

# **Neurological Alliance Australia**

## **Submission to the Productivity Commission's Inquiry into Disability Care and Support**

**September 2010**

## 1. Introduction

The Neurological Alliance Australia (NAA) is an alliance of not-for-profit peak organizations representing adults and children living with progressive neurological or muscular diseases in Australia. The Alliance was established to promote improved quality of life for people living with these conditions and funding to support research.

Members of the Alliance include Multiple Sclerosis Australia, Parkinson's Australia, Alzheimer's Australia, Huntington's Australia, Motor Neurone Disease (MND) Australia and Muscular Dystrophy Foundation Australia. This submission is also supported by BrainLink Services and the Younger People in Nursing Home Alliance (YPINH).

Each of the member organisations have made separate submissions to the Inquiry that address the specific needs of the people they represent. However, each supports the broad approach taken in this joint submission to establish an ongoing and tailored approach to meet the needs of people with a progressive neurological condition. Early intervention, ongoing assessment and case management and access to needs based care would support people with these conditions regardless of their age, location, cultural background or other circumstances

The Alliance supports the implementation of a Long term Disability Care and Support Scheme and believes that an insurance based funding mechanism is a superior way of managing the needs of progressive neurological diseases (PND). This scheme would provide the opportunity for an entitlement model to be developed with some diagnoses having automatic eligibility. Any new scheme must encompass a regular and responsive assessment process that will identify the changing and emerging unmet needs of people who acquire a progressive neurological disease.

Eligibility for the scheme must be needs-based, not aged-based. Service delivery should meet each person's needs with the consideration of individual symptoms and circumstances, perceived needs and rate of disease progression. Eligibility for the scheme based on PND diagnosis may not necessarily guarantee service from the scheme particularly if people are well supported in other service sectors. However provision should be made for early intervention and lifetime care management with seamless care pathways from and to other service sectors to ensure best practice in disease and disability management.

The group of PNDs represented by our member organisations is complex, disabling, life limiting, and does not fit well in the current disability system. This is evidenced by the participation rates of people with neurological conditions in the Young People in Residential Aged Care (YPIRAC) program compared to other programs available under the general disability system.

The AIHW found in 2008 that Acquired Brain Injury (ABI) was the primary disability group of close to half (46%) of all YPIRAC service users in 2007-08. This compares with 4% of CSTDA service users with ABI as a primary disability group. Two in five YPIRAC service

users (40%) had neurological disability with or without another type of disability. This compares with 13% of CSTDA service users with neurological disability.<sup>1</sup>

Historically this group has struggled to receive adequate services from the disability sector because of its inability to provide timely and targeted services.

This leads to residential aged care placement which is not usually the preferred place of residence for this group. While the YPIRAC program has demonstrated some success, overall numbers of younger people in nursing homes are increasing.

While there are some good models of coordination across the health, disability, aged and carer support systems for this group, the need to deliver timely and competent services in the community remains a challenge for a range of reasons.

Not least of these is the difficulty that complex and changing interactions of disease pathologies and disabilities presents to a disability service system historically designed around static disabilities and presentations.

A pro-active and forward looking care planning process is needed for people with PND and their families, and is something that can be delivered comprehensively through the scheme under consideration. Because of the changing nature of these conditions, individuals and families require specialized advice and support that can deal with existing situations, anticipate future needs and secure the resources needed for support services, including for children with neuromuscular conditions.

The current process of wait-turn for assessment and service allocation is anathema for people with emerging needs that require an immediate response. Yet this is the reality.

An entitlement scheme with planning and funding responsibility for individuals is required to work with disease-specific member organizations and specialized clinical services, distributing a suite of support services in a timely manner.

Doing so will enable individuals with PND to remain at home and in the community, thereby reducing the impost that greater involvement with supported accommodation services will carry.

## **2. About Progressive Neurological Disease**

Progressive neurological diseases are a set of complex and disabling conditions. While this broad group contains conditions with various characteristics, all are degenerative and incurable, resulting in significant disability, grief and need for personal assistance. A large number of diseases and diagnoses are represented by this definition, and include Huntington's disease, motor neurone disease, Alzheimer's disease, Muscular Dystrophy,

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<sup>1</sup> See <http://www.aihw.gov.au/publications/aus/aw09/aw09.pdf>

Multiple Sclerosis, Parkinson's disease, Leukodystrophy and Freidrich's Ataxia to name a few.

With different pathologies and onset features, some can be mediated through pharmacological and other treatments. Apart from the dementias, including Alzheimer's disease, their incidence is relatively low and specialist expertise is only found in small pockets in the health and disability system.

PND's are not a normal part of ageing but some are more common with age. Currently some 257,000 Australians have dementia including around 16,000 people aged under 65. In the working age category there are approximately 8,000 people with Parkinson's disease and 15,000 with MS. Overall there are 1,400 people with MND in Australia who range in age from 18 to 90 years.

As well as the progressive conditions that develop in adults, a number of neuromuscular conditions are diagnosed in children at a young age. For this group there are particular imperatives to keep families functioning well and for children to maintain genuine aspirations, a keen intellect and capacity to achieve. The challenge is to create life pathways for children who may only live to their teens or twenties, and a enabling them to develop and maintain friendships when they are confined to home. It is also essential to ensure that school and community establishments are inclusive of people with a physical disability so that normal life milestones can be achieved.

The costs of all these PND are high for individuals and families, and continuity of employment is generally poor for both. The costs of equipment and home modifications, pharmaceuticals, transport and other services are high, and these disease costs need to be incorporated in the benefit structure of the scheme.

Certainly not all people with PND will need high level care at all stages of their disease. Including them in the scheme to enable comprehensive coordination and support would, however, be prudent and would provide a way of managing the risks, costs and social sequelae of these conditions.

The neurological group makes up only a small proportion of users of disability services. This is partly due to incidence but also because of the difficulty accessing disability services. People with PND have a higher representation in the Home and Community Care (HACC) program and also in residential aged care (RAC).

Until recently, options for younger people with high needs associated with PND, particularly young onset dementia, have been mostly limited to the aged care system. In most states, it is common that people with PND begin using community aged care services when they first need support. If they cannot receive timely support from the disability sector, they then leapfrog disability services completely and enter residential aged care as the only option for high care services.

## **2.1 Employment and Superannuation**

As well as service needs, the issue of employment retention and accumulation and use of retirement incomes are important for this group. Until recently there were few opportunities for working people with PND to receive on-the-job support to ensure they could maintain employment as long as possible. Many people in this group leave work prematurely because of a combination of disease symptoms, poor workplace accommodation, discrimination or a lack of workplace flexibility.

The current Disability Employment Services program contracted by the Department of Education, Employment and Workplace Relations (DEEWR) has good job-in-jeopardy provisions that offer support services and workplace modifications to people with disease and disability at work. While these services are uncapped and available on demand, Disability Employment Service providers need to work with PND specialist services to market the services and ensure skilled interventions are provided to this group to ensure take up. The existence of demand driven labour market programs through DEEWR means that a new no-fault scheme does not need to fund its own program, but simply have individuals referred into the existing system.

Some individuals with PND who are forced to leave work because of their disease, may be able to gain early access to their superannuation savings. In reality, retirement income, these monies are very often used to meet the cost of disability in the form of care, equipment and home/vehicle modifications.

Unfortunately, doing so further compromises their financial position for these individuals. In MS, 85% of aids and home modifications are self funded, and it wouldn't be surprising if the same figure would be found in other disease groups.

These people are forced to use these savings to fund part of their care requirements and, as return to work is rare, have no capacity to replenish their retirement income. Early release also results in losses in compound interest and can, in some instances, give rise to penalty fees. One beneficial consequence of people with PND having their care needs fully funded is that these amounts can be used as streams of income rather than as a large co-payment for care and support.

## **2.2 Specialist PND organisations**

Some of the more well known conditions have organisations that provide information and advocacy and, in some cases, are also service providers. Other, rarer conditions are not represented by identifiable organisations and have far less recognition, particularly in the disability support system.

Because of their pathologies, these conditions require timely services from both health and disability; and a comprehensive co-ordination system to organise care, service delivery and manage risk. In her forthcoming submission to the inquiry, Dr Susan Mathers from Calvary Healthcare Bethlehem in Melbourne, provides a good summary of the impact of these conditions on individuals and their families:

*...the impact of many of these diseases can leave the individual physically and cognitively and socially disadvantaged. Mood, behaviour, personality and judgment can all be disturbed. The individual has to cope with the relentless challenges to their sense of wholeness and to what is meaningful in their lives. Even when cognition is preserved; fearfulness, demoralisation and depression commonly impair the person's ability to face the future and plan ahead. Most of these diseases have life-threatening complications or are in themselves life-limiting. Decisions around medical interventions and end-of-life care are also challenging for the individual and their family, who may end up acting as surrogate decision-makers. Without a pro-active framework to support decision-making, such issues are often left unexplored until a crisis occurs. The client may miss a 'window of opportunity' for timely action or suffer adverse consequences of late or futile intervention.*

*This client group has a high rate of social and financial disadvantage. (When the disease is genetic, the domestic and financial integrity of families can be challenged across generations). These diseases often begin in young people or middle-age and result in the early loss of employment. The sustainability of friendships and partnering are threatened. The person's spouse or partner is required to juggle the roles of breadwinner and carer, restricting their own career development and earning power.*

*Aging parents as carers become frail or ill themselves. Dependent children, by default, may become surrogate carers with sometimes profound effects on their own education and social development. Many relationships fail, further isolating and disadvantaging the person with the disease and increasing their reliance on social services. These people have a high risk of ending up, inappropriately, in residential aged care. Without help and understanding, people's lifestyle, autonomy and opportunities become increasingly constrained.<sup>2</sup>*

People with PND and their families come to the formal service system as novices, with little sense of what support is available or what they may need and when, or the exact detail about what may lie ahead. Even when they receive assistance from disease specialist organisations, the ability of the wider service system to deliver required supports is unpredictable.

Individuals with PND do not get comprehensive case management through their medical specialist, hospital clinic or GP. Case management generally available at the community level is not well informed about PND and usually limited to managing the program it is attached to, rather the person with need.

The need for well informed lifetime planning and coordination is a feature of a best practice approach to managing these conditions in the community. The PND specialist organisations work to coordinate services in this way. Some targeted programs funded by State Governments are mentioned in section 5 of this submission.

### **3. General scheme design**

The new scheme must encompass the purchasing of quality services to address unmet needs created by disability or disease. Case manager support must be available soon after

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<sup>2</sup> Dr Susan Mathers, *Submission to the Productivity Commission's Inquiry into Disability Long Term Care*, forthcoming.

diagnosis for those individuals who may wish to purchase case management services to assist them to identify needs and purchase services in a timely manner.

Creating a formal role for disease specific not-for-profit organisations to deliver life time management of support is imperative if

- service programs are to be well designed and linked with the lifestyle and community networks of the individual and their family,
- programs are to take account of the rate and impact of progression of the individual, and
- current community strengthening roles, such as community education, advocacy and sourcing philanthropy and volunteers, are to continue.

A national whole of government approach to Health, Disability and Aged Care services is needed to promote responsive, coordinated and seamless planning options and services for people with progressive neurological disease and their families and carers. We believe this scheme can develop a clear role in the wider reform of these systems.

Care needed by individual clients and carers is not a fixed quantity. It differs for each person over time as their condition progresses. It is important that the individual needs of carers and families be recognized in the new system, and receives greater attention in the assessment process.

### **3.1 Funding model**

Whatever funding model is chosen to support a life time care scheme, it should provide funding to purchase the services people with disability need to address the impact of their disability. The scheme needs to be complementary to existing funding programs in disability, health and aged care, rather than being set up as a replacement – particularly in its early stages.

As a complementary scheme that is intended for people with severe and profound disability, it should be funded through a new income stream and not take money from the existing, depleted, disability services system. Although it will draw its clients/claimants from the existing system, it is important that Governments do not reduce funding through the National Disability Agreement as a result. We note Anna Howe’s submission and her evidence that a catastrophic injury only scheme would release approximately 20% capacity back into the disability system.<sup>3</sup>

While the scheme should go further than catastrophic injury as Dr Howe describes and include the PND group, this additional capacity would result in overall system expansion, delivering capacity to meet the unmet needs of those intended to be covered by the

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<sup>3</sup> Dr Anna Howe, *Submission to the Productivity Commission Inquiry into Disability Care and Support*, Submission 56.

scheme; as well as other people with disabilities currently unable to access disability services at all.

The scheme should be funded by universal taxation contributions similar to the Medicare levy. Doing so will spread the risk and investment fairly across the Australian community. Income to the scheme should be pooled to create a corpus of funding with ongoing investment income and new contributions from taxation.

The scheme should not be required to make dividend payments to government (as is the case with the Victorian Transport Accident Commission (TAC) but surpluses should be retained to increase the capacity of the scheme to expand and include other disability groups over time; develop its research capacity; and meet future liabilities.

The scheme should be able to incorporate a range of purchasing methodologies, including funding of service providers, direct payments to eligible people, and provision of budget-holding capacity for designated support organisations to purchase services for clients.

While these methodologies can be arranged around an individual focus, it is important that the scheme can also extract purchasing efficiencies through economies of scale where it can. One example of this is with aids and equipment (on this please see the National Aids and Equipment Alliance submission, to which members of this Alliance contributed) where decentralized purchasing can lead to higher prices and inefficient supply chains. Services purchased via the scheme must meet national quality and operational standards already in existence, as well as those established by the scheme. The Scheme should not be a standards monitor.

#### **4. Eligibility**

The scheme needs to adopt a no-fault eligibility structure that is based on functional impacts of disease and disability across the life cycle, and without specific age exclusion.

Progressive neurological disabilities should have automatic eligibility given that

- they have a well known disease trajectory,
- experience severe, profound and a sometimes rapid onset nature of related disability,
- they have a clear need for early intervention and lifetime management.

While within each diagnostic group there is variation in individual disease progression, there is a clear need for early intervention and lifetime care for all people with a PND.

If all people with PND are eligible for the scheme it will enable overall disease and risk management that will create certainty and financial offsets through reduction in preventable hospital admissions and greater employment continuity for individuals and their carers. Automatic entry to the scheme for this group will not in itself create costs.

Those people with PND whose disease does not progress to the complex disability stage, will benefit from the lifetime care oversight but will simply not draw down services from the scheme unless they are needed and requested.

It is appropriate that people can be eligible for the scheme but only access partial benefits based on personal choice of informal or other support (ability to opt in); or an assessment of whether they are appropriately serviced in existing programs (such as aged care). In these cases, these arrangements should remain in place.

Access to the lifetime planning service delivered through the scheme may well, however, enhance these existing arrangements and strengthen transitions and community connections.

#### **4.1 Older people with PND**

People over 65 with a disability related to a PND must not be excluded from the scheme.

While progressive neurological diseases are not acquired as part of the natural process of ageing, many people do acquire these diseases in their 60's, 70's and 80's. As people age with a progressive neurological condition, their needs increase because of the progression of the disease, not because of ageing.

Many people with dementia will continue to have their needs, and the needs of their carer, met by the aged care system. However, there are numbers of people with younger onset dementia - including people with Down Syndrome who usually develop Alzheimer's disease in their 40s and 50s - who will benefit from the specialized coordination and supports available through the scheme working in collaboration with appropriate supports through the aged care system if applicable.

Some people in their 60's will similarly gain benefit from this type of support as they transition to using aged care services if these services are better able to meet their needs. Those in their 60s and older (including some in the broader under 65 group) may continue to be best supported under the existing aged care service arrangements, including specialized dementia units.

As it is presently constituted, the aged care system is unable on its own to deliver the type and quantum of support these individuals require. In these circumstances, the scheme's collaboration with aged care will deliver improved outcomes for individuals with PND. A whole of government approach with pathways to and from disability and aged care services is imperative if we are to achieve a seamless and coordinated approach to needs based care for older people with PND.

#### **4.2 Scheme gateway**

A gateway to the scheme needs to be designed that can test eligibility by utilising specialist assessment and opinion. Because of the variation in diagnoses that may be

included in the scheme, it is unlikely that that a single assessment type will be sufficient across the board.

It may be that a 'claim form' that demands a range of assessments and reports be completed to establish eligibility, should be used.

The process of care planning is, however, not the same as eligibility assessment and should not be combined. General or specialist medical practitioners and professionals within disease specific organisations can play a key role in validating PND diagnosis as part of their operations.

Eligibility screening, assessments and service planning would be best done by specialist neurological organisations independent of 'claims management' within the scheme and service providers. These organizations already have extensive knowledge and experience of the course of PND, assessment care coordination, advocacy and family support.

#### **4.3 Lifetime planning and care coordination**

Supporting people with PND needs to be driven by a number of factors and contexts. Due to the midlife onset of many of these conditions, people will have established lives and commitments. These need to be sustained and factored into planning and service delivery.

The prognosis and disease course for each individual also needs to be taken into account, with space created for informed decision making on key issues at critical disease transition points. The progressive and degenerative nature of PND means that the planning and coordination role needs to be relatively constant, while remaining flexible enough to keep pace with changes in the disease course; especially when the disease is rapidly progressive, and adapt services for the changing impact of disability on the individual and the family.

Planning and coordination also needs to be able to coordinate a range of inputs from specialist medical and health professionals (who need to manage the disease and educate direct care workers), service agencies, families, employers and others.

This coordinated planning function needs to commence at the time of an individual's diagnosis to ensure education and adjustment, maintenance of quality of life and choice, social inclusion and confidence in the service delivery system.

In the current fragmented system, the load on families is immense and service failures can have devastating effects.

In essence the Scheme needs to fund the delivery of the following suite of supports to people with PND in the community:

- Specialist care coordination and lifetime planning with budget holding capacity
- A range of specific long term care services to address needs based care that reflects the rapid progression, change and escalation of individual needs

- Secondary consultancy to train and educate service providers.

The scheme should limit its ambit to the group of long term care services that are delivered in the community, including specialist care coordination. Acute and sub acute services are provided through the health system and it is the responsibility of State Governments to ensure appropriate service coverage, including workforce management, is sustained and grown.

The scheme would not be viable if it was required to fill gaps and shortfalls in other sectors. It does, however, need to have well oiled administrative interfaces with these other service sector bureaucracies - in the case of PND: employment, health, palliative and aged care - to ensure that pathways are available for individuals and specialist case coordinators.

The dedicated lifetime planning and coordination function needs to incorporate ongoing assessment and service delivery without requiring each request for funded support to be separately assessed and approved by the scheme.

Managing PND is a dynamic process which requires a mix of planned services; access to flexible brokerage resources to cover immediate requirements (such as respite, equipment or additional care); and regular contact with the individual, families and specialist services.

The best features of the existing PND programs and pilots include the ability to access expertise and services required over time; and hold funds to purchase a range of urgent services in ways that meet emerging needs.

#### **4.4 Scheme benefits**

The following table is a brief summary of the types of services and benefits that should be provided by the scheme to make it comprehensive for people with PND. Pathways need to be established to the other service sectors, but duplication of existing, universally available services, needs to be avoided.

Inclusions	Exclusions
<p><b>Long term care services</b></p> <ul style="list-style-type: none"> <li>▪ Lifetime care management/specialist care coordination</li> <li>▪ attendant care</li> <li>▪ respite and carer support</li> <li>▪ shared supported accommodation</li> <li>▪ specialist rehabilitation services</li> <li>▪ aids and equipment</li> <li>▪ home and vehicle modifications</li> <li>▪ community allied health (including nursing, physio, OT, neuropsychology continence advisers)</li> <li>▪ community access and recreation</li> </ul> <p><b>Other benefits</b></p> <ul style="list-style-type: none"> <li>▪ TGA approved non PBS medications</li> <li>▪ Compensatory dietary supplements</li> <li>▪ individualized transport related to approved activities</li> <li>▪ education and secondary consultancy services for individuals, families and service providers</li> </ul>	<p><b>Health services</b></p> <ul style="list-style-type: none"> <li>▪ Acute care</li> <li>▪ PBS medications</li> <li>▪ Community health Centre services</li> <li>▪ Primary care</li> <li>▪ Palliative Care</li> <li>▪ Private health insurance</li> </ul> <p><b>Employment Services</b></p> <ul style="list-style-type: none"> <li>▪ DEEWR Job Network and Disability Employment services</li> </ul> <p><b>Income Support</b></p> <ul style="list-style-type: none"> <li>▪ Centrelink benefits</li> </ul> <p><b>Advocacy</b></p> <ul style="list-style-type: none"> <li>▪ Disability Advocacy services</li> </ul>

## 5. Current Successful Models in PND

There has been substantial work done to develop end to end models of coordinated care in PND, including undertaking pilots in a number of states to validate the concepts.

These models have a common set of features around

- combining clinical and social support expertise in prospective planning,
- capacity for immediate service delivery for changing needs,
- incorporation of individual and family decision making and
- supporting people in their desired location.

A direct claim type of funding for eligible individuals in the scheme would not necessarily be done through pools of funding organised in programs as we see now, but be done in a more direct manner for approved individual programs.

The examples of programs below do not, however, constitute a recommendation to use a program methodology. Instead, they highlight how the response to the PND group with high needs has to be organised, including operationalising the key features already referred to in this submission.

Some of these models are not dedicated programs, but represent the work of neurological organisations in navigating the current system with their clients.

Members of the Alliance will forward the relevant evaluation reports from these pilots or provide additional information to the Commission separately to this submission if required.

### **5.1 Fast track access to disability services packages of care**

People with progressive neurological disease in NSW and Victoria can have emergency access to Attendant Care packages delivered within the general disability services programs. MND NSW and MND Victoria have worked with government agencies over the last few years to highlight the need for a rapid response to assessment and service provision when a person with MND is referred for an Attendant Care package.

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 provide top-up funding for palliative care services supporting people living with MND.

Work is also underway to create specialist neurological case coordinators in regions to manage the PND group across health, disability and community aged care.

### **5.2 MND Care coordination**

In a number of regions the complexity of MND care has encouraged local health, community and disability services to initiate MND care coordination meetings on a regular basis.

These models have proved effective in developing a coordinated inter-disciplinary approach to MND care management minimising duplication of services and visits to the client's home. Support for innovative care coordination initiatives would improve timely service delivery and save costs overall.

### **5.3 Continuous Care Pilots**

The MS Society has run specialist coordinated care trials in Victoria and NSW that have utilized a risk management approach to keeping people with PND in the community and out of aged care. It has used a case coordinator to work with individuals and families, clinicians and community service providers to coordinate services across funding programs.

The care coordinator is employed by the MS Society and is linked to a Clinical Advisory Group to contribute to planning and management of care. Community case managers and services providers are exposed to the clinical decision making and have used the specialist coordinator for mentoring and advice. In these pilots, the coordinator maintained a caseload of 15-22 people.

#### 5.4 Top-up funding

Funding to allow targeted purchasing of packages of care for rapidly progressive disabilities is essential to address rapidly changing and emerging needs, and facilitate timely access to services. Existing state based models for targeted funding include ‘top-up’ funding for rapidly progressive neurological disease to address timely access to existing services and high level need.

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

Community Options NSW (COPS) has received funding from the NSW Department of Ageing, Disability and Home Care (ADHC) to pilot a project providing extra services to people with rapidly progressive neurological disease when their needs become more complex.

COPS case manager’s work in partnership with MNDNSW regional advisors 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.

#### 5.5 The WA Neurodegenerative Conditions Coordinated Care Program (NCCCP)

This program is a new pilot program providing services to assist people to remain in their own homes with support. This program is operated by the MS Society of WA. The NCCCP seeks to provide timely support for people with rapidly degenerating neurological conditions and whose support needs will increase over time.

Referrals for this program may be received from disease specific not-for-profit organisations, service providers, the WA Disability Services Commission, neurologists, general practitioners and self referral. People referred for NCCCP services must be eligible for Disability Services Commission funded services; and meet the specific program parameters.

#### 5.7 NSW – Flexirest program

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 state organisations including Multiple Sclerosis Limited and the Muscular Dystrophy Association of NSW. This consortium has been successful in obtaining funding from ADHC to provide flexible and innovative respite options for people with these progressive neurological conditions to support carers to maintain their caring role.

MS	116
MND	101
MD	78
<b>TOTAL</b>	<b>295</b>

Number of *FlexiRest* packs during 2009-2010.

## **5.8 Carer Support**

Support of carers is a vital component of managing PND, as people come to the system from families. Individuals and families overwhelmingly express a desire and a commitment to maintain family and friendship relationships despite the PND entering their lives.

Family carers must be supported to engage with their family members as family, not as primary carers as is currently the case.

All the Neurological organisations have a strong interest and experience supporting family carers as a specific target group. Carer specific information and education programs and other targeted resources have been developed in most states. Our organisations also have good links to Carer Associations and undertake work with them. Many family carers, particularly spouses of people with PND, do not readily identify as carers but still participate in family programs and have an ongoing need for support and information.

It is critical to understand that, in developing a fair and equitable system of care based on level of need, recognition is made that if timely service access is available to an individual, then carer burden can be reduced or avoided. Under a system of comprehensive lifetime care management and entitlement based services, the role of family carers would be very different in terms of outright burden. However, the need for information, peer support, advocacy and respite would remain as areas that a scheme would need to incorporate.

Models for these supports already exist and work exceptionally well in their own context, but the improving integration of carer support with the overall lifetime care management of eligible individuals, will enhance these systems. Victoria's BrainLink Services facilitates a range of very effective carer support programs that are companions to direct services in Victoria that are useful models for this integrated approach.

## **5.9 Specialist Neurological Nurse Educators**

Presently, the provision of health care services for patients and families affected by PND is concentrated around pockets of specialist care within metropolitan centres with a marked deficiency in rural and remote regions. For example, Parkinson's Victoria has a single specialist nurse educator which is a valuable resource but is inadequate to cover the State.

Parkinson's Australia has developed a program that would target regional communities with innovative initiatives. In the current system, this offers a clear opportunity to deliver improved care and measure the impact of interventions efficiently. Under a new scheme, these nurses would be routinely be used by the PND organisations with their clients.

This, like the other models sketched above, are examples of what the National Health & Hospitals Reform Commission (NHHRC) had in mind when it stated that "...effective management of people with chronic illness requires continuity of care...working

effectively together with defined care pathways [providing a] powerful framework to catalyse action on health improvement.”<sup>4</sup>

Significant offsets can be created by a targeted response, as has been evidenced in Britain. The UK National Institute for Health and Clinical Excellence (NICE) Guidelines estimated that access to specialist nursing care and therapy services would reduce hospital inpatient admissions by 50% and hospital outpatient attendance by 40%<sup>5</sup>.

## **6. The scheme and the role of neurological organisations**

The current system has numerous elements requiring clients to deal with multiple case managers; tell their story over and over again; and often be made to feel they need to justify their eligibility every time they request support. It is often unable to adequately meet the total needs of clients, often due to budget restraints, leaving people with a sense of frustration, anger and abandonment.

Not surprisingly, clients assume the system is “broken” due to this lack of capacity, as well as the need to continue to justify their circumstances to multiple case managers representing the various elements of the disability system.

In regard to PND, we do not believe that the current system is actually broken, but is under great demand pressure, struggling with the necessary rapid allocation of services. As indicated by the reference of this inquiry to the Commission, there is a desperate need to increase the financial resources available to the whole disability system.

One compelling aspect of the design of the new scheme is the creation of a dynamic lifetime care function where authority and responsibility are firmly located in one place. Eliminating the duplication of assessment and case management requirements and rolling these into a lifetime care system, would reduce the level of frustration and red tape currently experienced; and result in financial resources being diverted from administration to client service delivery.

Specialist neurological organisations can play a key role in the scheme as lead agencies responsible for lifetime care and case coordination for clients of the scheme. This could be added to the existing roles of advocacy and social change; peer support; community education; media; volunteer management; service innovation and information provision to integrate funded supports with informal supports and community life.

The scheme also offers the opportunity for specialist neurological organisations in Australia to work with governments to develop a national service framework for PND similar to the UK

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<sup>4</sup> National Health & Hospitals Reform Commission (NHHRC), *A Healthier Future for All Australians. Final Report of the National Health & Hospitals Reform Commission* (NHHRC), June 2009: 84.

<sup>5</sup> UK National Institute for Health & Clinical Excellence (NICE) Guidelines “Parkinson’s disease: diagnosis and management in primary and secondary care”, *National cost-impact report*, No 35, June 2006.

National health Service Framework for Long Term Neurological<sup>6</sup> conditions to guide service delivery across and between the various jurisdictions for this group nationally.

This would likely result in more streamlined and client-centered, needs based practices; and head off the risk of scheme clients being totally defined by their disability and service program.

Life with a PND or any disability is not an easy life. There remain many barriers to full participation in the community that need to be worked on by our organisations, but that will remain, even if people are fully serviced through the scheme.

A life time care scheme is but a part of the wider change that our organisations, members and clients work towards. Combining a formal service coordination role with wider social advocacy, can generate economies and synergies that will increase our effectiveness in generating better individual and community outcomes.

## **7. Organisations endorsing this submission**

### **Members of the Neurological Alliance of Australia**

Alzheimer's Australia

Huntington's Australia

MND Australia

Multiple Sclerosis Australia

Muscular Dystrophy Foundation Australia

Parkinson's Australia

And:

BrainLink Services

Younger People in Nursing Home Alliance (YPINH)

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<sup>6</sup> UK National Health Service Framework for Long Term Conditions, Neurological Conditions, 2005