

Submission No. 568
(Inq into better support for carers)

A.O.C. 7/7/08

Inquiry into Better Support for Carers

House Standing Committee on Family Health, Housing and Youth

Submitted via email by MND Australia

On: Friday 4 July 2008





TABLE OF CONTENTS

1. Introduction.....	2
2. Executive Summary	3
3. The role and contribution of carers of people with MND.....	5
4. Barriers to social and economic participation for carers.....	9
5. Practical measures required to better support carers of people with MND.....	15
6. Strategies to increase opportunity, choice and planning and transition for MND carers.....	25
7. Conclusion.....	28
8. References.....	29
Appendix 1	
Statement of Good Practice for the Management of ALS/MND.....	30
Appendix 2	
Avalanche – Our Journey with Motor Neurone Disease A talk given by Lisa Morgan at the National MND Conference for Health Professionals in Melbourne on June 24, 2008.....	31



1. Introduction

MND Associations in Australia were formed during the 1980's to meet the varying and complex support, equipment and information needs of people living with MND their carers and their families. MND Australia was established in 1991 as a national peak body for motor neurone disease (MND). In 2008 the MND Australia network comprises of six MND Associations, representing all states and territories, and the MND Research Institute of Australia (MNDRIA).

MND Australia members work together to advance, promote and influence local and national efforts to achieve the vision of a *World Free from the Impact of MND*.

Motor neurone disease is the name given to a group of rapidly progressive degenerative neurological diseases that cause increasing and complex levels of disability leading to death, usually within five years of diagnosis. The most common form of MND is amyotrophic lateral sclerosis (ALS). Currently around 1300 Australians are affected by MND and thousands more; family, friends and carers live daily with its effects. Each day at least one Australian dies of this cruel disease and a new person is diagnosed. Although MND was first described nearly 150 years ago there is still no known cause, no known cure and no effective treatment. Average life expectancy from diagnosis is about 27 months (Sach 2003). Average age of onset is 59 years (a very productive time of life); however, the age range of onset is 20 to 90 years.

The rapid progression of MND results in increasing support needs and reliance on a range of aids and equipment to maintain quality of life and social inclusion. Support needs can include assistance with: feeding, communication, breathing, movement, transferring, toileting and all daily activities. The social impact of MND is amplified by its complex nature, the speed of its progression and the spiraling series of losses, which pose:

1. huge problems of adjustment for people who have MND;
2. an escalating burden on carers and families; and
3. a challenge to health professionals involved in meeting the variable and complex care needs, particularly in regional, rural and remote areas of Australia.

2. Executive Summary

"It really did feel as though we had been picked up and dropped onto the top of a mountain and swept forward in an avalanche, unable to escape, not knowing how long it would last, but knowing how it would end." (Lisa Morgan, Appendix 2)

MND carers face a spiralling process of loss with consequent severe and traumatic impact on physical, emotional, psychosocial and financial well-being. Rapid progression and the high and complex care needs in MND are poorly met by existing statutory services. MND carers therefore play a significant role and contribution in assuming a very high and often unsustainable burden of care.

Currently in Australia there are a number of barriers within the health, community care and employment systems preventing optimal social and economic participation for carers which often impacts negatively on their long term emotional and physical health and well-being.

Barriers to social and economic participation for carers include:

1. The level and intensity of care
2. Waiting times for assessment and services
3. Inability to sustain employment
4. Complexity of service provision
5. Inequity of access to essential services including respite
6. Lack of awareness and understanding of best practice care in MND and in 'caring for carers'
7. Inequity in the capacity of state MND Associations for ongoing support and carer specific education and information
8. Failure to access aids and equipment in a timely manner including access to non invasive ventilation (NIV) equipment to support breathing
9. Lack of a meaningful level of reimbursement through private health funding.
10. Lack of awareness on the part of carers regarding the system of service provision including lack of knowledge of respite and its benefits
11. Inadequate awareness of MND within the general community
12. Inflexible and poorly defined workplace practices to support carer employment
13. Breakdown of carer confidence in re-engaging with the workforce



Key priorities for action:

1. A whole of government approach for provision of health and community care services
2. Establish best practice care pathways for MND
3. Ensure access to multidisciplinary care for all people with MND in Australia
4. Address medical, nursing allied health, palliative, aged and community care workforce issues
5. Provide effective case management of community services for all people with MND and their carers
6. Implement 'top-up' funding to address rapidly escalating levels of need
7. Provide adequate levels of flexible respite care
8. Address funding issues to facilitate equity of service provision from all MND Associations within Australia
9. Address specific needs of young and regional, rural and remote carers

Additional strategies to facilitate opportunities, choice and transition for carers include:

- Counselling
- Bereavement support
- Involvement in Advanced Care Planning
- Financial protection and assistance

The key priorities for action outlined in this submission provide practical measures to better support MND carers and carers of people with progressive disease and/or complex needs. The contribution of MND carers should be recognised by provision of equitable level of service from both statutory services and state based MND Associations that work in partnership to support specialised need in MND. This process can be facilitated by a national approach to care management and service and equipment provision. The establishment of Australian Standards of Care and Care Pathway for MND would enhance and streamline his process. Investigating current state based models of care and translating successful models nationally will help to improve the quality of life for MND carers in a cost- effective manner. In addition providing meaningful financial assistance and promoting flexible workplace practices will facilitate opportunities and choice for MND carers.

Inquiry into better support for carers
July 2008

3. The role and contribution of carers of people with MND

“The rapid nature of the debilitating effects of motor neurone disease means that the individual will need an increasing amount of personal assistance as the disease progresses. This task usually falls to a partner, close relative or friend.”

(Mockford et al, 2006).

MND carers are often inspirational in the levels of care they are able to sustain during their loved one's illness. They face a precipitous “learning curve” in undertaking and implementing new strategies to manage disability. Caring tasks are likely to include:

- transferring and repositioning the person with MND
 - This becomes more complex as the person with MND becomes increasingly disabled
- modifying food and fluids, feeding small, regular meals and undertaking alternative methods of feeding as swallowing deteriorates
- managing an increasing range of medical equipment to sustain homebased care and independence. This may include technology to support breathing
- learning and applying strategies to communicate including use of new technology as intelligibility of speech deteriorates
- striving to plan ahead to manage a situation of constant change and increasing need
- caring around the clock during the later stages of MND
- providing emotional support to the person with MND and other family members and friends as they confront multiple levels of loss.

The role and contribution of MND carers is immense and can have a traumatic impact on carers as they struggle to manage escalating levels of need.

“The months of Deb's illness were marked by a game of chasing our tails.”

“I was about to learn something that you know only too well: being a carer is very hard. Physically caring for Deb got hard very quickly. We had to learn new skills of



lifting, showering, dressing and feeding. We learned on the run, for virtually every day presented a new challenge.” (Armstrong D, The Accidental Carer)

The current capacity of statutory services to provide even basic support of this level of need is minimal. MND carers therefore carry a tremendous burden of care. The impact that caring has on the social, emotional, financial and physical well-being of carers in general has been well established. The extreme 'burden of care' required in supporting a loved one with MND is likely to result in particularly high levels of anxiety, uncertainty, stress, fear and fatigue for carers. The health of carers will suffer due to long hours of caring and the physical strain involved. The impact of managing in this situation has long term emotional, psychosocial and financial implications for the carer and family.

The role of carers in keeping people with MND out of residential care facilities must be acknowledged. Continued care within the home is the preferred option for the majority of people with MND. The alternative, residential care in an aged care facility, is a very poor option for people with MND. The complex physical needs of people with MND are poorly managed in these facilities. MND Associations receive constant feedback that staff / time ratios are inadequate to meet the needs of their residents with MND. Staff lack expertise in managing complex and high dependency needs. Difficulties in communication can exacerbate the frustrations experienced by both the MND resident and the staff. The majority of residents of aged care facilities have dementia. In this situation, feelings of vulnerability and frustration can be extreme for the intellectually capable but physically dependent resident with MND who struggles to communicate basic needs. Carers fear that their loved one will not be attended to adequately and staff consistently report their fear and lack of knowledge in how to care for a person with MND.

How should the role of MND carers be recognised?

“Yet “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. Here again I



support your inclusion of the emotional, physical and financial strains carers face in your explanation of what a carer is.” (Armstrong D),

It is a good investment and responsible health care spending to recognise the vital role of carers of people with MND and to provide adequate levels of financial support and service provision to sustain the primary carer in providing home-based care. This investment will provide further returns in minimising the risk of long term detrimental impact on carers.

To maintain family carers in their role it is important to acknowledge the burden of care for primary carer and the fact that MND is likely to progress rapidly. Consequently care needs will increase exponentially over time. The level of care involved in caring for someone with advanced MND is enormous and the provision of timely and responsive health and community services including a meaningful level of respite care is essential.

Optimal care provision will help sustain carers and avoid adverse outcomes including:

- costly emergency admission of the person with MND to acute care
- costly and inappropriate admission to residential care and
- long-term negative effects on the emotional, physical and financial well being of carers and their families.

“Carers may become ill themselves unless adequate support is given to them throughout the course of the disease.” (Mockford et al)

Ideally, adequate levels of service provision will enable carers to continue some level of involvement in the workplace for as long as possible. However employers will also need to recognise the role of carers and be supported to provide a flexible approach for carers in their workplace.

The provision of carer education which includes disease specific components will formally recognise the vital role of carers within the care provision network and will support home based care. Targeted carer information and peer support is also



imperative to recognise their specific needs to assist them to maintain their caring role.

The role and contribution of MND carers should be recognized in the following ways:

- Carer recognition, support and involvement should be included in the health planning process.
- The contribution of MND carers to the total health care management of the person with MND should be validated by increased funding and carer support structures including education and information to maintain the carer's own health, well being and capacity to sustain their vital role
- Ensuring that community care systems can respond to individual need in a timely and more comprehensive manner
- Educating health and community service providers to be inclusive of disease specific and carers' needs
- Improving financial support and protection for carers
- Promoting carers needs within the workplace; including flexibility of working hours and respite to facilitate continued employment

4. Barriers to social and economic participation for carers

1. The level and intensity of care

The major barrier to social and economic participation for carers is the level and intensity of care required to support their loved one with MND. As their level of disability progresses people with MND become increasingly vulnerable and dependent on their primary carer. Care becomes particularly intense during the night. This increased dependency limits time and energy for social and economic participation

2. Waiting times for assessment and services

The rate of progression and change in MND means that it is easy for people with MND and their carers to fall through the 'net' of service provision. The existing wait-time for assessment and acceptance for a basic level of service is insupportable in this situation. Carers often spend a lot of time and energy seeking services in addition to providing all the care themselves during the assessment and waiting period.

3. Inability to sustain employment

Escalating dependency needs of the person with MND typically result in the loss of employment for both the person with the disease and the partner/carers. Lack of availability of appropriate respite further compounds inability to maintain employment. This leads to financial and emotional distress and increasing social isolation for the carer and family.

4. Complexity of service provision

Care provision for people with MND crosses traditional departmental boundaries including; health, disability, aged, chronic disease and palliative care and involves a combination of local, non-government, state and federal funding bodies: it does not fit into a single established funding stream. People with rapidly progressive neurological disease and their carers struggle to navigate this complex system and are consequently one of the most 'under provided for' diagnostic groups within the current health system. Carers

consistently report to MND Associations that they become lost in the service provision maze.

This situation is exacerbated by:

- the current focus of service provision based on age rather than need i.e disability services for under 65 and Aged Care services for over 65
- the potential for responsibility, blame and cost shifting between state and federal providers and funding bodies and
- the lack of clear care planning and access to an overview of services available to provide care

5. Inequity of access to essential services

Goldstein et al (1998) reported that the satisfaction of MND carers with formal services and the number of social groups to which carers belonged correlated with carers' self predicted ability to cope in the future.

There is significant inconsistency and inequity in levels of care of people with MND and support for their carers across Australia. Some major metropolitan centres are able to achieve best practice, evidence based care of people with MND, whereas rural and remote areas often fall short of even basic levels of care provision. This is related to resources available including:

- Short-fall of professional workforce available on the ground throughout Australia including medical, nursing and allied health, aged, palliative care and community support service providers
- Inadequate funding for essential services including, packages of care, case management and respite

6. Lack of awareness and understanding of best practice care in MND and in 'caring for carers'.

The general knowledge and skill base of busy medical, nursing, allied health, aged, palliative care and community care providers may not extend to the needs of specialised diagnostic groups. In the case of MND health professionals and community care providers may have little experience or



understanding of MND and the impact of this disease on family carers and how to deliver care and support. This leads to potential barriers to social and economic participation for carers from the pre-diagnostic stage onwards. GPs may not be aware of the initial symptoms of MND which may delay referrals and consequently the diagnosis. MND Associations continue to receive reports regarding the way the diagnosis is given by the Neurologists who may not be expert in MND and have little understanding of the impact on the family of a diagnosis of MND. When families are told that there is nothing that can be done hope is dashed and this poses a huge barrier to accepting help and support in the future.

Lack of understanding of MND is particularly acute in rural and remote Australia compounding the barriers for carers living outside the major metropolitan centers.

In addition lack of availability of evidence based research to guide MND care management and support for carers further compounds this barrier.

7. Inequity in the capacity of state MND Associations

Where capacity allows, MND Associations, work in partnership with statutory services and provide five main family support services to meet identified needs:

- i. Information
- ii. Educational and support programs
- iii. Regional/Care Advisors
- iv. Aids and equipment
- v. Volunteers

The amount of support provided by MND Associations varies considerably with those states receiving recurrent state government funding i.e NSW (NT and ACT), Victoria and Western Australia providing a much higher level of family support than South Australia, Queensland and Tasmania who are not supported by their state governments. At present family support services in these three states cannot respond effectively to increasing demand and need.



Equity of access to services from MND Associations therefore remains inconsistent.

8. Failure to access aids and equipment in a timely manner

A range of specialised equipment is essential to assist carers in maintaining home based care. The more established MND Associations can supply most of their client's equipment needs free of charge. Equipment can sometimes be accessed through state and federally funded programs (eg HACC, palliative care, CAEP, PADP etc). However, equipment provision programs can vary within and between states. The application process is usually too slow to be of benefit to people whose level of disability can change quickly. Lack of the right equipment can also jeopardise carers' physical well being and restrict their eligibility to access vital services due to OH&S requirements. If equipment services fail to deliver people with MND may have to purchase their own equipment which has a profound financial impact on carers and families.

Access to non -invasive ventilation (NIV) equipment for respiratory support varies throughout Australia. MND clients and carers in Victoria receive a much higher level of support than other states from the Victorian Respiratory Support Service (VRSS) administered through the Austin Hospital. This service includes provision of NIV equipment free of charge and home visits by the respiratory team to monitor need and support the client and carer. If not subsidised by MND Associations (as is the case in NSW) the cost of NIV management can be prohibitive in other parts of Australia. Lack of availability of respiratory support services also leads to barriers related to referral from neurologists for respiratory assessment and support.

"This then brought us in contact with the Victorian Respiratory Support Team who over time provided us with a range of equipment and support. They were even able to grant us a wish by providing a portable battery powered BiPap that enabled Richard to leave the house and watch our youngest daughter transition from a three wheeler bike to a two wheeler. A very emotional moment on our family journey" Lisa Morgan (Appendix 2).

9. Lack of a meaningful level of reimbursement through private health funding.

Vital services required to support people with MND and their carers including allied health services, equipment provision including non invasive ventilation, palliative care, counselling and attendant care services receive negligible levels of reimbursement from private insurers.

10. Lack of awareness on the part of carers regarding the system of service provision

People with MND can deteriorate rapidly from being active, independent individuals to a level of dependence that they or their carer could never have anticipated. The speed of this process severely impairs the capacity to plan ahead and to link into services in a timely manner. There is often a failure to come to terms with and face the personal level of need. Barriers in this area include:

- i. feelings of failure and guilt for needing help in caring for partner/family member
- ii. difficulty navigating the health provision system
- iii. difficulty understanding the 'jargon' of service provision
- iv. Lack of knowledge of respite and its benefits

"We were asked to make decisions as to what list we wanted our names to wait on....how many hours we thought we would need... for what and why and what did any of this mean ? Nothing to us and we both found it incredibly difficult to get our heads around this new language, let alone apply it to ourselves." Lisa Morgan, (Appendix 2)

11. Inadequate awareness of MND within the general community

MND Associations are constantly engaged in raising community awareness of MND and of the extreme burden of care this entails. Despite this on-going focus MND carers continue to report feeling isolated and poorly understood by the community at large compounding their social isolation.

12. Inflexible and poorly defined workplace practices to support the carers continued employment

Employers are often unable or unwilling to provide flexible hours and working arrangements to maintain MND carers in the workplace for as long as possible. This can result in long term financial and emotional distress and social isolation for the carer. These impacts have potential long term negative effects on the emotional and financial well being of carers following bereavement.

13. Breakdown of carer confidence in re-engaging with the workforce

Many MND carers fall within the 50 – 60 age range. The impact of the caring experience can leave them feeling depleted in many areas including their capacity to resume employment. The fear of failing to regain employment is compounded by the current attitude of age discrimination within the workforce. This in turn can increase anxiety about long term financial distress.

5. Practical measures required to better support carers of people with MND

Key priorities for action:

1. A whole of government approach for provision of health and community care services
 2. Establish best practice care pathways for MND
 3. Ensure access to multidisciplinary care for all people with MND in Australia
 4. Address medical, nursing allied health, palliative and community care workforce issues
 5. Provide effective case management of community services for all people with MND and their carers
 6. Implement 'top-up' funding to address rapidly escalating levels of need
 7. Provide adequate levels of flexible respite care
 8. Address funding issues to facilitate equity of service provision from all MND Associations within Australia
 9. Address specific needs of young and regional, rural and remote carers
1. **A whole of government approach for the provision of health and community care services** is essential to provide equity of access to service provision for people with MND and their carers throughout Australia.

Reform of the health system to enhance access to essential services for people with MND and their carers must be focused on a needs-based, not aged based, model of service delivery. Service delivery should strive to meet each person's needs with the consideration of individual symptoms, perceived needs and rate of disease progression. Care required by individual MND clients and carers is not a fixed quantity, but differs for each person over time. It is important that the individual needs of carers and families receive a greater focus in the health reform process.

National consistency is also important in provision of NIV equipment and respiratory support. The VRSS scheme should be translated nationally so that all Australians with MND and their carers have equal access to this technology that can have



significant benefit on both quality and quantity of life. Home visits by the respiratory team can be very reassuring for the carer.

A national approach to MND management is important to avoid confusion, inequity of access and sometimes duplication of services.

2. Establish best practice care pathways for MND that reflects evidence-based, best practice care.

A national audit should be implemented to assist with the development of National Standards of Care in MND and to implement a national MND Care Pathway specific and relevant to the Australian context.

Healthcare and social research should be adequately supported, funded and implemented to provide evidence to guide practice for the multidisciplinary team into the future.

3. Ensure access to integrated multidisciplinary care

Best practice care to meet complex and changing need requires seamless, continuous and integrated service delivery from a number of health and community care providers across state, federal, and the non-government sectors. Care providers include medical, nursing, allied health, community care, aged, palliative care and MND Associations.

“Coordinated multidisciplinary care is the cornerstone of management and evidence supporting this approach, and for symptomatic treatment, is growing. Hospital based, community rehabilitation teams and palliative care teams can work effectively together, shifting emphasis and changing roles as the needs of the individuals affected by MND evolve. In the UK, MND care centres and regional networks of multidisciplinary teams are being established. Similar networks of MND centres exist in many other European countries and in North America.” (Leigh et al, 2003)

Traynor et al (2006) also describe the functions and benefits of multidisciplinary care in MND. Miller et al (1999) advocate early diagnosis from neurologist's expert in MND and regular reviews as does the International Alliance Statement of Good Practice for



the Management of ALS/MND (see Appendix 1). Increasingly in some capital cities in Australia people with MND are able to access neurology led MND clinics which are able to provide early diagnosis, expert management and ongoing review. Miller's (1999) evidence based review cites a number of papers that show that multidisciplinary clinics or models of care improve care management and may extend survival. MND specific clinics or models of care ensure effective communication and coordination. This in turn facilitates regular review of the changing needs of people with MND and their carers. The identification of a key worker to assist with care coordination and to liaise with the patient, carer and local care providers is integral to a multidisciplinary approach.

MND clinics currently in operation, apart from Calvary Health Care Bethlehem in Victoria, are not supported financially by the hospital in which they operate. The existence of these clinics relies solely on the goodwill and commitment of the specialists and allied health providers involved. Patient numbers have increased dramatically and the current clinics are unable to keep up with demand and their future operation is tenuous.

MND clinics need to be formalised within the healthcare system and networks of MND multidisciplinary teams encouraged and supported.

The Victorian state government is currently funding a project to review models of multidisciplinary MND care management. The outcomes of this project could be translated nationally.

4. Address health and community service workforce issues

Ready access to quality care that strives to deliver care according to individual needs and preferences cannot be achieved without developing and sustaining an appropriately remunerated and qualified workforce with access to professional development in specialised areas.

Workforce shortages are a key barrier to the provision of client and family-centred care. Shortages of appropriately qualified nursing, allied health, aged, palliative care



and community care professionals are associated with limited access to vital health and community care services in rural and remote Australia.

More emphasis should be given to MND specific information and education for care providers involved in the care of people with MND and their carers. MND Australia has recognised the need to seek funding to develop and establish easily accessible, online MND information for practitioners specifically for those in rural and remote areas and those who may not have encountered MND before.

5. Provision of effective case management of community services

As previously stated the provision of timely and responsive community services is vital to the physical emotional and financial well-being of MND carers.

The Home and Community Care Program (HACC) provides services for older people and people with disability and their carers. This program is jointly funded by the Australian government (60%) and state and territory governments (40%).

Historically, there have been difficulties for people with MND and their carers accessing community services in a timely manner. The assessment process for HACC services, including wait-time, fails to accommodate the situation of rapidly changing need.

MND carers are often too busy with 'hands-on' care to be able to investigate and source the services they need. A case management model for community service provision is essential to help carers access and obtain vital community support services. Where capacity allows state based MND Associations contribute towards the case management process. The Associations move in and out of lives of people with MND, while operating continuously in the background to ensure that the emerging needs of people with the disease, their carers and service providers are adequately identified assessed and addressed.

Effective and timely case management services to support the carer in providing home based care need to be available throughout Australia.



6. Implement 'top-up' funding to address rapidly changing/escalating need

The rate of progression of MND results in failure to access existing funding packages which require a lengthy assessment and wait-listing.

Dedicated funding to address rapidly changing needs and facilitate timely access to services must be considered. Existing models for targeted funding include dedicated funding packages for rapidly progressive diseases or 'top-up' funding to address timely access to existing services and high level need. Life expectancy in MND limits the length of time that individuals are likely to receive targeted funding, therefore funding packages have the potential to assist a number of individual clients within a relatively short time frame.

Initiatives in Victoria, NSW and Western Australia provide models incorporating case management and 'top-up' funding to allow rapid response and additional levels of service provision:

- In the recent Victorian state budget, funding was provided to implement some of the recommendations of The Motor Neurone Disease Pathway Project report to develop the key worker model within palliative care services and to provide top-up funding for palliative care services supporting people living with MND.
- The WA government disability department (DSC) has recently directed specific funding for progressive neurological diseases to provide equipment and extra services based on needs.
- Community Options NSW (COPS) has received funding from DADHC to pilot a project providing extra services to people with MND when their needs become more complex. COPS works in partnership with MNDNSW to identify people with MND who need extra services and to ensure a timely and coordinated response.

The number of initiatives involving 'top up' funding demonstrates the high level of need for this type of service and future MND carers will be negatively affected if these initiatives are not supported with recurrent funding.

7. Provision of adequate levels of respite care

Service provision for MND carers must include adequate levels of emergency and planned respite care from appropriately trained staff in a variety of locations. Timely respite at home is essential to enable carer wellbeing and continued participation in the community and in the workforce for as long as possible.

"For what turned out to be Richard's last ten days, we received funding from DHS for an overnight carer - the package that had been discussed with us so early on in our journey finally came to fruition. This carer was a young fellow, but with enormous compassion, kindness & respect and Richard trusted him to care for him competently over night, which meant I could get some sleep" Lisa Morgan (Appendix 2).

- **Overnight respite**

As MND progresses care is necessary around the clock and sleep deprivation becomes a major stressor for MND carers. It is extremely detrimental to the health of the carer and their ability to maintain home based care. Currently the cost of overnight respite precludes this option for most carers.

- **Respite within a facility**

Carers sometimes need to be able to take a complete break. Ideally, this should be introduced early and continue on a regular basis to sustain the carer. Care should be flexible and appropriate. Staff of the facility must be adequately trained and resourced to manage complex and high level need.

- **Holiday respite**

Holidays strengthen the family unit and allow continued community participation for the family.



- **Respite for education and support**

Education and support programs can be a great benefit for MND carers. However, they may be anxious about taking 'time-out' to attend education and support programs unless flexible and appropriate respite care is available.

A recent initiative in NSW is the flexible respite program - FlexiRest - which provides a model that has the potential to be translated nationally. MND NSW has established a consortium with Multiple Sclerosis Limited and the Muscular Dystrophy Association of NSW. This consortium has been successful in obtaining funding from DADHC to provide flexible and innovative respite options for people with these progressive neurological conditions to support the carers to maintain their caring role.

Investigating the potential to extend the FlexiRest concept nationally would provide a practical measure to support carers.

8. Equity in service provision from MND Associations

MND Association family support services work in partnership with statutory services to cost effectively supplement service provision in the areas of MND specific information and education, loan of specialised equipment, individual and groups support from professional staff experienced in MND.

Where capacity is adequate state based MND Associations provide important carer specific programs and services these include:

- **Information for carers**

Miller et al. (1999) confirm that people with their families need:

'printed information about the disease and the support available at diagnosis and MND specific information that is timed appropriately for decision making and delivered well in advance of major management crossroads'

The right information at the right time is essential to support MND carers and to empower them and the person with MND in decision making and planning ahead. The well resourced MND Associations are able to provide timely information and



support to MND carers. Non recurrent funding through NSW Health Care for Carers projects enabled MND NSW to develop a comprehensive information kit - The Carers Kit. This covers many aspects of caring for people with MND and is accessible to all MND carers in NSW.

- **Carer education**

MND Association family support services strive to supply a range of innovative and flexible education and support programs.

There is considerable evidence that educational support groups can improve carers' knowledge of the condition and competence in coping (ADD 1999). This is particularly true in the case of MND where rapid change and complex need leaves many carers unprepared and floundering. Preliminary studies presented by Adams et al. and Carroll et al. at the Eleventh International Symposium for ALS/MND, 2000, demonstrated the value of group support in mutual problem solving and sharing of issues and that care and training of the caregiver has a positive effect on keeping the person with MND in the community.

Carer education should include strategies to manage symptoms, the use of aids and equipment, familiarisation with service provision including respite care and dealing with the emotional aspects of caring. It should also include the personal safety of carers. Occupational health and safety training is mandatory for professional care staff. However, MND carers are usually required to use assistive devices to lift, transfer, reposition and feed the severely disabled care recipient without adequate preparation or training.

More established MND Associations are able to provide specific education and support programs for carers. This has often been achieved through specific seed funding to pilot and develop support models eg the Carer for Carers project funded through NSW Health. This model is currently being translated in Brisbane as part of the MND Australia Confident Caring Project funded through the Dept of Health and Ageing Local Palliative Care Grants Round 4, Transition to Home.



Funding should be available for all state Associations to adopt and modify these models and approaches to suit their own context.

- **Information and education of health and community care professionals regarding the needs of MND carers**

People with MND and their carers consistently report the need for care providers to have a greater understanding of this disease. MND Associations provide a range of information for professional care providers including bi-monthly special interest group e-bulletins.

Regional Advisors from the MND Associations play a vital role in providing education sessions/in-services for a range of health professionals, residential care staff and community care providers on MND and symptom management. The needs of MND carers are also highlighted through these sessions enhancing the advocacy role of the regional advisors.

- **Individual and group support**

The MND Association's family support model enables Regional/Care Advisors to assist the transition of people with MND to, from and through the service sector by providing, information, education, ongoing support, timely referrals. A large part of the Regional/Care Advisors' role is to support individual carers directly; to provide timely information and to talk through options, plans and decisions.

Once again, through state funding, some Associations have been able to establish a team of Regional/Care Advisors. By contrast the smaller states are not funded adequately to employ adequate staff for people with MND and their carers to achieve equity of access to this vital service.

MND Associations also strive to provide group support programs for both people with MND and their carers, either through face to face contact or by telephone link. Their capacity to achieve this again depends on their staffing levels and funding base.

- **Timely, access to specialised aids and equipment is essential to support carers and maintain on-going care within the home.**



As stated previously the better resourced MND Associations can supply most of their client's' equipment needs. The under resourced states should be funded to achieve national consistency, reliability and equity in the funding and provision of specialised equipment.

Equipment service reviews in NSW and Victoria by external consultants promote alternative models of equipment distribution to those currently in existence and cite the MND Association's equipment loan service as appropriate and efficient models. These could be used to establish a national model of equipment provision.

10. Address specific needs of young and regional, rural and remote carers

- **Special attention must be given to the needs of young carers**

Young and adolescent children may be involved in the care of a parent with MND either by assisting the carer parent or delivering care alone. The long term psychosocial well being of these young people need particular care and consideration. Appropriate and specialised services including respite and support to sustain education or employment must be provided. Young people must also be helped to develop resilience and continue other dimensions of their life including social and personal development.

A few specialised services and programs through the Carers Respite Centres are in place to support young carers which may provide models for national application.

- **Special focus on the needs of regional, rural and remote carers**

Workforce issues mean that most regional and remote areas have limited and inconsistent capacity to adequately manage MND clients. This situation could be addressed by creative programs using information and communication technology to deliver MND specific information and education and support. Using this technology, teams with proven expertise in managing MND could mentor remote service providers and MND Associations could deliver carer specific support.

6. Strategies to increase opportunity, choice and planning and transition for MND carers

Addressing the key priorities stated in this submission will help to preserve the wellness of MND carers and assist their transition back to community involvement and, where necessary, to resume employment.

Additional areas that will help to increase opportunity, choice and planning for carers and also support transition back into the community include:

Counselling

There is acute need for access to a meaningful level of counselling for MND carers and their families. Counselling by clinicians who have a real understanding of the situation is very difficult to source.

“observing and processing the degeneration in my beautiful husband, the disintegration of our family life, the reality of the disease and the speed at which it seemed to be progressing....”

“We saw a child psychologist very early on – who whilst extremely saddened by our story, was nonetheless very empowering, supportive & affirming of our decisions with our then 5 & 7 year old daughters.” Lisa Morgan (Appendix 2)

Counselling can help sustain the carer emotionally through a very challenging time and reduce the sense of isolation. Ideally, counselling should be available at the time of the diagnosis and at regular intervals throughout progression of the disease and into bereavement at minimal cost.

Bereavement support

MND carers have particular need of support during bereavement. They have lived in a ‘surreal’ world of striving to cope with a constantly changing reality. They have been totally focussed on caring and a new range of support people may have entered their lives, only to withdraw suddenly after the death of their loved one. The



experience of the 'void' of bereavement may seem overwhelming for a prolonged period of time.

"The results are revealing and somewhat surprising, and show lasting impact of the disease and ongoing need for information and involvement in ALS issues". (8.Martin and Turnbull)

MND Associations and palliative care teams may be well placed to provide a meaningful level of bereavement support. However, it is difficult for these organisations to extend beyond supporting families currently living with disease. Capacity and resource base are once again dependent on levels of funding.

MND Victoria has a four week established program of support for carers – the 'Living On' program which provides an established model of bereavement support that could be replicated in other states if funding were available.

Wherever capacity allows, MND Associations work with palliative care teams (including volunteers) to enhance bereavement support for MND carers. This could be generalised around Australia by application of the MND NSW Volunteer Visitor Program nationally. This program is currently being translated in Queensland as part of the Confident Caring Project.

Involvement in Advanced Care Planning

"It is essential that people living with ALS/MND are enabled to make informed decisions about living with ALS/MND so as to achieve quality of life, and dignity in living and dying. Adopting a proactive approach to disease management and respecting the needs and wishes of the individual and their caregivers is imperative."
(Appendix 1)

Establishing national standards for Advanced Care Planning and involving carers in this process will empower carers and reduce potential confusion and stress regarding the treatment wishes of the care recipient. Carers will be more protected emotionally and better able to plan ahead.

Financial support for carers

Inquiry into better support for carers
July 2008



The impact on carers of the depletion of the family fiscal resources during the care of people with MND must be reduced to assist the well being of carers and family living on after bereavement.

"The disease imposed lasting financial difficulties on many families, with 26% expressing moderate hardship and 22% severe or extreme hardship." (Martin and Turnbull, 2001)

Strategies to reduce the financial impact of caring include;

- meaningful financial support for carers during the time of caring
 - increase in Carers Allowance and the Carer Payment
- greater access to subsidies for home modifications
- reliability and equity in access to expensive specialised aids and equipment
 - including non invasive ventilation
- increased availability of financial advice/counselling
 - this must be free, independent and include budget development and superannuation
- increased assistance with transport costs nationally

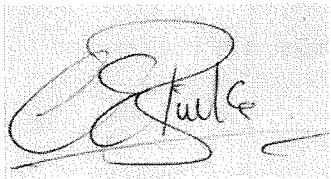
7. Conclusion

This submission has identified the specific role and contribution of MND carers in providing for and coping with the complex and intensive needs of people living with MND. The attached paper, written by a carer who recently travelled the MND journey, provides a personal perspective highlighting and confirming the issues raised in this submission. Existing barriers have been outlined and effective strategies to overcome them have been suggested, many of which were recommended in the Senate report following the recent CSTDA inquiry, or are already in place or being piloted in some states.

Considerable variation exists in the level of support that MND carers receive in Australia both through statutory services and through state based MND Associations which play a pivotal role in providing specialised support. There is growing evidence to demonstrate that inadequate levels of support will be detrimental to the long-term physical, emotional, psychosocial and financial well-being of carers. A whole of government approach and investment is vital if we are to overcome current inequities for all carers in Australia.

The current political climate offers an exciting opportunity to work towards achieving national consistency and equity of support for MND carers. Relatively small amounts of recurrent and seed funding would assist states to utilise and translate existing models of care to facilitate this process in a cost and time effective manner.

MND Australia would welcome the opportunity to provide further information and to participate in any public hearings.



Carol Birks

National Executive Director, MND Australia
Locked bag 5005, Gladesville, NSW 1675
carolb@mndaust.asn.au
www.mndaust.asn.au
Phone: 02 9816 5322 Mobile: 0408 416 932
Inquiry into better support for carers
July 2008



8. References

Adams RM, Tunna KH, Ellis J, Birmingham UK. Abstract from the Proceedings of the 11th International ALS/MND Symposium, 2000, Denmark

Ageing and Disability Department, work prepared by Barbara Murphy, Literature Review Relevant to Carer Framework, 1999

Armstrong David. *The Clare Stevenson Lecture*, Carers New South Wales, Sydney, November 28, 2002

Carroll-Thomas S, Cote-Grimes S, Litepo J, Payette L, Pepin P Ridgeway N. Ottawa, Rehabilitation Centre, Canada, *Caring for the Caregiver*, abstract from the Proceedings of the 11th International ALS/MND Symposium, 2000, Denmark

Goldstein LH, Adamson M Jeffrey L, Down K Barby T Wilson C and Leigh PN. *The psychological impact of MND on patients and carers*, Journal of Neurological Sciences. 160 Suppl 1: 1998, S114-21

Leigh et al. *The management of motor neurone disease*, Journal of Neurology and Neurosurgery Psychiatry, 74: 2003, iv32-iv47 Journal should be in full

Martin J and Turnbull J. *Lasting Impact in families after death from ALS*, ALS and other motor neurone disorders, 2, 2001, 181-187

Miller R.G. Rosenberg D.F. et al. *Practice Parameter: The care of the patient with amyotrophic lateral sclerosis (an evidence-based review): Report of the Quality Standards Subcommittee of the American Academy of Neurology*, Neurology, 52; 1999, 1311

Mockford C, Jenkinson C and Fitzpatrick R. *A Review: Carers MND and service provision*, Amyotrophic Lateral Sclerosis, 7: 2006, 132-141

Traynor B.J, Alexander M, Corr B, Frost E and Hardiman O. *Effect of a multidisciplinary amyotrophic lateral sclerosis (ALS) clinic on ALS survival: a population based study, 1996–2000*, Journal of Neurology Neurosurgery and Psychiatry, 2003;74:1258-1261



APPENDIX 1

THE INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS STATEMENT OF GOOD PRACTICE FOR THE MANAGEMENT OF ALS/ MND

Support and care management for people living with ALS/MND is underpinned by five basic principles:

- Management of the disease determined by the needs and wishes of the person living with ALS/MND, treating the person with ALS/MND with care, respect and dignity
Timely response to identified needs
- Access to a coordinated and integrated care plan
- Regular monitoring and review of the person's condition, and appropriateness of the care plan
- Information about the person's medical condition held in confidence

The International Alliance of ALS/MND Associations recommends the following good practice that will result in effective management of the diagnosis and care of people living with ALS/MND.

Before Diagnosis...

Early recognition of symptoms and access to a physician competent to diagnose complex neurological diseases

At Diagnosis...

Diagnosis given by a physician who is informed about ALS/MND, in a sensitive way appropriate to the person with ALS/MND and, in an appropriate setting with family and/or friend(s) present

Information provided in verbal and written forms about the disease, including its impact, sources of help and support, and referral to the ALS/MND Association as appropriate to the needs of the individual

Information sent to the patient's principal health practitioner about the disease, management implications, and the ALS/MND Association

The opportunity to return to the diagnosing physician for further information, care and follow up

After Diagnosis...

Access to:

- information and support services
- planning and coordination of support and care

These include:

- advice about personal care and equipment, clinical interventions, treatments and therapies, palliative care
- support for caregivers and families eg: respite care, bereavement support
- health and financial benefits
- research and clinical trials
- access to support from the ALS/MND Association

In summary, it is essential that people living with ALS/MND are enabled to make informed decisions about living with ALS/MND so as to achieve quality of life, and dignity in living and dying. Adopting a proactive approach to disease management and respecting the needs and wishes of the individual and their caregivers is imperative.

November 1999 © Revised: November 2007

Inquiry into better support for carers
July 2008



APPENDIX 2

Avalanche – our journey with Motor Neurone Disease

A talk given by Lisa Morgan at the MND Conference for Health Professionals in Melbourne on June 24, 2008

Hello, my name is Lisa Morgan. In June 2005 my husband Richard was diagnosed with MND and this is our story from the perspective of what worked for us, what didn't & what could help:

I am a fixer, a doer, an organiser, I sort things out, I make things happen ...

In my personal life, I am a wife, a mum, a sister, a daughter, a friend, a nurturer, a provider, a shelter.

In my working life, I am an Executive Assistant to a very senior Director. I am used to achieving positive outcomes & changing things for a result that is desirable.

With Richard's illness, we found ourselves in a totally foreign world – the medical world and the world of disability; but I was flexible, I was adaptable, I thought I would be able to get help and support and change the prognosis...

Motor Neurone Disease did not allow me to achieve a desirable result...

A brief snapshot of our journey:

In January 2005 my husband experienced an extremely sharp cramp whilst boogie boarding, he really thought he had torn a muscle, but there was nothing apparent the next day.

More changes occurred over the following months - muscle fasciculations, lethargy & energy loss. By May his gait was changing, energy levels dropping and we both became aware of 'foot drop' on the right side.

Our family GP referred him to a Neurologist who subsequently diagnosed Richard with MND.

By October he was using a motorised scooter outside the house and we had grab rails installed in the bathroom and a hand rail up two steps inside the house.

November saw Richard wearing an orthotic on his right leg and no longer able to drive. We also had our first visit to Bethlehem.

Inquiry into better support for carers
July 2008



February 2006 the bathroom was remodelled and we re-wrote our wills.

I moved into the spare room in March as Richard had ropes tied onto the bed to enable him to move around and change position.

On April 15 - Easter Sunday, whilst sitting on the toilet, Richard lost the remaining use of his legs & could no longer stand and his lungs & breathing were impacted. The Bethlehem Community Nurses started weekly visits, using the hoist & commode. At this stage Rich can still do a slide transfer to get on & off the scooter, couch, bed & shower chair, but I assist him on & off the toilet and I dress & undress him & help him dry himself after he showers.

In May, Richard's sister & family sold their home in the outer eastern suburbs and moved to the other side of town, a few minutes away from us.

Our friends & local community held a Benefit night for us.

Mid June, Richard & I did an interview for ABC Radio Victoria that was later replayed across Australia. At the end of June Richard nearly died at home and was admitted to intensive care under a respiratory specialist and returned home 5 days later, with a BiPap machine.

Richard suffered successive bouts of pleurisy and in September, the funeral director visited and the Mercy Western Palliative Care nurses replaced the Bethlehem Community nurses.

November 7 was Richard's last trip out in the car.

Mid December my beautiful sister arrived from Qld to stay for as long as needed.

On Monday December 18, his best friend visited from Sydney and together they held hands and watched Australia bring the Ashes home.

On Tuesday 19, Richard's lungs were suctioned (at home) by an intensive care nurse and the respiratory specialist with me and his sister assisting.

And on Saturday 23 December 2006 at 1245am, less than 2 years after diagnosis, with me and his sister by his side and our daughters asleep across the hall, Richard's heart stopped beating and his life on this earth was over.

It really did feel as though we had been picked up and dropped onto the top of a mountain and swept forward in an avalanche, unable to escape, not knowing how long it would last, but knowing how it would end.

The Emotional impact:

MND is a journey of milestones, going in the wrong direction.

Inquiry into better support for carers
July 2008



Mentally the journey was very tough – I knew the night Richard was diagnosed that he would die of the disease, but I had to think positive, act positive - for him, for our children and for me. My mind was in a surreal state – I had two realities, on the one hand – hope, wanting to believe and needing to believe that Richard would get better, recover, regain his life and that our life as a family unit and as a couple would go on...

And on the other hand, observing and processing the degeneration in my beautiful husband, the disintegration of our family life, the reality of the disease and the speed at which it seemed to be progressing....

Even from the night of diagnosis, our aim was to stay in the present, to stay in today, which was the best place to be. We were still all together in the present.... Despite that, I'm a planner and I need to know what is required for a given situation. But during the early months on the journey, it was pretty hard to be pro-active and to prepare for the unknown. It was only once we were along the road and Richard had lost so many of his abilities and we had lost so much of our life as we knew it, that we were able to accept that he was not going to be the miracle survivor and that emotion had now only a hidden place on our journey. It had become all about conserving his energy and finding tools and people to help us achieve what we wanted – for Richard to spend his remaining life at home, in as much comfort as possible.

A second neurologist had told us about Bethlehem Hospital, but we didn't want to contact them because we certainly didn't want to see people who were further along on their MND journey – and we wouldn't need them anyway, because Richard's disease was going to arrest!! We were also told about the Motor Neurone Disease Association, but that didn't sound appealing either...however the disease had other ideas and its progress made me pick up the phone and ring MND AV several months later.

Late April 2006 the Bethlehem Community nurses started to visit on a weekly basis – even though we were not in their zone – they knew the need was there and found a



way to accommodate that need. It allowed me to continue to work one day a week and receive some much needed respite, for which I was very grateful.

But it was actually with great sadness that I welcomed the nurses into our home. Not only did it force the issue of using the hoist and the commode – more independence lost, another milestone reached – it meant another separation between Richard and I; a stranger caring for him now as well as me.

I had had to move out of our bed into the spare room a month earlier - Stealthily the disease kept forcing us apart.

It was very challenging become 'public property' because often in these situations, people want to help, but in some cases it can be solely for their benefit, not ours... With one person, there were times when we actually had to turn our lights off & not answer the door or the telephone so numerous were the phone calls, text messages & surprise home visits! The intention of these visits was not only to dig into our lives, both past & present, but also to be the 'owner & conveyor" of the news on Richard's current state of health.

Managing that aspect of our journey was very challenging for me as we were a very private and basically shy couple, but it got to the point where our privacy took priority over so called 'assistance' & I had to replace our personal boundaries & remove these people from our lives.

The tricky stuff:

Late Friday afternoon of the Queens Birthday weekend – 10th of June 2005, Richard was under the care of a neurologist we had met only once before a couple of days previously. His original diagnosis was 97% certain it was a rare muscle fasciculation syndrome, treatable with medication, but to make sure Richard was to go for nerve conduction testing...

It turned out to be the short straw, the 3% and the way that diagnosis was delivered to us was left wanting, to put it mildly. It seemed that that medico had made no preparation for the delivery of a possible worst case scenario – that Richard's life expectancy was now reduced to 1 to 3 years. The neuro was shocked but he showed us no kindness, no empathy, gave us no comfort, no hope.



I pulled myself together & said we needed to speak to a counsellor because I knew I needed professional support in order to best help my family, but was told we would discuss that the following Tuesday when we saw him in his rooms.. (the unspoken words were that we were to get through that long weekend as best we could) Also during that time, a nurse and an electrician entered the room several times... as jobs needed to be completed & they wanted us out of that room...

Where was the humanity... where was the compassion... the need for privacy...the fact that fellow human beings lives as they knew them were shattering around them...

We were then shown to the lift!

It was the blackest night of our lives and if you were a single person who lived on your own, you may well have ended your life that night.

The trauma and shock at both the diagnosis and the delivery impacted both emotionally and physically and it would be weeks before Richard noted on the calendar – 'first good day.'

Was that doctor true to his Hippocratic oath – Do No harm... I think not; was he even aware of going against that oath...I think not...

Fast forward 12 months to when our radio i/v went to air and the talkback response was overwhelming. Far too many people had received the diagnosis of their own or a family member's terminal illness in much the same clinical, blunt, thoughtless way and in fact, the following day when the Head of the AMA was talking to the radio interviewer, he admitted something along the lines of 'in today's medical training, the 'delivery of diagnosis component' has been replaced by litigation training'. What a sad indictment of our society. ...

A fellow I'm in phone contact with, who sadly, is travelling the same speedy journey as Richard, told me that he saw 12 – twelve !!!!! neuros....before he was diagnosed, and not one of them mentioned MND AV or Bethlehem hospital. He found out about



both by trawling the internet, hoping to find some help out there. Can you believe that

It seemed to us that the neuro we saw got swept away by his own feelings and put himself first, something that we were astounded to experience a few times on our journey.

The psychologist we saw soon after diagnosis, quickly told Richard not to expect that he could really help him....so Rich never went back again!

And the impact of that statement was momentous on Richard & on me. Rich then became incredibly wary of seeking professional psychological help – in fact he never did again & that left me as the key person supporting him emotionally & I know we both would have really benefited from that type of assistance..

In another instance a pastoral care worker spent most of his several visits with us dissecting & discussing his own life.

We had our first visit to Bethlehem at the end of November 2005 and that was very scary. We had to enter through the Neurological Day Clinic and were very shocked to see people in varying stages of ability & disability. It was like having a curtain flung open to the future. I remember wheeling Richard through the room in the manual wheelchair muttering, "Don't look darling, don't look" trying to protect him from what lay ahead. That took an enormous toll – mentally and physically and we didn't find out until many visits later that the majority of the people in that room were living with neurological diseases other than MND.

You may think we were naive not to realise that straight away, but we were just too overwhelmed to think straight.

During one visit, Richard was helped into a powered wheel chair and shown how to use it. I think it was brand new, comfortable and certainly easy to manipulate and manoeuvre, but he said to me on the way home, he wouldn't be needing that, would surely have no use for it.



Some time later, it arrived at our home by taxi and we were absolutely devastated. Here was the horrific confirmation of the progression of the disease. We could certainly understand the professional perspective – “we have got a good wheel chair for you, it will enable your independence and mobility”, etc etc... but we felt like we had had no mental preparation for this moment. It was such a confirmation of the degeneration of Richard’s body and the unrelenting progression of the disease. But we weren’t ready for that. We still had hope that his journey would be arrested.

It took Richard many weeks before he grudgingly started to use that wheel chair and of course it did provide all the things that the professionals knew it would – comfort, independence, mobility....

I don’t know how you get around that combination of mental acceptance but loss of hope, but some form of preparation would be good

Late in our journey – October 2006 I think, Richard was almost totally quadriplegic but had a tiny bit of movement left in his right thumb and was ok-ish from his neck up. He could speak through his respiratory aids but not with any power.

We had a huge problem that seemed insurmountable. Richard could press the big buzzer that MND AV had supplied if it was placed under his thumb; but that didn’t work through the night, if his hand moved even a fraction. I was pinning his pyjama sleeve to his top & pinning the buzzer there as well, but there were several horrific times when I woke - in the spare room, to hear Richard - through the baby monitor, calling me to help him & he had been calling like that for over an hour – because his hand had slipped fractionally but enough not to be able to reach the buzzer - *I can still hear his voice.*

Comm Tech then became involved & brought along a ‘head buzzer’ which solved the problem, though I still had to place that in exactly the right position...

And our Regional Advisor had pursued DHS to meet with us, which eventuated close to the end of our journey. As the young woman repeatedly asked us ‘what our goals were’ and ‘what time frame we wanted to set them to’, it was unbelievable, she had absolutely no idea, no understanding of what the illness was about & what we were living with & Richard was so obviously closing in on the end of his life. Incredibly

Inquiry into better support for carers
July 2008



frustrating to us and our Regional Advisor and it felt like such a waste of our precious time.

And I then had to spend a lot of energy chasing DHS (as did others on our behalf) to ensure we received the services that had been agreed to in the time Richard had left – and sadly they only pulled their finger out when my radio colleague rang them offering to do an interview on the general delay in providing disability services. DHS was very cross with us about that, but it spurred them on. What do people do who have no contacts, no courage to speak up or just don't have the language skills?

The good stuff:

The morning after the diagnosis I spoke to a friend who happens to be a neurologist & he gave us some comfort, support, some medication and a small hope. He spoke to us, to Richard, as a human being - Was any of that too much to ask ?

Our family GP was an absolute champion – he always made room for us, in his surgery and with home visits; and after Richard died he made sure I saw a grief councillor and has remained very considerate and caring.

We saw a child psychologist very early on – who whilst extremely saddened by our story, was nonetheless very empowering, supportive & affirming of our decisions with our then 5 & 7 year old daughters.

The people who work at MNDVic were incredibly kind and thoughtful and not at all put off by my prickly attitude in my early contact with them. They just kept being pro-active and thoughtful and caring and kind.

When we went to Bethlehem we met with many wonderful people who treated both of us with great respect and kindness, who were pro-active and compassionate, who made us feel safe in their care.

(And over the next months as we got to know one another, we developed relationships with some and realised others were more interested in the guinea pig side of things, charting the degeneration in the name of research which is fair enough, it must be done.)



And the Bethlehem Music Therapist commenced fortnightly visits with our girls, even though our suburb was out of the zone. This was organised by the OT at Bethlehem, it's an absolutely fantastic resource and really helped our girls on their journey.

June 2006 was a big month. We met our new MNDA Regional Advisor and learned how beautiful a human dynamo can be and also the Respiratory Specialist (who had come into our lives through someone hearing our radio i/v), was one of the most remarkable human beings I expect I shall ever meet - the antithesis of the original neurologist. Maybe we had to experience one to be blessed with the other...

This then brought us in contact with the Victorian Respiratory Support Team who over time provided us with a range of equipment and support. They were even able to grant us a wish by providing a portable battery powered BiPap that enabled Richard to leave the house and watch our youngest daughter transition from a three wheeler bike to a two wheeler. A very emotional moment on our family journey.

Our local council was very helpful and the Council Personal Carer gradually won over Richard's trust and respect. He was a very caring and funny fellow, again, it meant another person in our lives who came between us but we couldn't achieve our goal of Richard remaining at home without outside assistance and that was the pay-off.

The Mercy Western Palliative Care nurses replaced the Bethlehem nurses and again, we were shown the diamonds in humanity.

Whilst this was extremely scary for Richard and he railed against their involvement, the support, kindness, friendship & respect that was shown to both of us was nothing short of a life line.

I had many conversations with them including what to do when Richard died, what was required, what was allowed & most gratefully, this gave me time to plan, to mentally prepare and to broach it with Richard & we were able to make some decisions together.



For what turned out to be Richard's last ten days, we received funding from DHS for an overnight carer - the package that had been discussed with us so early on in our journey finally came to fruition. This carer was a young fellow, but with enormous compassion, kindness & respect and Richard trusted him to care for him competently over night, which meant I could get some sleep.

My Suggestions:

When we returned to see the original neuro, we got the referral for a second opinion, left & never saw him again. But we did give him feedback while we there – we told him, politely, what we thought of his delivery of the diagnosis & how he could have done it differently! He wore it!

Would it have been so difficult for him to have said that he needed to check further into the results of the tests & that we would get together the following Tuesday...? Isn't it well known that you don't deliver bad news on a Friday afternoon..?

It seems to me that what is sorely missing from the medical profession is acknowledgement that they do not necessarily have the communication skills required, to deliver tough news in a compassionate and caring way. I believe a package of material should be made available to all health professionals in preparation for those conversations – a package that not only gives them advice on how best to deliver the information, but that also contains names & numbers of people & organisations who can help, so that the families aren't left stunned, shocked & floundering, not knowing who or where to turn to. As well as having that package available the health professional must have the desire and willingness to use it, to hand it over, to know that they may not have the people skills to handle this situation in the best possible way & that they too may not know what to do next.

A point about jargon - the first conversation with our then Regional Advisor was conducted in a language unknown to us – containing phrases such as: "You'll need to go on the waiting list for a package" & "case manager, who accesses services and brokers funding" & "DHS Support & Choice package' offers between 3 & 12 hours per week"



We were asked to make decisions as to what list we wanted our names to wait on...how many hours we thought we would need... for what and why and what did any of this mean ? Nothing to us and we both found it incredibly difficult to get our heads around this new language, let alone apply it to ourselves.

(Most fortunately, both our immediate families had lived in great health & we'd no experience of disability services and to be thrust into the world of 'available services & support' was tricky in so many ways).

Firstly, we couldn't accept that we would have any need to access these supports as Richard was going to get better

And therefore, we had no understanding that we would most certainly need them

By putting Richard's name down, surely we were depriving those who were genuinely needy..

It has a language all of its own, which we struggled to decipher

It runs to its own time frame, which is slow, slow, slow

The bureaucracy and systems are daunting

I don't know how because, quite rightly, we have privacy regulations in place, but I believe that the diagnosing specialist should be allowed to give your name to the Motor Neurone Disease Association and to Bethlehem. You'll then be in their field of vision right away. And even if it is only the carer who initially receives the support, that's certainly extremely worthwhile.

Another point I want to make here is to do with the provision of equipment, such as the portable battery powered BiPap . Whilst the Vic Respiratory Support Team had the equipment and happily provided it, it actually came down to me asking the right question to get the right result.



(I'd left a very emotional message for the physio asking if there was such a thing as a battery powered breathing machine. . they then made phone calls and magic!
...There it was and home delivered too.)

The same thing with the hand buzzer needing to be replaced by the head buzzer....
We didn't know such an aid existed...

Is there such a thing as a communal list of resources provided by various services & bodies that shares the knowledge of who has what & what it does...? And can this be provided not only to MND AV, Bethlehem, Vic Respiratory Services, Comm Tech, etc, but also to the families so that they know what's available, who to ask and what to ask for.

I spent too many highly anxious hours brainstorming for solutions and if very early on in the journey I was pointed to this list, it would have given me great comfort to know that down the track I could access this or that or the other. That solutions were already out there and available for borrow or hire or even to buy. And that I didn't have to try & come up with the ideas myself..

Where we are now:

The girls and I do our best to stay in the present, to stay in today and to live life.
(We're doing OK). Ways of breaking bad news and the impact on the family -Be honest, don't be cruel, but be brave and speak frankly and compassionately (at least to the carer)

Implement automatic referral from neuro to MND AV & Bethlehem
Health Professionals and Government Agencies should NOT assume that the families understand the jargon OR know what equipment and resources are available anywhere – remember to treat us as beginners, put yourselves in our shoes & ask yourselves the questions “Do I know what this jargon means, what will help me to work around this particular challenge”

Children – speaking only for myself, we were honest with our daughters, but never brutally and always left them with hope.

Know that you are the diamonds in humanity

Lisa Morgan – June 2008

Inquiry into better support for carers
July 2008