Multidisciplinary Care – The Evidence:

Mitchell and others 2008 Multidisciplinary care planning and teamwork in primary care:
Multidisciplinary care occurs when professionals from a range of disciplines work together to deliver comprehensive care that addresses as many of the patient’s health and other needs as possible. This can be delivered by a range of professionals functioning as a team under one organisational umbrella or by professionals from a range of organisations, including private practice, brought together as a unique team. As a patient’s condition changes over time, the composition of the team may change to reflect the changing clinical and psychosocial needs of the patient. From the individual patient’s point of view, this distinction is not critical — patients “see” care delivered in similar aliquots, and by a similar range of disciplines.

Miller and others 2009 Practice parameter update: The care of the patient with amyotrophic lateral sclerosis: drug, nutritional, and respiratory therapies:
Conclusions
Two Class II studies and 1 Class III study show that multidisciplinary clinics specializing in ALS care are probably effective in several ways: increased use of adaptive equipment; increased utilization of riluzole, PEG, and NIV; improved quality of life; and lengthened survival. However, 1 Class II study with low use of treatments found no survival benefit.

Recommendations
Specialized multidisciplinary clinic referral should be considered for patients with ALS to optimize health care delivery (Level B) and prolong survival (Level B), and may be considered to enhance quality of life (Level C).

Ng and others 2009 Multidisciplinary care for adults with amyotrophic lateral sclerosis or motor neuron disease
This review did not find any high quality randomised controlled trials that examined the effectiveness of such multidisciplinary care. The evidence from low quality studies suggests that such care may improve some aspects of quality of life, reduce the frequency of hospitalisation and hospital length of stay and improve disability in persons with ALS or MND. The evidence for multidisciplinary care on survival is conflicting. The gap in current research should not be interpreted as proof that multidisciplinary care is ineffective. Further research into types of appropriate studies, caregiver needs and various aspects of multidisciplinary care in the MND population is needed.

Implications for practice
In the absence of randomised controlled trials or controlled clinical trials, the 'best' evidence to date, based on five observational studies, supports the current European Federation of Neurological Societies (EFNS) (Anderson 2005) and the British Society of Rehabilitation Medicine (BSRM) guidelines and standards (RCP 2008) for multidisciplinary care in MND or ALS.

The absence of proof that multidisciplinary care is effective must not be interpreted as proof that this approach is ineffective. There are multiple, well-defined interventions, such as nutritional support and respiratory support, and interventions by physical, occupational and speech therapists which have individually had significant impact on disease course. The gap in available trial data showing efficacy when offered simultaneously in a multidisciplinary setting should not at all implicate therapeutic nihilism in the treatment of ALS/MND.

Leigh and others: the management of motor neurone disease, J Neurol Neurosurg Psychiatry.2003; 74: iv32-iv47:
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.
1 PURPOSE

To:
• provide a brief history of the development of MND Models of Care in Australia
• outline the role of MND Multidisciplinary Clinics and Services within the wider context of service delivery for people living with MND
• outline a strategy for establishing a MND specific service
• provide background information on MND Multidisciplinary Clinics internationally

2 BACKGROUND

The MND Association of NSW Needs Survey conducted in 1997 and the MND Victoria Sach Reports 2000 and 2003 highlighted the specific needs of people living with MND and their family carers in Australia. In particular they highlighted that access to coordinated multidisciplinary care and support from health and community care providers who understand MND and MND care management is a priority.

The promotion of best practice care and support from diagnosis onwards has been a priority for the MND Association’s in Australia since they were established during the 1980’s. The overall aim is to enhance quality of care for people living with MND through:

• facilitating access to needs based multi/inter disciplinary care for people living with MND in their own locality
• increasing and improving access to best practice and evidence based MND information for health and community care providers
• encouraging the development of MND specific models of care as centres of expertise in the management of MND

Promotion of coordinated multi/inter disciplinary care management for people living with MND since 1998, has encouraged a number of health professionals with an interest in MND to establish MND specific models of care within their existing health systems. MND Services and MND clinics in Australia all differ but most bring together neurologists and palliative, rehabilitation, primary, aged and community care professionals to ensure a coordinated seamless interdisciplinary approach to care for people living with MND.

3 OVERVIEW OF SERVICES AND CLINICS IN AUSTRALIA

In NSW:

MND services:

<table>
<thead>
<tr>
<th>Name of service</th>
<th>Region</th>
<th>Year established</th>
<th>Lead professional</th>
<th>Team</th>
<th>Funding</th>
<th>Model</th>
<th>Date service ceased</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hornsby/ Neringah Hospitals MND Program</td>
<td>Northern Sydney</td>
<td>1997</td>
<td>Dr Phillip Funnell, Rehabilitation Specialist</td>
<td>Palliative/ Rehab/ community</td>
<td>Not specifically funded</td>
<td>Bi- Monthly team meeting/case conference to coordinate care – MNDNSW RA included</td>
<td>2004</td>
</tr>
<tr>
<td>Port Kembla Hospital MND program</td>
<td>Wollongong/Illawarra</td>
<td>2001</td>
<td>Established by Lesley Brennan, Nurse Consultant</td>
<td>Rehab/ community</td>
<td>Not specifically funded</td>
<td>Bi - Monthly team meeting/case conference to coordinate care – MNDNSW RA included</td>
<td></td>
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</tbody>
</table>
# MND Australia

<table>
<thead>
<tr>
<th>Name of Service</th>
<th>Region</th>
<th>Year Established</th>
<th>Lead by</th>
<th>Team</th>
<th>Funding</th>
<th>Model</th>
<th>Date ceased</th>
</tr>
</thead>
<tbody>
<tr>
<td>Calvary/St George Hospitals MND Service</td>
<td>Southern Sydney</td>
<td>2001</td>
<td>Established by Dr Helen Herz, Palliative care physician</td>
<td>Palliative/ community</td>
<td>Calvary Healthcare and MND NSW</td>
<td>• dedicated funded nurse coordinator – two days a week • formal link to neurologist • MND NSW RA attends each meeting</td>
<td></td>
</tr>
<tr>
<td>Sacred Heart Hospice MND Service</td>
<td>Eastern Sydney</td>
<td>2003</td>
<td>Established by Dr Phil McAuley Palliative care physician</td>
<td>Palliative/ community</td>
<td>Not specifically funded</td>
<td>• Case conference/team meeting every 6 weeks • MND NSW RA attends • Coordinated by Calvary St George MND service nurse coordinator</td>
<td></td>
</tr>
<tr>
<td>Clare Holland House</td>
<td>ACT</td>
<td>2004</td>
<td>Established by Dr Margherita Nicoletti, Palliative Care Physician Now Andrew Skeels Palliative Care Physician</td>
<td>Palliative/ rehab/ community</td>
<td>Not specifically funded</td>
<td>Case Conference/team meeting Bi- monthly with MND NSW RA Currently developing a clinic model</td>
<td></td>
</tr>
<tr>
<td>Community Outreach Team (CORTS)</td>
<td>Central Coast</td>
<td>2004</td>
<td>for people with neurologic conditions including MND</td>
<td>HACC</td>
<td></td>
<td>Case conference/team meeting every 3 months – MND NSW RA attends</td>
<td></td>
</tr>
<tr>
<td>Camden Community</td>
<td>South West Sydney</td>
<td>Established 2005 to 2006 Re-established 2010</td>
<td>Community team</td>
<td>Rehab/ community</td>
<td>Not specifically funded</td>
<td>• Case conference/team meeting every 6 weeks • MND NSW RA attends</td>
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</tbody>
</table>

### MND Multidisciplinary Clinics:

<table>
<thead>
<tr>
<th>Name of Clinic</th>
<th>Region</th>
<th>Year established</th>
<th>Lead by</th>
<th>Team</th>
<th>Funding</th>
<th>Model</th>
<th>Date ceased</th>
</tr>
</thead>
<tbody>
<tr>
<td>RNS Hospital MND Multidisciplinary Clinic</td>
<td>Northern Sydney and Central Coast Area Health Service</td>
<td>1999</td>
<td>Professor Dominic Rowe, Neurologist</td>
<td>RNSH employed specialists, allied health, respiratory, rehabilitation professionals</td>
<td>Co-ordinator position only: Neurology Depart. capital research funds, fundraising</td>
<td>• Dedicated nurse coordinator – full time • Monthly clinic and case conference • formal link to palliative</td>
<td>2009</td>
</tr>
<tr>
<td>Hospital Name</td>
<td>Location</td>
<td>Year</td>
<td>Lead Neurologist</td>
<td>MND NSW Responsibilities</td>
<td>MND NSW RA Responsibilities</td>
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<tr>
<td>Prince of Wales Hospital</td>
<td>Southern Sydney and the Illawarra Health Service</td>
<td>2002</td>
<td>Professor Matthew Kiernan, Neurologist</td>
<td>POWH employed specialists, allied health, respiratory, rehabilitation professionals</td>
<td>Co-ordinator position only: Neurology Depart. capital research funds, fundraising and MND NSW.</td>
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<td></td>
<td></td>
<td></td>
<td>• Dedicated nurse coordinator – 3 days</td>
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<td></td>
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<td></td>
<td></td>
<td>• Monthly clinic and case conference</td>
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<td></td>
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<td></td>
<td></td>
<td>• Formal link to palliative care</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• MNDNSW RA</td>
<td></td>
<td></td>
</tr>
<tr>
<td>St Josephs, Auburn, Sydney</td>
<td>Western Sydney Area Health Service</td>
<td>2004</td>
<td>Dr Steve Vucic, Neurologist</td>
<td>St Josephs Hospital employed allied health, respiratory, rehabilitation professionals</td>
<td>Co-ordinator position only: MND NSW</td>
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<td></td>
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<td></td>
<td></td>
<td>• Dedicated coordinator (Speech pathologist)– 2 to 3 days</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td>• Monthly clinic and case conference</td>
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<td></td>
<td></td>
<td></td>
<td>• Formal link to palliative care</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• MNDNSW RA</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Macquarie Neurol Multidisciplinary MND Service</td>
<td>Macquarie Private Hospital</td>
<td>2011</td>
<td>Professor Dominic Rowe, Neurologist</td>
<td>Neurology, respiratory, nursing, physiotherapy, dietitian, speech therapy, social work, orthotics, and occupational therapy.</td>
<td>MND NSW provides partial funding for the MND nurse coordinator also generously supported by donations</td>
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<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>• Dedicated nurse coordinator</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• MNDNSW RA</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Bi-monthly clinic</td>
<td></td>
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</tr>
</tbody>
</table>
**MND Australia**

**In Victoria:**

<table>
<thead>
<tr>
<th>Name of Clinic</th>
<th>Region</th>
<th>Year established</th>
<th>Lead professional</th>
<th>Team</th>
<th>Funding</th>
<th>Model</th>
<th>Date service ceased</th>
</tr>
</thead>
</table>
| **Calvary Health Care Bethlehem** | Caulfield    | Early 1990s      | Dr Susan Mathers, Neurologist | CHCB allied health, respiratory, rehabilitation professionals MNDV RA | CHCB         | • Dedicated nurse coordinator  
• clinic three days per week  
• case conference three days per week  
• formal link to palliative care  
• MNDVic RA                      |                     |
| **Bundoora Extended Care**  | Bundoora     | About 6 years ago | Dr Jim Howe, neurologist    | CHCB neurologist, CHCB clinical nurse consultant, BEC allied health MNDV RA | Staff time by CHCB | • Dedicated nurse coordinator  
• clinic monthly  
• case conference prior to clinic |                     |

**Palliative Care and MND Victoria - shared care workers**

The Motor Neurone Disease Pathway Project - The Department of Human Services (DHS) in Victoria funded a six month project to establish a pathway using the best available evidence to identify criteria that trigger a referral to specialist palliative care for a person with Motor Neurone Disease (MND). The report (see link below) recommends that a document should be developed and piloted to provide health professionals with the range of needs and providers for people with MND to assist them to access palliative care and community services. It recommends that a key worker model be developed for people with MND when referred to palliative care and that a comprehensive education program be developed for palliative care staff involved in caring for people with MND. The report recognizes the need for guidelines and supplementary funding for people with MND with high care needs. It recognizes the need for timely and appropriate respite and after hours support. In the recent State Budget, funding was provided to implement the key worker model and to support top-up funding for palliative care services supporting people living with MND.

*Motor Neurone Disease and palliative care - Interim report on the MND Pathway Project - April 2008 (PDF File 505kb)*

**In Queensland:**

<table>
<thead>
<tr>
<th>Name of Clinic</th>
<th>Region</th>
<th>Year established</th>
<th>Lead professional</th>
<th>Team</th>
<th>Funding</th>
<th>Model</th>
<th>Date service ceased</th>
</tr>
</thead>
</table>
| **Royal Brisbane and Women’s Hospital MND Clinic** | Brisbane    | 2004             | Dr Robert Henderson, Neurologist | RBWH allied health, respiratory, rehabilitation professionals | Co-ordinator position only: Neurology Depart. capital research funds, fundraising, HACC | • Dedicated nurse coordinator – full time  
• Clinic and case conference 2nd and 4th Friday of the month  
• formal link to palliative care Links with The Prince Charles Hospital: |                     |
## MND Australia

<table>
<thead>
<tr>
<th>Name of Clinic</th>
<th>Region</th>
<th>Year established</th>
<th>Lead professional</th>
<th>Team</th>
<th>Funding</th>
<th>Model</th>
<th>Date service ceased</th>
</tr>
</thead>
<tbody>
<tr>
<td>MND Clinic Fremantle Hospital</td>
<td>Perth Metro</td>
<td>2009</td>
<td>Neurologist</td>
<td>Neuro nurse MND Care Advisor</td>
<td>Link to hospital services and local allied health thro’ referrals from Neuro, nurse and MNDWA CA</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MND Clinic Royal Perth Hospital, Shenton Park Campus</td>
<td>Perth Metro</td>
<td>Been operating for 7+ years</td>
<td>Neurologist</td>
<td>Neuro nurse MND Care Advisor</td>
<td>Link to hospital services and local allied health thro’ referrals from Neuro, nurse and MNDWA CA</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### WA Health - MND Model of Care:

**MND** Model of care exists but currently unfunded directly by WA Health Dept., currently supported by respective hospitals and MND association. Funding anticipated in 2011 State budget. The model works but is limited. Plan to extend to secondary hospitals in outer areas of metro area has not eventuated. The model currently works on informal arrangement of consulting neurologists coordinating all appointments for MND patients on one day.

## In South Australia

<table>
<thead>
<tr>
<th>Name of Clinic</th>
<th>Region</th>
<th>Year established</th>
<th>Lead professional/s</th>
<th>Team</th>
<th>Funding</th>
<th>Model</th>
<th>Date service ceased</th>
</tr>
</thead>
<tbody>
<tr>
<td>MND Clinic Repatriation General Hospital</td>
<td>Accepts people with MND throughout South Australia</td>
<td>2001</td>
<td>Dr Peter Allcroft, Respiratory and Palliative Care Physician and Karen Glaetzer, Nurse Practitioner – Palliative Care Dr David Schultz, Neurologist</td>
<td>Access to other specialist services, such as Respiratory, Gastroenterology, Allied Health, Rehabilitation and Palliative Care is available if and when required</td>
<td>Clinic funding provided by Southern Adelaide Palliative Services (SA Health)</td>
<td>Links to regional palliative care services and MNDSA</td>
<td></td>
</tr>
</tbody>
</table>
ROLE OF THE MND CLINICS WITHIN THE WIDER CONTEXT OF SERVICE DELIVERY

The three key areas of activity of a MND Clinic and Service, where applicable, should be:

1. To deliver the highest standard of coordinated/integrated care to people living with MND within the local catchment area, linking people living with MND into community based services as needs are identified
2. To act as a tertiary centre – building a body of expertise in clinical management available to health and community care providers, and people living with MND who may access the centre outside the catchment area
3. To provide educational opportunities, and to disseminate good practice.

However in addition to the above, the MND clinics will also be the likely sites for clinical drug trials and so may see a higher number of people living with MND. Clinical research may also be undertaken, and applications for funding this research can be made to the MND Research Institute of Australia or other funding bodies.

The outcomes against which the performance of the MND Clinic or service should be assessed are:

- speed in acquiring a confirmation of diagnosis
- enhancing the standard of communication of the confirmation of diagnosis
- identifying a single point of contact
- ensuring effective outreach to community services, and the MND Association
- effective dissemination of MND information and evidence based practice

On a day-to-day basis the key to achieving these outcomes are liaison between the medical specialists, the Coordinator, the multi-disciplinary team and the MND Association’s Regional Advisor (RA), and the establishment of effective communication links with locally based primary health, palliative care, disability services and community care providers.

The potential for the roles of the Coordinator and the Regional Advisor to overlap is recognised. The MND Association Regional Advisors all have a professional health or disability background and the focus of their role is to secure the highest standards of care for people living with MND via their own health and community care providers and also through the MND Association. This involves working directly with people living with MND, their carers, health and community care providers and volunteers. They act as a catalyst advocating on behalf of people living with MND ensuring that needs based and timely care and support are available and provided by local health and community care providers and the MND Association.

Apart from direct involvement with families, the other key element of the role is in providing information and education for health and community care providers and volunteers. Regional Advisors have taken a lead in influencing service provision regionally; promoting best practice and facilitating the growth of community based multidisciplinary teams with knowledge of MND. MND Regional Advisors work cooperatively with MND clinics, services and multidisciplinary care teams to ensure person centred and optimal care and support for people living with MND and their families.

It is not the intention that the MND Clinic or Service undermines locally based generic clinics, or therapy teams, but that the existence of the Clinic or Service enhances local services through achieving the points identified above.
A comprehensive network of MND models of care within Australia would enhance access to best practice care for people living with MND and their families. There is a need to focus particularly on areas outside the metropolitan regions. The use of video conferencing, Skype and other e-health initiatives as they emerge has the potential for city based MND clinics to outreach to MND services and people living with MND in regional, rural and remote Australia.

The Collaborative Care in Motor Neurone Disease in Victoria final report, April 2009, prepared by Dr Susan Mathers and her team at Calvary Healthcare Bethlehem confirmed that the literature supports a model of collaborative, multidisciplinary care for people living with MND which links quality primary and specialist clinical care with social and emotional supports in the community. It identifies the need for timely access to decision making support, medical and social interventions. The report highlighted the evidence for a ‘neuro-palliative rehabilitation’ model of clinical care. From this report a hub and spoke model of care has been recommended with care provided close to home by local providers who are supported, via e-health and technology, by a MND specialist team. The report identified that new models of care and technology need local clinical ‘champions’ and strong, coordinating leadership if innovations are to be implemented.

Key areas of activity are to:

- develop the working relationship and partnership approach between MND Clinics, Programs/Services and the Association, Co-ordinators and Regional Advisors
- contribute to the National Registry of people diagnosed with MND in Australia (AMNDR)
- develop regular Clinic Director meetings, and meetings of Regional Advisors and Clinic Co-ordinators – encouraging and supporting the dissemination of information, learning and practice
- encourage the implementation of patient/carer satisfaction surveys
- encourage and facilitate the dissemination of evidence based practice nationally
- grow and develop the MND Special Interest Group bi-monthly E-Bulletins to encourage a network of peer support for health and community care providers nationally
- support the dissemination of advances in care, research and MND management through the MNDcare website, the International Symposium in Sydney in 2011 and the Annual National MND Conferences
- encourage the use of technology to provide specialist support to local providers and people living with MND and their carers living in rural and remote Australia

Apart from the areas of development outlined above, there is a need to maximise the impact of MND Multidisciplinary Clinics and services in order to enhance the clinical care of people living with MND nationally. This would include for example:

- the formalisation of MND Clinics and services within the healthcare system
  - Health Departments to fund MND Clinics in each jurisdiction
  - Health departments to support e-health technology
- networks of MND multidisciplinary teams encouraged and funded where necessary
- the development of a national framework for MND care management and local MND care pathways based on evidence and experience
- the development of education packages, in collaboration with Regional Advisors, to inform and educate health and community care providers in management techniques
- championing and influencing change in practice amongst peers and other providers eg: promoting a patient and carer-centred coordinated approach and development of models of care; endorsing the contribution of the MND Association
Internationally

In Canada

Eight of the 10 provinces and three territories in Canada have at least one ALS Multidisciplinary Clinic situated in their capital city. See web link below for more details:
http://www.als.ca/if_you_have_als/health_clinics.aspx

The clinics are not specifically funded but are supported through the health care budget at a provincial level. Each given hospital may have foundation money that is raised and designated to go to the ALS clinic, but that would be a case by case situation, and donations may be more commonly directed to research. In British Columbia the team conducts outreach visits to the rural regions in that province.

In USA

ALS clinics are well established in the USA and are part of the usual program of care for people diagnosed with ALS/MND. Some of the clinics are classified as ALS Certified Centres whereby the Centre (certified) is a site that has met ALS Association (ALSA) criteria and has gone through the review process with ALSA and been approved. The entire certification process is very detailed and takes up to two years.

There are also clinics that have not been certified by ALSA either because they choose not to or because they don’t meet ALSA criteria or ALSA have not been able to certify them because of other sites being in the queue.

ALSA originally provided funding of $25,000 per Centre, but with the financial challenges in the US this has now decreased to $10,000 per site. The local chapter at least matches this national funding. At this time, there has to be a Chapter (local ALS association) to have a Centre. The Chapter has to provide a chapter liaison as the health care professional to attend all clinic sessions.

ALS Association Certified Centre’s SM

The mission of the ALS Association Centre Program is to define, establish and support a national standard of care in the management of amyotrophic lateral sclerosis (ALS), sponsored by The ALS Association. The objective of the ALS Center Program is to encourage and provide state-of-the-art care and clinical management of ALS through:

- The involvement of all necessary healthcare disciplines in the care of the ALS patient and family
- The offering of care from a team of people specially trained to meet the needs of those living with ALS, regardless of the ability to pay whenever possible; when not possible, providing advice to treating physician
- Collaborative work among Centres to enhance ALS patient care and techniques

An excellent brochure outlining the centres can be downloaded from the ALSA website:

In the UK

The MND Association of England, Wales and Northern Ireland makes grants available to establish MND Care Centres. Applications can be made by clinical and community neurological services for consideration by the board. The association has developed Standards of Care and an audit tool to assist clinic establishment and development.

Since 1990 the MND Association has developed a network of 17 MND Care Centres across England, Wales and Northern Ireland. The MND Care Centres:

September 2010
MND Australia

- are based in Regional Neuroscience Centres
- have a dedicated MND clinic
- have a dedicated single point of contact for people with MND
- have access to a multi-disciplinary team
- build up expertise in the management of MND
- have strong links with local community services
- have strong links with the MND Association
- spread expertise across the region through:
  - education
  - sharing good practice with other colleagues in the community
- undertake clinical research
- are the location for clinical drug trials

7 CONCLUSION

It is anticipated that a network of MND Multidisciplinary Clinics and Services has the potential to make a significant contribution in enhancing the clinical care and management of people living with MND – championing and influencing change in practice within the health and community care sector in partnership with the MND Association’s. MND Australia will continue to promote MND multi/inter disciplinary clinics, services and networks and work to influence governments to formalise these services within the health care system nationally.

Carol Birks, National Executive Director