THE NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NSW

MOTOR NEURONE DISEASE

FORUM

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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March 2003

Motor Neurone Disease Week

6-12 April 2003

All members of MNDA are invited to the **launch of MND Week at Government House on Wednesday 2 April.** If you would like to attend, please telephone the office (9743 5872) before Friday 21 March. Numbers are strictly limited so be sure to reply early.
Her Excellency Professor Marie Bashir AC, Governor of NSW, is officiating as the MNDA's Patron and speakers are Prof Garth Nicholson of the University of Sydney, Dr Arun Aggarwal, Neurologist and Dr Paul Brock, MNDA NSW Board Member and Director of Strategic Research, NSW Dept of Education & Training.
Registration is from 11 am and guests are invited to stay for a light lunch.

This heralds the beginning of activities and, by popular demand, another concert has been arranged at the **Sydney Conservatorium on Saturday 5 April** at 7.30 pm. Following the concert (tickets are $30) there will be a reception (an additional $25) in the lower foyer where the archeological remains are on display. Phone 9743 5872 for bookings.

A special service will be held at **St Andrews Cathedral at 10.30 am on Sunday 6 April** to mark the beginning of MND Week. Members are all invited to attend and bring the family too.

Where to buy your cornflower …. This year, the Association is joining with HCF's statewide chain of branches to ensure that the people of New South Wales know where they can find a cornflower. If anyone is talking to the media, don't forget to mention that HCF is the place to go to buy a cornflower during the whole of MND Week. Of course, merchandise (pens, shortbread etc) and posters are readily available for people who wish to do their own promotion – the more the merrier.

The MNDA has worked together with the Department of Education and Telstra to produce a series of **maths puzzles for primary school children**. Access to each of ten questions is obtained by phoning a 1900 number – releasing a special code. Children then need to work out the answer to be able to phone to access the next question. Revenue from the calls (at a fixed 50 cents each) comes to the Association and there are links to the Association's website too. It's fun and children can print their own certificate on completion of the project. More information will be available through the schools as MND Week approaches. Of course, this does not stop other children from having a 'blue' day at school or carrying out any of the innovative projects that they come up with.

On **Cornflower Blue Day** (Friday April 11) there will be collections in Sydney at Circular Quay, Martin Place, Qantas Domestic Terminal, Town Hall and Wynyard. In order to be able to approach the greatest number of people, we need people prepared to, say, rattle a bucket from 7-9 am. Do you know anyone who will give the MND Association that time?

The blue cornflower has been adopted in most countries as the symbol of hope for MND - the hope that a treatment and a cure will soon be found.

From the President's Desk

Annual Report for the financial year ended 30/6/02. In December 2002 we sent our annual report to all the members of the Association. The annual report showed our achievements during the year and contained a detailed financial statement. Your comments would be welcomed.

Business Plan for 2003-2006. The present Business Plan is being reviewed. The new Business Plan will consider the responses to the questionnaire sent to you late last year.

Family Resource Centre. Significant progress is being made towards acquiring a building at Concord Repatriation General Hospital. Since moving into our present office in 1995, the staff numbers have grown from one and a half to twelve. Even though most staff members work part-time, working conditions are now extremely cramped and unmanageable. It is hardly possible to answer the phone without tripping over a wheelchair, and privacy for consultations or quiet telephone conversations is not available. New premises are essential to allow greater efficiency in use of staff resources and to provide a place that members will feel welcome to visit. We also need room to comfortably accommodate the volunteers who so generously provide help when it is needed. Our equipment pool has grown exponentially and needs a home that is not the present 15 minutes drive away from the office.

Caroline Gleig and Helena Karnolz
Making Connections at the NSW Premier's Forum on Spinal Cord Injury and Conditions 27—28 January

The Family Resource Centre has been a subject of discussion since the early days of the MND Association in 1981. A brick and mortar project was then created and it was later decided that all unsolicited funds would be put aside for the Centre. This was a very sound decision as it not only helped to create a healthy investment for the Association, but it also allowed the Association to meet any unexpected challenges.

Making Connections – NSW Premier's Forum on Spinal Cord Injury & Conditions was held at the Sydney Convention Centre on 27 & 28 January 2003 and I represented the Association along with Dr Robert Marr, Dr Paul Brock, Janet Nash and Caroline Gleig.
Keynote speakers included Professor Perry Bartlett, President of the Motor Neurone Disease Research Institute of Australia, and other noted researchers from around Australia and overseas.
The theme referred to making connections - between families, nurses, care providers, scientists, researchers, patients, care and cure. Christopher Reeve was an inspiration in his determination and drive towards better care and research to find a cure. Although the main focus of the Forum was spinal injury, research reports related to other neurological conditions with MND at the forefront. The Forum provided an atmosphere of collaboration creating real hope for the future.

MNDA NSW was one of thirty-one organisations with a booth at the forum and we were included in the forum showcase profiles. Our regional adviser, Caroline Gleig, manned the booth which was very well patronised.

Our thoughts are with all those who have lost loved ones.

Kevin Langdon
President

The Seekers are holding concerts at the State Theatre, Sydney on March 11&12, Civic Theatre, Newcastle on March 13 and Tamworth Entertainment Centre on March 15.
Once again they are supporting MND and the bucket brigade will be there to collect donations.

Rilutek

Rilutek is the trade name for a drug called riluzole which has a neuroprotective function. It is the only drug that has been shown in scientific trials to have an effect on life expectancy in MND. Rilutek was registered as a treatment for ALS by the Therapeutic Goods Authority in Australia in May 2002.

Two applications by Aventis Pharma to have Rilutek listed under the Pharmaceutical Benefits Scheme (PBS) have been unsuccessful, but a third application is currently under way (March 6–7).

Rilutek is now available for purchase in Australia by prescription but, unless PBS listing is successful, it is very expensive ($695 for 4 weeks supply - phone the MNDA office for distribution details). Health insurance rebate, tax deduction and/or repatriation benefits may be applicable.

The MND Association of Australia has been a driving force in the mission to achieve ready availability of this drug for all people living with MND. Thank you also to our many members who wrote to the Minister for Health and local Members of Parliament seeking their support. This effort must continue until PBS listing for Rilutek is obtained.

Editor

Family Support

The nature of MND and the people affected by the disease has a profound impact on all those associated with them, including all MNDA staff and volunteers. This impact appears to result in a desire to try to do as much as possible to support people living with MND and their families throughout their journey with MND. The International Symposium, the Australasian Family Support Day, the Member Survey and our day-to-day contact with people with MND have given us much food for thought and 2003 promises to include new family support initiatives and changes to help us better meet the needs of people with MND in NSW.

A recent exercise for the **review of the business plan** included listing achievements, current gaps and future objectives for family support. Since the last business plan was written in 1999, MNDA NSW has increased both staff numbers and hours allocated to each regional family support worker and equipment. This has enabled us to provide more home visits, telephone support, education and support sessions for people with MND and their family, more equipment loans and more education for health care providers. It has been salutary, however, to recognise and discuss the gaps that still exist, which prevent many people with MND and their families from receiving adequate care and support. The future objectives we identify, during discussions over the next few months and from the results of the Member Survey, will guide us in our endeavors to fill some of the gaps and indicate where to advocate and lobby most effectively for optimal care and support for all people with MND in NSW.

Thank you to over 100 people who responded to the Member survey. Mr Bob Ballinger has very kindly entered the data into the computer. Analysis of your responses will guide us in providing better support for people with MND.

We are very pleased to introduce to you a new member of the family support team, Maree Hibbert, who has joined Linda Hager in the job share **equipment officer** position. Maree is a registered nurse with some business experience. Linda has worked very hard to keep up with demand recently and she will certainly welcome someone with whom to share the load! There will now be an equipment officer available each weekday from 9am to 3pm to discuss equipment issues and to organise delivery and pick up of equipment. Janet Nash has had the dual role of equipment and information officer for a number of years and has been instrumental in creating the equipment loan service, developing the computer tracking system and the excellent reporting procedures. She will now hand over the equipment side of her position to Linda and Maree allowing her to concentrate on the revision and development of information and, of course, editing the *Forum*. We thank Janet for her enormous input into the equipment service.

Our Outreach Workers have become **Regional Advisers**. This title, or similar, is used by other Australian MND Associations and the UK MND Association and we hope more clearly describes the role.

The Hunter Seminar for Health and Community Care Providers and a meeting for people with MND their family and friends was held on February 11 at South Newcastle Rugby Leagues Club. The day was a great success with health professionals from the region and from Sydney very kindly giving their time to present on various aspects of MND care and management. Approximately 65 health care providers attended in total, which is testament to their interest in providing optimal care for people with MND in Newcastle, the Hunter and the Central Coast. Members from the region came along to listen to the excellent presentations in the afternoon and to donate samples to Dr Roger Pamphlett for the DNA bank.

The 6th Annual Conference for Health and Community Care Providers will be held on Monday April 7 during MND week. The theme of this year's conference is the challenges care providers face in planning and providing care and support for people with MND and their family, particularly in cases that progress rapidly. The Conference is entitled "*A Race Against Time: The challenge of complex care in MND*". Speakers include health professionals from Melbourne, Sydney and Orange and people with MND and carers from Sydney and the Hunter. Invitations have been sent out to health care providers throughout NSW. Please ask the people involved in your care to contact us if they have not received a conference flyer.

The Rural and Regional Seminars and Annual Conference would not be possible without the support of Neurologists, Respiratory Physicians, Palliative Care Teams, Registered Nurses, Community Service Providers, Carer Respite Managers and Allied Health who always readily agree to participate whenever they are approached to give presentations. Their input and expertise is so important to ensure that other health and community care providers, who may not have had as much experience in MND, are able to learn from their peers. A heartfelt thank you from MNDA NSW to all those health care providers who assist us so willingly!

Carol Birks
Manager Family Support

Research

Recent grants made by the MND Research Institute of Australia

Dr Mark Bellingham, *University of Queensland.*
Mechanisms underlying motor neurone death due to glutamate receptor-evoked calcium influx in vitro.
To determine whether different levels of glutamate (essential for communication between cells) causes differing levels of death in motor neurones.

Dr Surindar Cheema, *Monash University.*
Developing a combinatorial therapy for the treatment of ALS.
To test two drugs on MND-affected mice to determine success or otherwise of delaying the onset and progression of the disease.

Ms Helen Cooper, *Walter and Eliza Hall Institute of Medical Research.*
Exploration of a novel cell survival pathway for motor neurones.
The identification of new molecular pathways governing motor neurone death and survival that may lead to the development of innovative therapeutic strategies with which to combat motor neurone degeneration.

Dr Sandra Feeney, *University of Melbourne.*
Antioxidant and excitotoxic reducing agent multitherapy treatments in MND.
This project is designed to examine potential therapeutic treatments for patients with MND. It will hopefully define more clearly several mechanisms of degeneration in MND affected mice and which agent(s) will offer the most effective neuroprotection and enhance the survival of diseased motor neurones.

Dr Mark Habgood, *University of Melbourne.*
Mechanisms of neuroprotection by metal chelating agents.
The project intends to determine the mechanism through whether and which metal chelating agents (those agents which remove metal ions from the cell) are able to protect neurons subjected to oxidative and excitotoxic stress (conditions that have been implicated in both sporadic and familial MND).

Professor Nigel Laing, *University of Western Australia.*
Application of Genomic Mismatch Scanning to the identification of the other genes mutated in familial MND.
This project aims to use a technique which has only relatively recently been applied to human genetics called Genomic Mismatch Scanning to try to identify the other genes (apart from SOD1) mutated in familial (hereditary) MND.

Professor Garth Nicholson, *Concord Hospital.*
Electrophysiological estimation of motor neurones in SOD1 mutation carriers.
Professor Nicholson and Dr Aggarwal have studied a group of 87 (human) family members over the last four years, some with SOD1 gene and some without. The objective of this project is to study the rate of motor neurone loss in SOD1 mutation carriers to determine when motor neurone loss occurs before MND-symptoms become obvious.

Brief reports from the researchers who received grants from MNDRIA during 2002.
The actual aspect of the research that was funded is summarised in italics.
Projects funded for 2003 will be reported in the next issue of Forum.

Dr Roger Pamphlett, *University of Sydney.*
Gene-environment interactions in MND.
Dr Pamphlett has previously set up a MND DNA bank to allow gene analysis to be undertaken for different genes. This project will enable the sequencing of one gene (metallothionein 3). The success of the project may provide evidence that the combination of a toxin in motor neurones, a genetic defect in metallothionein 3 and advancing age leads to MND.

Do you want to participate in research?

THE MND research group headed by Dr Roger Pamphlett at Sydney University is seeking blood and tissue donations for two research banks. The first, the **MND DNA bank**, needs blood samples for genetic research into MND. Please contact Dr Pamphlett on 02 9351 3318 (or rogerp@med.usyd.edu.au) if you are interested in giving a blood sample for this bank.

The second bank is an **MND tissue bank** in which people with MND are asked to consider donating their nervous system tissue after they die for research into the disease. New genetic techniques make this type of tissue particularly valuable for research into finding the cause of MND. If you are interested in making a future tissue donation, please contact Therese Garrick or Helen Blake who run the "Using our Brains" program on 02 9351 2410. They can tell you about the program, and send you a consent kit with more details.

In addition, you can get more information at the website www.braindonors.org (don't forget to put the 's' in braindonors) or via email at info@braindonors.org.

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BUSINESS PLAN 2003 – 2006

Some three years ago MNDA NSW completed a three year Business Plan based on a considerable amount of consultation within the Association. The resulting plan (2000 to 2003) has been used by the Board and Management to focus our efforts to meet the identified needs. The plan has proved to be a very valuable tool and was also made available to the Minister for Health to 'prove' our ability to meet our members' needs and to gain funding from the Department of Health to assist with provision of the service.

The current Mission Statement for MNDA NSW is:
To provide and promote the best possible support for people living with motor neurone disease, their families and carers and to raise community awareness.

This is the basis of the Board establishing the following team to produce a draft Business Plan for the next three years:

Convenor:	Bob Howe
Members:	Carol Birks
	Dr Paul Brock
	Elizabeth Herbert
	Janet Nash
	Paula Trigg
Ex Officio:	Kevin Langdon

The team will meet to discuss the current Mission Statement as well as the current objectives to see if they meet our future needs.

Following initial discussions, our revised Objectives for 2003 to 2006 are:

- Family Support
- Research
- Information
- Fundraising
- Accommodation
- Administration

Coordinators for each Objective have selected subcommittees and identified:

- A short statement of intent
- Successes to date in this area and any specific gaps
- A set of explanations of how we will achieve our Objective in the specific areas above.

The next stage is to draft final production of the new Business Plan prior to communicating to our Members for their comments, with a final draft on 30 June for ratification by the Board.

Bob Howe, Convenor
On behalf of the Business Planning Committee

(continued from page 4) ***…Participate in research***

St Vincent Clinical Trial Centre

is running a company sponsored study to assess the safety and effectiveness of medication for treating ALS.

This study has been enrolling participants since September last year, but more volunteers are needed for the trial. Adult patients with a clinical diagnosis of definite or probable sporadic ALS and of no more than five years duration may be eligible for the study.

If you would like more information, please contact the Clinical Trials Centre or Professor Bruce Brew on 02 8382 2233.

Depression and demoralisation in patients with a life threatening illness.

The research team at Monash Medical Centre invites you to participate in a research project investigating the emotional impact of living with a life threatening illness. The project aims to study and describe the quality of emotions experienced in MND and to understand this in terms of the stage of disease, and personal and social characteristics. The investigation is entitled *Depression and demoralisation in patients with a life threatening illness*. However, we want to speak with all individuals with MND, regardless of whether depression and/or demoralisation are amongst their emotions or not.

We are hoping that one of the outcomes of this study will be to clarify the distinctions between depression, demoralisation and grief.

By speaking with you and others with MND we may be able to clarify these emotional experiences and gain a better understanding of the emotional impact of MND.

By having a better understanding, we may then be able to help doctors, carers and health professionals attend to the emotional concerns of patients more sensitively and specifically.

My role as a Research Assistant, as part of the research team, is to meet with individuals who are interested in completing an interview. During the interview I will ask a series of questions in relation to the range of emotions involved in living with a life threatening illness. This will take approximately one hour. I will also leave a questionnaire with you to complete in your own time (this also takes approximately one hour).

I will travel to NSW in March and meet with all people with MND who are able to help. If you would like to participate, please contact me (details below) so we can arrange a convenient meeting place and time. Alternatively, you can phone MNDA NSW on 02 9743 5872 and they will pass on your contact details to me.

Janet McLeod, Research Assistant
Monash Medical Centre
246 Clayton Rd, Clayton, VIC 3168
Ph: (03) 9594 1480
email janet.mcleod@med.monash.edu.au

SUPPORT GROUP CONTACTS

Central Coast
Audree Dash
Phone: 02 4384 2907

Central West
Mary Campbell
Phone: 02 6851 4403

Coffs Harbour
Lily Jenkins
Phone: 02 6652 2571

Illawarra
Lyn Bedford
Phone: 02 4223 8239

Newcastle & Hunter
Alistair Fyfe
Phone: 02 4947 1983

New England
Robyn Barton
Phone: 02 6766 6065

Northern NSW
Phil Bower
Phone: 02 6743 4218

Northern Rivers
Noelene Kidd
Phone: 02 6624 4684

Riverina & Sth West Slopes
Wes Russell
Phone: 0408 692 127

Hornsby
(Anita Richter)

and

Panania
(Caroline Gleig)

and

Penrith/Blue Mountains
(Ruth Quaken)

are coordinated through the MNDA office.
Phone: 02 9743 5872

Regional News

Central West

This support group provides an opportunity for people in the Central West, who may be particularly isolated, to get together and discuss common issues. The group will alternate general discussion and support meetings with guest speakers as required. The group is very flexible, willing to travel and anxious to include as many people from the region as possible. Their last meeting was in Molong in February.

Contact Mary Campbell if you would like to receive details of forthcoming meetings or to suggest a meeting in your town.

Carol Birks

Hornsby

Meetings are held bi-monthly commencing 11.00 am at the Thornleigh Community Centre.

We are grateful to Janet Nash and Elizabeth Herbert who discussed the latest research and awareness/ fundraising activities at our February meeting .

MNDA president, Kevin Langdon AO (a person living with MND) will talk at our next meeting, on April 16 about his many activities and involvements on behalf of the Association and provide an overview of MND Week.

Anita Richter

Illawarra

The group will continue to meet monthly at the new time of 10am to 12 noon at Port Kembla Hospital. Meetings are informal get togethers, with a guest speaker or group discussion, followed by lunch. All interested people are invited to attend.

Penrith/Blue Mountains

The group meets on the third Tuesday of the month at the Kingswood Community Centre and will be inviting guest speakers to talk. Everyone is welcome.

The February meeting enjoyed hearing Margaret Erdminis, Physical Therapist, talk about the benefits of massage, aromatherapy and physical therapy for people with MND.

Ruth Quaken

Newcastle & Hunter

Plans are in place for the Seekers concert being held at the Civic Theatre Newcastle on March 13. MND Balloons and collection buckets are all ready to go.

Mayoress Ellen Kilpatrick will officially launch the sale of our Bone China coffee mugs on Saturday March 22.

Thanks from our group to the organisers of the MND seminar at Newcastle, which was well attended by health professionals and people living with MND.

During MND week we will be manning stalls in five major shopping centres.

Alistair Fyfe

If you would like to be on the mailing list for a local MND support group, or if you would like to start a new group in your area, please phone the office on 9743 5872 and let us know which location is the most convenient for you.

Panania

The group meets at Uniting Church Hall, Marco Avenue, Panania 11 am – 1 pm on the first Tuesday every second month. There is plenty of off street parking, easy access and no steps.

Meeting dates for 2003: April 1, June 3, Aug 5, Oct 7 and Dec 2. The group is friendly and welcomes new members. The central location of Panania means that it is no more than a half hour drive from Sutherland, Liverpool, Bankstown, Strathfield, or the airport area.

Caroline Gleig

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 *www.hotkey.net.au/~ozpals*

Internet Chat - Living with MND

Every Tuesday at 1pm & Thursday at 8pm DST. Go to *www.mnd.asn.au/* then click on the chat room link.

Also try *http:/neuro-mancer.mgh.harvard.edu/brainchat/classic.shtml* for a chat room which is open 24 hours per day.

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

Fundraising

MND Week 6 - 12 April

This year's target is to raise $200,000.
It is ambitious. And, in order to achieve our goal, we need lots of help. If you have friends who can give us some of their time, please ask them to contact us.
If family or friends can put posters in prominent positions and host a box of cornflowers, let us know.
If anyone can spare a day (or two) we need volunteers who will be manning shopping centres throughout NSW (see the enclosed flyer for locations).
Please phone the office or your local Support Group if you can help.

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.
Join those who support the work of MNDA NSW through bequests from their Estates.

HAVING A BALL!
The mid-winter solstice - and Global Awareness Day for ALS/MND- coincide on 21 June. It is also the Association's 21st birthday. In order to celebrate, a Ball is being held at the Four Season's Hotel in Sydney. Music will be supplied by James Morrison and the evening's Gold Sponsor is the Australian Stock Exchange (ASX). In addition, the organiser, Sally Gole, has worked together with her father, Bill (who has MND) to attract sponsorships from Adcorp, and Macquarie Bank.
Several businesses have also committed to take a table at $2,000 for ten guests. However, there is still plenty of room for anyone interested in what promises to be a fabulous evening of fine dining, dance and great music. Tickets for members and friends cost $165 per person.
Several magnificent gifts have already been received. Villeroy & Boch, for example, have donated a full cornflower dinner set valued at nearly $2,000. It is magnificent.
Tickets? Call the MNDA for bookings.

Elizabeth Herbert

Volunteer Visitor Pilot Program

We are thrilled to announce that MNDA NSW has been successful in obtaining funding though the ***Caring Communities Program***. The aim of this program is to improve the quality of palliative care in the community. An application was made to the **Commonwealth Department of Health and Ageing** to fund an MND Volunteer Visitor Pilot Program in the Hunter and Central Coast. We are very grateful for the approved $73,000 over 2.5 years to fund this pilot project.

Christina Jason, Northern NSW Regional Adviser, will coordinate the program, working closely with Palliative Care Teams and Support Groups in the region to recruit and train suitable volunteers. Christina's interest and enthusiasm in this project were the impetus for the funding submission. Anita Richter will be involved with the carer support and bereavement component of the program.

We plan to commence recruitment of volunteers in May once funding agreements have been finalised. If you live in the Hunter, Newcastle or Central Coast Region and would be interested in becoming an MND Volunteer Visitor we would love to hear from you. The volunteers will be caring, practical people who are good listeners and understand the impact of MND on a family. A comprehensive training program will be implemented and ongoing support provided. Volunteers will visit or telephone people living with MND in the Newcastle, Hunter and Central Coast region who would like to access this kind of support and assistance.

We look forward to implementing this very challenging project, which we hope will improve quality of care and support for people living with MND and their families.

Carol Birks

(Continued from page 8)

Carers

Carers Kit reminder

We have already received a number of requests for information from our Carers Kit. Please note that the checklist sent out with the last newsletter did not include the sections on *Communication* and *Swallowing*. The printed form or CD are the most workable options for distribution, so we will no longer offer to send the Kit information by email.

The Carers Kit is available as a complete kit or as selected sections without charge to members with MND and their carers. However, due to the cost of production and distribution, a charge of $50 will be requested from others who would like to have the Carers Kit, or $25 to receive it on CD.

We would welcome your feedback and suggestions regarding the information contained in the Kit. It is a resource that will continue to be fine-tuned to the needs of those who use it.

Anita Richter, Carer Coordinator

The Accidental Carer

October 25, 2000 was a big day in our family: my wife, Deb Bailey, and I had been married for 20 years. So I had quietly planned for us to celebrate in style. A chauffeur in a hire-car picked us up from our home and drove us to the city, to a then-fashionable restaurant overlooking Circular Quay. We each had a pre-dinner drink. Deb had her favourite, a margarita. She was barely halfway through her drink when her voice began slurring. Deb rarely drank very much, so she had only a couple of glasses of wine with dinner. The slurring, however, worsened. …

People become carers in different ways. Some volunteer; some are paid; and some develop friendships or even enter relationships with others who are handicapped or ill. But most become carers by accident, in the sense that the role is not one we planned or intended – as the Carers NSW definition of the role, "Who Is a Carer?" makes clear. The role is thrust upon us by a terrible turn in life's fortunes. That night of October 25, it transpired, gave us the first sign that whatever forces control the fates had prepared a cruel future for us. My wife was to become a patient and I (along with our girls) was to become a carer. …

Until that period two years ago I thought that carers – if I thought about them at all – were dedicated people who probably spent a lot of time feeling physically exhausted. I never expected to become one. …

"Carer" remains an inadequate word – or, least, the outsider's understanding of it is inadequate. For the word conveys nothing of the emotional stress, and distress, that carers can live with – and nothing of the heart-tearing moral and ethical issues many carers confront, especially if they are helping the terminally ill. …

In the case of an incurable progressive disease, the emotional strain on family members starts well before they become carers, for first there is a period of uncertainty, confusion and worry to negotiate. What follows, however, is a desperate sense of futility: no matter what you, or anyone else does, no matter how hard you try, or how tenderly, to look after your loved one, nothing can stop the disease. In the case of motor neurone disease, it means the grieving starts early: as the weeks and months go on, so much is lost that can never be regained. …

Deb's death came two days short of nine months after the wedding anniversary dinner. She was 48.
"I feel," she wrote in a letter to be opened after her death, "that we have been the victims of some great cosmic accident." …

I have the deepest admiration for carers, for I now know what they have to cope with, in many cases for much longer periods of time that I had to. …

Few people ask to be carers, in the sense in which you use the word. But being a carer is one of the greatest gifts we can give to those we love – even though we wish it were a gift we never had to give.

David Armstrong
Former Editor-in-Chief, The Australian

These extracts, reproduced with the kind permission of David Armstrong, are from The Clare Stevenson Lecture presented at Carers NSW in Sydney on November 28 2002. For a copy of the complete lecture, phone MNDA on 9743 5872.

Care for Carers Workshops 2003

Another Care for Carers Program will commence in May this year and include four workshops to be held at Concord Hospital on Monday May 19, May 26, June 2 and June 9 between 10.00 am to 3.00 pm. The workshops will address both physical and emotional aspects of caring for a person with MND, including aids and equipment and techniques for caring and services available to support the carer.

A short follow-up session will be held in the afternoon of July 21 for course evaluation and on-going support.

The Program is most suitable for carers of people who are in the middle to later stages of living with MND and may not be so appropriate for carers of people with slowly progressive disease. We have found the Program functions much better if participants commit to attend all sessions. However, we appreciate the difficulty in taking "time out" for carers and we will work with local Carers Respite Centres to provide respite care in the home to enable carers to attend the workshops.

There is no charge for attendance and MNDA NSW will refund train and bus fares. Lunch and refreshments are provided.

A flyer will be circulated in April providing details of the Program and an application form.

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Editor: *Janet Nash*