthering the aims and objectives of MND NSW.

All state and territory MND Associations are monitoring the current debate on the Commonwealth State Territory Disability Agreement (CSTDA) after a bipartisan Senate Committee unanimously recommended, "That Commonwealth, State and Territory governments jointly commit as

part of the fourth CSTDA to substantial additional funding to address identified unmet need for specialist disability services, particularly for accommodation services and support." We will wait to see the Commonwealth, State and Territory governments responses and feel that this will provide a guide for the MND Week's 'Call to Action'.

After nearly eleven years of service, Anita Richter has resigned from her Special Projects/Carers Services role at MNDA NSW. During the past decade Anita has made an outstanding contribution towards improving the wellbeing of people with MND and their carers. We are pleased that Anita is able to continue her work on the 'Talking with Young People about MND' project, a joint endeavour of MNDA Victoria and MNDA NSW that is funded by the Australian Government. Thank you, Anita.

In the past weeks we have welcomed two new staff members Noelle Smith, to a Regional Advisor role and Jane Barrett, who has commenced as Family Support Coordinator. Noelle will be based in our Newcastle office and Jane at Gladesville. Further information about their roles is provided by Gina Svolos, Family Support Manager on page 3.

During the next few months our efforts will be focused on MND Week, which will be held from 6 to 12 May. The launch of MND Week is planned for 3 May at Bicentennial Park, Homebush. Details can be found on page 12 in 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

3rd National
Motor Neurone
Disease
Conference

19 June 2007

Esplanade
Hotel
Fremantle

www.mndawa.iinet.net.au

The Importance of Accepting Community Services

MNDA NSW has spent several years advocating for the community care needs of people with MND within NSW Health and the Department of Ageing, Disability and Home Care (DADHC).

Now, as a result of joint negotiations, **Community Options Projects (COPS)** will be **receiving funding from DADHC for a pilot program to provide a more responsive level of service provision for people with short term need, including clients with MND.** This pilot program will be targeting particular areas in NSW and will be commencing soon.

People who are diagnosed with MND value their independence. The potential number of services

offered can seem bewildering and disruptive, especially if people feel that they are currently managing quite well.

Despite this understandable need for independence it can be very hard to 'go it alone' with MND. Studies of carers/families of people with MND have shown the importance of receiving adequate support services to maintain the physical and emotional health of carers as well as quality of life for the person with MND.

Due to potential delays it is important to link into community support services as early as possible. **A minimum level of service can be then increased rapidly if/when necessary.**

As the Pilot Program with COPS will be a test case to improve the previously perceived gaps in services **it is important that people use this opportunity and accept services when offered**, confirming the importance of responsive services. This will have important long term benefits for people with MND and their carers/families.

We recommend that people with MND are **referred for COPS case management as early as possible** to ensure adequate and responsive service provision.

Please let your regional advisors know if you have any difficulty in accessing important services.

Family Support

At the end of February we farewelled Anita Ritcher from her Special Projects/Carers Services role at MDNA NSW. During the short time I have been working at the Association I have appreciated not only the expertise Anita brought to her role, but also her generosity and warm welcome. We are fortunate that Anita has agreed to undertake some project work with us and will continue her involvement in the 'Talking with Young People about MND' project over the next few months.

As a result of Anita's retirement we have created the new position of Family Support Coordinator. Jane Barrett commenced on 5 March in this role. She is responsible for special projects including carers services and will also assist with coordinating the Info Line and group programs.

During February, Noelle Smith commenced in a new regional advisor position located in the Newcastle office. She will be working 14 hours a week. This new position has provided us with the opportunity to review the geographical areas covered by MND NSW regional advisors. Noelle will cover the Hunter, Lake Macquarie and New England Regions. Christina Jason will continue to work in the Greater Newcastle area, Port Stephens and the mid North Coast. Fern Linden will look after the Far North Coast and Illawarra Regions as well as South Western Sydney.

Changes to regional advisor geographical areas can be disruptive to our members however we feel that this new arrangement will better meet members' needs, especially as we have an additional regional advisor.

In February we held our first 'Information Evening for People Newly Diagnosed and their Families and Friends' for 2007. These evenings provide people with an opportunity to meet with others who have been recently diagnosed and to learn more about MND and the supports available through the Association. Our next evening will be held on 5 June.

Gina Svolos
Manager Family Support

New phone system at MND NSW

A new phone system has recently been installed at the MND NSW Gladesville Centre. During the installation period some calls may have been missed. There have also been some line drop-outs. We are sorry if this has caused any inconvenience to you.

The new system is up and running now and will result in considerable savings on our current phone costs. Thank you for your patience during this time.

Past Carers

The annual lunch for carers who had lost a loved one through MND during the previous 12 months was held on 19 February at MND NSW Gladesville Centre. This was a small gathering but those present appreciated the opportunity to share experiences with others in the same situation.

The first of our regular three monthly groups for **Past Carers** will be held at Gladesville on **Friday 30 March from 12 to 2pm**. This will provide an opportunity for past carers to meet our two most recent members of staff - Gina Svolos, Manager of Family Support Services and Jane Barrett, Family Support Coordinator. Judy Ford our Fundraising Manager will come along to talk about activities being planned for MND Week 2007.

The meeting is planned over lunch time to make it easier for people to travel and take a little 'time out' from a busy routine. To avoid difficulty in obtaining accurate numbers for catering purposes we suggest that participants bring a small contribution towards lunch and we will provide some basic refreshments. There is usually plenty of food, so please do not worry if circumstances prevent you from bringing a contribution to lunch - you will be most welcome!

Talking with Young People about MND

'Talking with Young People about MND' is a joint project of MND Victoria and MND NSW, funded by the Australian Government. Although I am retiring from my permanent role at the Association I will be continuing to work on this project.

I would like to thank the survey respondents who put so much time and thought into the project issues survey. The responses we have received are very perceptive and will be of great assistance in guiding the information resource we develop for families living with MND. Although the survey stage is now complete, your ideas are still welcome and I can be contacted through MND NSW on 8877 0999.

The next phase of this project is to seek input from teachers and school counsellors about information that would help them in supporting children who have a parent with MND or other life threatening illness. We have placed an article in *Side by Side*, the newspaper for NSW public schools, seeking input from teachers. However, personal suggestions from our membership regarding schools/teachers who could be contacted to help develop this information resource would be most helpful.

If you are a parent living with MND with school age children and if you and your children would be happy for me to contact their school or teachers to investigate their information needs, please let me know by contacting Gina Svolos, Manager of Family Support Services and leaving a message for me to contact you.

Anita Richter

Past Carers Meeting
MND NSW
Centre,
Gladesville

30 March 2007

Special Projects and Carers News

It is rewarding to reflect upon how services for people with MND and their families have improved during the last ten years. Not only has MNDA NSW grown enormously in its capacity to support people with MND and their families but awareness of the needs of people with MND in the health and community care sectors has increased substantially.

In 1997 MNDA NSW undertook a needs assessment of people with MND. A priority identified by this survey was the need for care providers in the health and community care sectors to have more awareness and knowledge of the process of MND and the needs of people living with this disease.

Targeting health professionals

In response MNDA NSW instituted an educational program of promoting **multidisciplinary care** for people with MND around NSW. This involves a team approach to managing MND with the concept of a coordinator or key worker to coordinate services and communication within the team. Information on developments in standards of care in the field of MND helped to harness a great deal of interest and goodwill amongst health professionals in their efforts and commitment to the field of MND.

Teams of health professionals who have knowledge and experience in working with people with MND are now functioning throughout NSW and the ACT.

Specific MND Clinics and programs of care are now well established. Some were initiated independently and others were inspired by the educational programs mentioned above.

There is always change in the sector with new clinicians commencing work with MND clients. Therefore there is a constant need to maintain a flow of information to assist clinicians working in this specialised field. This is achieved through:

- Family support team providing information packs and education sessions
- Direct liaison between regional advisors and the range of health and community service providers involved in the individual's care
- MND annual conference for health and community care professionals
- MNDA NSW Special Interest Groups for health professionals with Annual Special Interest Group Workshops and a bi-monthly e-Bulletin

What about community care services?

Through the needs survey and during subsequent years MNDA NSW received consistent feedback from people with MND and their families regarding difficulty accessing community services including **Home Care Services** in a timely and responsive manner. This is because the situation for people with MND can change quite rapidly and the process of assessment and referral for these services can be problematic and time consuming.

The service provision system is very complex and it can be compared with a jigsaw. It is very difficult to know how the pieces fit together without specialised knowledge of the type and level of service available in specific geographic areas. MNDA NSW regional advisors can help with this as can local case managers who can coordinate community support services and liaise with health services.

This form of local case management can be provided by **Community Options Projects (COPS)**. MNDA NSW and the COPS Executive are working together to facilitate more responsive delivery of community services for people with MND.

MNDA NSW has spent several years advocating for the needs of people with MND within NSW Health and the **Department of Ageing, Disability and Home Care (DADHC)**. Now, as a result of joint negotiations, COPS will be receiving funding from DADHC for a **pilot program** to provide a more responsive level of services for people with MND.

MNDA NSW and the COPS Executive Director are also participating in an **MND Advisory Group** initiated by DADHC. This Advisory Group is currently tracking and monitoring services for people with MND with the aim of improving service delivery and will monitor the pilot program.

Although access to essential services remains a little 'patchy' in some areas, it is exciting that after several years of advocacy the needs of people with MND and their carers are receiving greater attention within the health system and from DADHC.

There are many people to thank for these developments including:

- The dedicated health professionals in the Clinics and teams whose commitment to the care of people with MND is extraordinary
- Minister Della Bosca and the Department of Ageing Disability and Home Care
- NSW Health
- Carers NSW and the New South Wales Council of Social Services
- The Executive Director of Community Options Projects
- Our dedicated staff and volunteers at MNDA NSW – a great team!!

As I say farewell and set sail into retirement I would also like to thank the wonderful researchers, including a significant number here in Australia who are working with dedication to find a cause and a cure for MND and to improve approaches to MND care.

And of course, thank you to the people with MND and their families who show great resilience, strength and resourcefulness and who inspire us all tremendously - We will also never give up!!!

Anita Richter

Special Projects/Carers Services

People with MND should be **referred** for **COPS case management as early as possible** - see page 2 for more information

Noticeboard

Economic Impact of MND on Well-Being

Last year, members of MND NSW were asked to participate in a research project looking at the Economic Impact of MND on Well-Being. This is a collaborative research project between Deakin University and MND NSW. Professor Marita McCabe and Dr. Lucy Firth of Deakin University are researching the financial impact of MND on the quality of life of people with MND and their families.

People who participated last year will soon be receiving a follow-up questionnaire in the post. Thank you for your participation and we look forward to your continued involvement with this project. If you have any questions or comments regarding this project contact Elodie O'Connor, Deakin University ph. 03 9251 7258 or email elodie.oconnor@deakin.edu.au.

Research into Motor Neurone Disease

Professor Garth Nicholson and a research team at Concord Hospital are carrying out research to locate new genes causing MND.

Their current research is aimed at locating and mapping new MND gene mutations. It is hoped that this will lead to treatment strategies for people with MND and to study how the gene mutations cause the disease.

If your family has had more than one person with MND (even a distant relative, for example, second cousin) you can help their research. Participation in the project is likely to benefit future generations rather than provide any immediate benefit to any family member currently affected.

Participation involves the donation of a blood sample to be stored indefinitely and included in current and future DNA research into motor neurone disease.

For more information contact Carolyn Cecere ph. 9767 7016 or email ccecere@anzac.edu.au

Northern Sydney Carer Support Service Male Carers Cooking Course

Free 6 week course at North Ryde on Thursdays commencing early July, for men who are caring for a family member or friend who has a longer term illness or disability. Learn how to cook those favourite recipes, share a meal and share some time with other male carers.

Carers Courses

Carers courses are planned in several locations. Different topics are offered each week, including coping with caring and practical skills.

May, St Leonards; June, Eastwood; July, Manly; August, Hornsby.

For more information on cooking and carers courses contact Northern Sydney Carer Support Service, ph. 8877 5349.

Wesley E-Recycling

Wesley E-Recycling is an activity of Wesley Mission specialising in the refurbishment of computers for individuals, families and community organisations in need.

If you need a computer for the home, why pay full price? Computers are internet ready and can be



customised to suit your needs. All refurbished computers are fully tested and come with a three-month back to base warranty. Cost ranges from \$50-\$420. For more information ph. 9572 3200 or see www.wesleycomputers.org.

For Sale - Toyota HiAce Commuter Bus

1996, 5 speed, 85980kms, white, 5 seater plus seats wheelchair. Reg 04/07. Certified Braun hydraulic hoist. \$18,000 ono. Ph. Lisa 0427 700 498.

Medical Expenses Tax Offset

The Australian Taxation Office on 8 September published two ATO Interpretative Decisions (ATO ID) that might assist with tax rebate for the cost of modifying vehicles and repairing or maintaining speech aid equipment.

ATO ID 2006/250: accepts that the cost of purchasing and installing a folding ramp to allow wheelchair access to a car is a medical expense and able to be claimed as part of the medical expenses rebate for tax purposes.

ATO ID 2006/252: allows the purchase and maintenance of a speech aid to be subject to the medical expenses rebate for tax purposes.

For more information see your accountant or visit <http://law.ato.gov.au> and search using the decision number.

Bladder and Bowel Information

The new National Continence Management Strategy provides for:

- the National Continence Helpline, which is a free information and referral telephone service for people affected by incontinence ph. 1800 330 066
- a new Government web site dedicated to bladder and bowel health at www.bladderbowel.gov.au
- the National Public Toilet Map Web site at www.toiletmap.gov.au which provides information on the location, opening hours and availability of wheelchair access of more than 14,000 public toilets nationally
- the Continence Aids Assistance Scheme eligibility for subsidised continence products up to the value of \$470 now also includes those over 64 years ph. 1300 366 455

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

Support Groups

Riverina/South West Slopes

The Riverina/South West Slopes Group continues to meet every second month at 12.30pm for lunch at the Commercial Club in Gurwood St, Wagga. The group is friendly and welcoming, and are more than happy to talk about anything from MND to football. Those with MND and their families, as well as past carers, attend the group with some members travelling from Griffith and Cootamundra to enjoy the get together.

It is a great opportunity for people in the region to meet and be with those who fully understand the impact MND has on those affected - the person with MND, their family or carer. For further information on the group contact Susan Chambers (a group member) ph. 6942 3970 or Allison Pearson ph. 6238 3769.

Allison Pearson
Regional Advisor

Central West

As the new Regional Advisor for the Central West, I visited this lovely area of New South Wales last week on an outreach visit. Over three days, I visited Forbes, Dubbo and Orange. In my travels I met with health professionals, members and their families, attended the Central West Group and gave two presentations (with the odd technical hitch or two) about MND. It was most valuable to meet with such diverse, interesting and inspirational individuals.

The next support group meeting will be on 17 April at the Orange Ex-Serviceman's Club. Graham Opie, Chief Executive Officer, MNDA NSW will be at the meeting to talk about the Association's strategic plan. The date for the June meeting has been changed to 12 June and will most likely be held in Dubbo. Maree Hibbert, Equipment Services Coordinator, MNDA NSW is hoping to attend the August group meeting, but this will confirmed at a later date.

I would like to thank everyone for their interest and input, and their hospitality during my visit. I'm looking forward to a close and rewarding relationship with members and families in the Central West.

Jenny Judd
Regional Advisor

Young Carers

There is growing awareness of the role and needs of children and young people who are involved in the support of a parent living with a chronic or life threatening disease. Young Carers (a support service from Carers NSW) provides information and support for young people in this situation. This includes a Young Carers Kit and camps for young carers of different age groups. Children who have a parent living with MND would be eligible to participate in these camps.

Ph. 1800 242 636 or see www.youngcarersnsw.asn.au for details of the support Young Carers provides.

Gladesville

The Gladesville Group had its first meeting for 2007 on 7 February. Following morning tea, the group exchanged stories of their holiday adventures of the December-January period. We also watched a short video, made by one of our members, about how carers can help someone who has speech difficulties. This was followed by some helpful discussion about ventilatory assistance.

It was decided by the group that they would like to continue meeting every two months from 10.30am to 12.30 pm at the MNDA NSW Centre at Gladesville. Planned meeting dates for 2007 are 4 April, 6 June, 1 August and 3 October. New members, including those passing through Sydney, are welcome to drop in. At our next meeting we will be having some discussion around maintaining diet and weight. Please contact the MNDA NSW on 1800 777 175 or 8877 0999 for further information.

Caroline Gleig
Regional Advisor

Northern Beaches

The Northern Beaches Group meets bi-monthly on a Thursday morning at the Palliative Care Cottage, Mona Vale Hospital. Refreshments are provided, there is easy wheelchair access to the building and a drop off zone at the door.

Graham Opie, Chief Executive Officer, MNDA NSW and Gina Svolos, Family Support Manager, MNDA NSW were our guest speakers for the first meeting of the year on 1 February. They enjoyed chatting with members, past carers and allied health professionals. Graham spoke about the Association's strategic plan and outlined the exciting strategies which will enhance the profile of MNDA NSW. He also discussed his advocacy role in shaping the direction of care and research through MNDA NSW activities with other multi-disciplinary care providers and stakeholders. Gina told us she has settled well into her new position as manager and is enjoying getting to know the staff and all those closely connected to MNDA NSW. If you missed out on a copy of the strategic plan or other information about the Association, you can request the information by calling MNDA NSW Gladesville Centre on 8877 0999.

The next meeting is on 5 April and our guest speaker will be Maree Hibbert, Equipment Services Coordinator, MNDA NSW. Maree will be talking about issues relating to the safe use of equipment and will be happy to answer any questions you may have.

If you would like further information about the group or if you would like to offer fresh ideas to enhance the running or the focus of the meeting, please call me on ph. 8877 0909.

Jo Fowler
Regional Advisor

The annual program of Carers Workshops at the MNDA NSW Centre at Gladesville is scheduled for September 2007

Support Groups (Cont'd)

Kingswood

The next meeting of the Kingswood Group will be held on 24 April. Graham Opie, Chief Executive Officer, MNDA NSW will be speaking about the Association's strategic plan and this is an excellent opportunity to hear about the direction for the organisation and to provide some feedback. In addition to this, we will be having lots of informal discussion about living with MND. Members, family members, carers and past carers are all welcome to attend. Any inquiries, please call me at MNDA NSW ph. 8877 0906.

Jenny Judd
Regional Advisor

Port Kembla

The meeting of the Port Kembla Group on 9 February was so well attended that someone queried whether a bigger room was needed! Our speaker was Katherine Underhill from Palliative Care at Port Kembla Hospital. Katherine spoke about the role of a palliative care team and what assistance can be offered to people diagnosed with MND and their families. We are most grateful to Katherine for giving up her time to talk to us and also appreciate her offer to show people around the palliative care ward if anyone would like to organise a visit. If you are interested please call Marie Alwert ph. 4223 8122 to arrange a time.

With so many people in attendance it was a great opportunity to discuss events for the year ahead. So for those who couldn't attend last time, or who are considering coming to a future meeting, the program for 2007 is as follows:

13 March - Helpful hints
10 April - Advance care planning, Julie Hutchings
8 May - Belly dancers
11 May - Cornflower Blue Day fundraising stall
12 June - Guest speaker, occupational therapist
10 July - Christmas in July
7 August - To be decided
11 September - Guest speaker, speech pathologist
9 October - Guest speaker, dietitian
13 November - To be decided
11 December - Christmas lunch

Loris Kelton and Ron Wallace have kindly offered to look into the feasibility of fundraising stalls for Cornflower Blue Day on 11 May at Shellharbour Shopping Complex and Corrimal Court. Thank you Loris and Ron. However, we still need volunteers to assist on these stalls and our group facilitator Julie Hutchings has offered to put together a roster of those who are able and willing to donate some time to both educate our community and raise some funds.

Thanks to everyone who provided food and thanks for making the effort to come to our meeting.

Fern Linden
Regional Advisor

Equipment

Since September 2006 the MNDA NSW Equipment Loan Pool has received over 417 new requests from health professionals for member equipment loans. A total of 444 items of equipment have been loaned during the same period, as some of the items dispatched were for members who had been on the waiting list before September.

Also during the past six months, electric medical beds have been hired for twelve members in regional areas of NSW. These twelve beds are in addition to those beds for which hire commenced in the prior period. MNDA NSW may hire beds in regional areas if Equipment Loan Pool medical beds are not available. When necessary, MNDA NSW can organise bed hire for members living from Coffs Harbour in the north, to Wyndham, Cooma, Goulburn in the south and Dubbo in the central region of New South Wales. These beds are arranged through regional equipment suppliers.

The Association has purchased over \$54,000 of new equipment during this time. The most recent additions to the Equipment Loan Pool are five new electric pivot hoists and slings.

Unfortunately demand for all items of equipment is high and most of the new items of equipment are allocated and sent out on loan within three days of delivery, as was the case with the new electric hoists and slings.

Maree Hibbert
Equipment Services Coordinator



MNDA NSW recently purchased five new electric pivot hoists and slings for the Equipment Loan Pool

WANTED: PHOTOS MAKE A DIFFERENCE FOR MND

The 'March of MND Faces' banner features a photographic display of people with MND. MNDA NSW has already produced six 'March of MND Faces' banners and will soon be producing a seventh.

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

Family members are also able to submit a photograph in remembrance of a person who has died from MND. For more information ph. 8877 0999 or email info@mndnsw.asn.au



Information
Evening for
People Newly
Diagnosed and
their families
and friends
MNDA NSW
Centre
Gladesville
5 June 2007

Financial Matters

It is impossible to compensate carers for the value of the contribution they make in caring for their loved one with MND.

Caring has many hidden costs and it is important not to feel embarrassed in seeking whatever financial assistance is available to offset these costs, if only to a small extent.

What sort of financial assistance is available through Centrelink?

Carer Payment

Carer Payment is an income support payment for people who are unable to support themselves through participation in the workforce while caring for someone with a disability, severe medical condition or who is frail aged. Caring must be on a long-term basis. The maximum single payment is \$512.10 per fortnight (Jan 2007) is income and assets tested. Eligibility is also dependent on an assessment of care needs.

Carer Allowance

Carer Allowance is a supplementary payment for carers who provide daily care and attention for adults with a disability, severe medical condition or who is frail aged at home. Carer Allowance may be paid on top of Carer Payment or other payments, such as Age Pension. This allowance (\$98.50 per fortnight - Jan 2007) is not income and assets tested and it is tax free.

Disability Support Pension

Eligibility for the Disability Support Pension is dependent on an assessment and inability to work for at least two years because of disability. To be eligible you must have lived in Australia for a total of ten years as an Australian resident, or your disability occurred while you were an Australian resident. The maximum single payment is \$512.10 per fortnight (Jan 2007) is income and assets tested.

Mobility Allowance

May be available for those who are able to continue employment, paid or voluntary, for more than 8 hours a week but have a level of disability that precludes the use of public transport. This allowance (\$74.30 per fortnight - Jan 2007) is not income and asset tested.

Bereavement Allowance

This allowance is payable to a person whose partner has died. It is income and assets tested.

Concession Cards - Pensioner Concession Card and Health Care Card (HCC)

These cards entitle the holder to many concessions including prescription medicines, transport fares, rates, power bills and car registration. Check whether you or the person you are caring for are eligible for these cards.

www.centrelink.gov.au

What other organisations may be able to provide financial assistance?

Department of Veterans' Affairs (DVA)

Provides some financial assistance and specialised equipment to veterans and war widows ph. 13 32 54.

Disabled Taxi Subsidy

The Taxi Subsidy Scheme, administered by the NSW Government, provides taxi travel at a half rate subsidy to people who are unable to use public transport because of a qualifying severe and permanent disability such as MND. The application form needs to be completed by the person with MND or carer, and a medical practitioner. Forms are available from MNDA NSW. For further information contact the Taxi Subsidy Scheme ph. 9689 8888 or 1800 623 724 fax. 9689 8813.

Home and Community Care (HACC) - Home Modifications Scheme

This scheme provides a level of subsidy to assist with home modifications to facilitate on going care at home. This is income and assets tested and referral by an occupational therapist is necessary. It is well worth seeking assistance through this scheme; however, a HACC accredited builder must do the alterations. It is important to apply for this assistance early, as there may be delays in accessing HACC accredited builders.

Program of Aids for Disabled People (PADP)

This scheme provides certain types of equipment, at a small cost, to help people to remain independently in their own home. Occupational therapists can help with PADP applications. Sometimes there is a long waiting time for equipment provided through this program or funds may not be available in your area. If equipment is unavailable or if there is a waiting period then people with MND may source equipment through:

- Veterans' Affairs - veterans may be able to access equipment through their veteran's entitlements.
- MNDA NSW Equipment Loan Pool - equipment is loaned to members while the PADP application is being processed. An assessment by the appropriate health professional is necessary.

Telstra's Disability Equipment Program

For people unable to use a standard telephone handset Telstra may be able to provide a suitable product at the same cost as the standard annual rental. For more information Telstra's Disability Hotline ph. 1800 068 424 or www.telstra.com.au.

Travel for medical reasons

ITPAAS (Isolated Patient Travel and Accommodation Assistance Scheme) ITPAAS provides financial assistance towards travel and accommodation costs incurred by people who are required to travel more than 200kms one way for specialist treatment. For more information contact Carers NSW ph. 1800 242 636.

Centrelink enquiries related to disability, sickness or carers can be made to ph. **13 27 17**. For languages other than English ph. **13 12 02** between 8am-5pm Monday to Friday

Financial Matters (Cont'd)

Can you access superannuation?

Some people might want to access 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, however, limited circumstances where benefits may sometimes be released early, including serious illness.

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, contact APRA ph. 1300 131 060 or see www.apra.gov.au

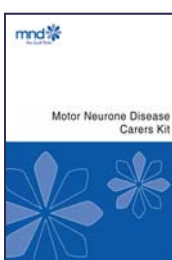
Can you access life insurance?

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 on this regard.

Are there other people who may be able to give me advice?

- A financial counsellor - contact through the Financial Counsellors Association of NSW www.financialcounsellors.asn.au
- Your bank, solicitor or accountant may be able to help with financial planning
- A social worker from your local hospital or community health team
- Your union or trade organisation
- Commonwealth Carer Resource Centres ph. 1800 242 636 or see www.carernsw.asn.au
- Aged Care Information Line ph. 1800 500 853 or see www.agedcareaustralia.gov.au
- Australian Tax Office Helpline ph. 13 28 61 or see www.ato.gov.au



'Financial Matters' is an excerpt from the Motor Neurone Disease Carers Kit (2nd Edition) 2007. The Carers Kit is a comprehensive resource for people living with MND.

In addition to updated content, the 2nd edition has an expanded section on holidays and travelling with MND. Many thanks to Chris Douglass, a MND Carer, for her assistance with the travel section.

For more information contact your MND Regional Advisor ph. 1800 700 175 or 8877 0999.

Support Group Contacts

Central Coast

Audree Dash
Ph: 02 4384 2907

Central West

Jenny Judd
Ph: 02 8877 0999
jennyj@mndnsw.asn.au

Coffs Harbour

Lily Jenkins
Ph: 02 6652 2571

Illawarra

Julie Hutchings
Ph: 02 4223 8000

New England

MNDA NSW
Ph: 1800 777 175

Newcastle & Hunter

MNDA 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
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Gladesville

Caroline Gleig
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and

Northern Beaches

Jo Fowler
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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 MNDA office.
Ph. 02 8877 0999 or Freecall 1800 777 175

Family Support Calendar

30 March Past Carers Meeting
MNDA NSW Centre, Gladesville

5 June Information Evening for People Newly Diagnosed and their families and friends
MNDA NSW Centre Gladesville

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.

Happy Feet brings smiles to Tamworth

A pre-Christmas showing of the movie 'Happy Feet' gave residents of Tamworth an opportunity to see a great film and contribute towards finding a cure for MND. Organised by Colin and Helen Pearce, whose daughter-in-law has MND, it was a great success and raised thousands of dollars for research into this terrible disease. Although there is little to smile about MND the movie certainly brought many smiles to faces. Thank you to all those involved in making this happen.

Running in memory of Dad



Margaret (right) with Loris Kelton, also from Kiama, who lost her husband recently after living with MND.

Margaret Mappas wasn't going to let a bout of the 'flu stop her from running in the City to Surf last year, in memory of her dad.

Margaret's father died from MND three years ago and she felt it was time to do something which might, in its own

small way, help others living with MND. She ran with her husband Garry and raised, through sponsorship, an outstanding amount of over \$7,000. Her contacts at Wollongong Hospital where she works, the Ambos and her husband's clients at GP Accounting all supported her as well as friends from Kiama where she lives. Margaret also sold chocolates on our behalf to augment her fundraising.

We are most grateful for this kind of support. If anyone would like to run in this year's City to Surf as a MND NSW representative or team we will provide suitable singlet tops for you to wear. Just contact MND NSW ph. 8877 0999.

Christmas lights twinkle in Cowra

Once again the Oliver Family and parents, Sue and Bob Dunn, put together a spectacular Christmas light display for the lucky people in Cowra. Still hurting from the drought and the closing down of the abattoir, the community managed to put their hands in their pockets and donated a large sum of money to buy needed equipment for people living with MND. The Oliver children handed out lollies and lots of Christmas cheer to the visitors. We really do appreciate this great effort and support from the Dunns, Olivers and people of Cowra.

New Volunteers' T-Shirts

This year we are encouraging all our volunteers who sell merchandise during MND Week to wear a special Volunteer T-Shirt. These round necked white cotton T-shirts have the new MND logo and VOLUNTEER printed on the front and NEVER GIVE UP printed on the back.

These shirts are complimentary for all volunteers ordering merchandise to sell this year. Please make sure you indicate on the form your size(s).

Every deal counts for MND

Thursday 7 December 2006 was ICAP's 14th global annual Charity Day and this time MND NSW was chosen as one of the nine charities to benefit. ICAP is the world's largest voice and electronic interdealer broker with a daily average transaction volume in excess of \$1 trillion. The group is active in the wholesale market for over-the-counter derivatives, fixed income securities, money market products, foreign exchange, energy, credit and equity derivatives.



(top right) Graham Opie, MND NSW with ICAP dealers

Each year the various branches of ICAP across the world have a day on which all revenues and commissions are given away to just a few charities, which means that each receive a large amount of money to really make a difference to their operations. To make the day more fun for the participants, traders dress up in costumes, competing for the best dressed group.

Graham Opie, Chief Executive Officer, MND NSW attended the day and was well received by 'knights' and 'pirates' while he watched 'geisha girls' working the boards and 'bikies' sending millions of dollars across the world! When the cheque arrived in the mail a few days later we discovered we had been blessed with a total of \$74,000. Thank you ICAP.

Is your ID up to date?

Anyone selling merchandise or asking for donations on our behalf must, in keeping with the Office of Charities requirements, wear ID issued by MND NSW.

If you need a new badge please call ph. 8877 0999 or email roslyna@mndnsw.asn.au for a form. If you had an ID last year this will be automatically renewed when you send in your merchandise order form.

Try Lookle

LOOKLE is a search engine that searches through Australian web sites, finding exactly what users are looking for accurately and clutter free! And it helps raise funds for charities.

Every time you use Lookle it will donate 1 cent to MND NSW (provided you have named us as your charity.) It may not sound much but if 100 people use this service three times a day it will raise \$1,095. If you tell your friends about Lookle this amount will increase greatly.

Go to www.lookle.com.au for more information.



Order your
MND
Global Day
raffle ticket
books today.

Ph. 8877 0999

ALS/MND Global Day - 21 June

Every year, since 1997, the International Alliance of ALS/MND Associations has celebrated 21 June as the global day of recognition of ALS/MND - a disease that affects people in every country of the globe. The International Alliance is the peak body for national organisations who support people living with ALS/MND.

21 June is a solstice - a turning point - and each year the ALS/MND community undertakes a range of activities to express their hope that this day will be another turning point in the search for the causes, effective treatments and cures for this disease.

Research presentations from the 17th International Symposium on ALS/MND are now available. See www.mndassociation.org

MND Global Awareness Day Dinner Dance



The Roseville Memorial Club, 64 Pacific Highway, Roseville, is a small recently refurbished community club with the motto "community owned, working for our community"

The 7th Annual Charity Fundraising Dinner and Auction will support the Motor Neurone Disease Association of NSW

Saturday 23 June 2007

For more information and for bookings
ph. 9419 6849
www.rosevillememorialclub.com

Don't forget our Global Day Raffle

To be drawn on Thursday 21st June 2007

1st prize: Beautiful hand-made quilt for double bed with autumn tones (215 cm x 215 cm) donated by the Hunters Hill Quilters : Value \$2,000

2nd prize: 1 dozen 2005 Sauvignon Blanc donated by Blue Metal Vineyard and a set of 4 Trace Flute Waterford Crystal Glasses donated by Janice Scheinecker : Value \$400

3rd prize: Bessemer 34 cm Baking Dish Base and 34 cm Lid : Value \$350

Order your tickets today!

Phone 1800 777 175

All tickets
\$5 each

Special prize of a **Techline MP3/MP4 Multi-audio Player** for the person who sells the most books. (Each book has 10 tickets)



Two New Items for sale during MND Week 2007



This fun luggage tag is great for airport luggage, school bags, and any other piece of luggage that needs special identification. Our Aussie Blue Heeler "Hope" says "Never Give Up" for MND and the tag glows in the dark for extra interest.

Price: \$5.00

Protect your eyes and head with this stylish cotton cap sporting the new MND logo. Adjusts to all sizes.

Price: \$10.00



Kick up your Heels at an Evening of



IRISH CRAIC

Saturday 12 May 2007

8.00pm - 12.00am

Penrith Gaels Club

75 Richmond Rd

Kingswood

\$10 p.p.

Entertainment by
George and the Unicorns

Proceeds to **mnd**  **Week**
New South Wales

Dates for the Diary

17 March	Fun and Dance <i>Coffs Harbour RSL Club</i>
17-25 March	Tour de Mid-North Coast, Taree <i>www.bigride.com.au</i>
19 March	Foodservice Industry Association and MNDA NSW Charity Golf Day <i>Camaron Golf Club, Lidcombe</i>
20 March	Benefit Night for Motor Neurone Disease - The Australian Wool Fashion Awards (TAWFA) <i>Tamworth ph. 67712733</i>
20 March	MonStar Cup <i>Pennant Hills Golf Course</i> <i>www.monstarcup.com</i>
3 May	Launch of MND Week <i>2-5 pm, Lake Room</i> <i>Waterview Convention Centre</i> <i>Bicentennial Park</i>
6-12 May	MND Week
9 May	Competition Bowling Day <i>Newport Bowling Club. 9am-5pm</i> <i>Mark Newlan, ph. 9979 7677</i>
11 May	Cornflower Blue Day
11 May	Dinner with an auction at the Motel Royal Tara in Binalong. <i>Lorraine Walker ph. 6227 4365</i>
12 May	Irish Craic <i>Penrith Gaels Club, Kingswood</i>
21 June	MND Global Day <i>Drawing day of the MND Global Day</i> <i>Raffle</i>
23 June	MND Global Day Dinner Dance <i>Roseville Memorial Club</i> <i>Ph. 9419 6849 or</i> <i>www.rosevillememorialclub.com</i>

Launch of MND Week 2007

3 May

Commencing at 2pm

*Lake Room, Waterview Convention Centre,
Bicentennial Park, Homebush*

Instead of flowers....

...another way to honour your loved one

When someone close to us dies, we experience grief, sadness and, ultimately, an appreciation of all the memories we have of that special person.

In our sadness, we look for a way to express our feelings, to let close ones know our feelings.

Traditionally, we send flowers

There is another way that is far more lasting to show we care. It's a way of expressing hope that one day a cure for motor neurone disease will be found, a way in which we can offer a continuing and meaningful tribute.

Give comfort and hope with a gift to find a cause and cure.

Your gift to the Motor Neurone Disease Association of NSW will give comfort and hope to those touched by MND. You will also help find a cure.

Your gift to MNDA NSW makes a difference.

Research – finding answers.

Donations given for research are forwarded to the MND Research Institute of Australia. Each year a group of experts reviews all applications for funding for research throughout Australia and allocates the available resources. This ensures that the money is spent on the most worthy research projects – those that show the greatest promise in changing the future.

Support people living with MND.

Support to people living with MND and their families is provided through telephone contact, information, personal visits, practical help and the loan of necessary equipment.

Your gift is special

When you make an In Memoriam donation to MNDA NSW, we will send the bereaved family a card acknowledging your gift. The card identifies you and provides your address, but does not identify the amount given. A receipt is issued to you for income tax purposes.

An annual gift

As the date of your bereavement comes around each year, you may find it comforting to know that you have already taken action in the quest to find a cure or to help others living with MND, by making an annual gift.

To make an annual gift, an In Memoriam gift or to organise envelopes for a funeral, please contact the MNDA NSW Centre at Gladesville and we will send out the necessary information.

**Do you have
a letter or
ideas for
Forum?
Contact The
Editor,
Forum,
MNDA NSW,
Locked Bag
5005,
Gladesville
NSW 1675**

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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