



**Submission from the Strategic Carer Action Network (SCAN) to the House of Representatives Inquiry into Better Support for Carers**

Carers NSW is pleased to provide this submission on behalf of the Strategic Carer Action Network (SCAN). The aim of SCAN is to enable the development of strong partnerships, promote the need and advantages of supporting and working with carers, and provide expert advice, support and assistance across the sector to better address the needs of carers across NSW.

The membership of the SCAN is made up of NSW peak level community, health and residential care non government organisations; NSW regional human service organisations; and NSW large and small non government service providers who directly or indirectly support carers in the community, health and residential care sectors. There are currently 30 organisations on the membership list.

To complement Carers NSW submission, four SCAN members have provided information to the Inquiry on needs of carers for the specific population groups in which they work. This information has been collated by Carers NSW on behalf of the SCAN members and is presented below.

**Mental Health Coordinating Council (NSW)**

Families and Carers of People with Mental Health Issues

*Needs and Priorities for Action*

Recent research has revealed distinctive characteristics and needs of families and carers of people with mental illness for respite and support services. In particular, consultations conducted Australia wide by the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) in 2007 and by the consultancy group HMA for Community Mental Health Australia (CMHA) in 2008 have raised concerns that existing frameworks and services for respite derived from the aged care and disability sectors do not adequately meet the distinctive needs of carers and consumers supported by the mental health sector.

The research indicates that models for mental health family and carer support and respite service need to make provision for episodic nature of mental illness and the resulting changes in levels of functional independence of the care recipient. Support and respite service delivery must be inclusive of the needs of the whole family and not just the primary carer. This is particularly the case in indigenous and CALD communities. Service delivery needs to be flexible and responsive to the changing needs of the consumer and the carer. These needs will vary according to the nature and course of a person's illness and recovery journey, their age, and the particular situation and experiences of family members. Opportunities for assessment at critical points are a vital component of respite and support. The well-being of carers improves, and stress reduces, as the consumer progresses on their recovery journey.

CMHA through the national Building Capacity in Community Mental Health Family Support and Carer Respite Project has identified the distinctive characteristics and needs of families and carers of people with mental illness accessing support and respite services include:

- **Stigma**

Families, carers and people experiencing mental illness might shun respite and support because of stigma still associated with mental illness in parts of the community. Personal factors that may reduce access to respite and support include the carer and family's own values of privacy and self-reliance and their limited understanding and knowledge of mental illness. This may result in failure to identify symptoms or seek help as they feel they are to blame and must face the situation alone. Furthermore many families and carers who want support do not know where to start to get help. Most families are not familiar with support services, some workers do not discuss such services or the information provided may not be useful or relevant to their needs.

- **Perceptions of carer role**

The terms '*carer*' and '*respite*' are difficult terms in the mental health area as many people in relationships and families where there is mental illness do not identify or view themselves as 'carers' nor do they readily perceive the relevance of 'respite services'. A more flexible approach to respite is required in order to best to meet the needs of a carer for 'a break' and to sustain their ongoing role.

- **Service relevance**

Families, carers and consumers will not use respite services if they are perceived to be unsuitable or irrelevant, or more suited to the needs of elderly frail aged people or people with intellectual or physical disability. A key element in the uptake of services is that the services provided must contribute to the recovery of the care recipient. A lack of staff skills and appropriateness of design and flexibility in delivery of generic programs can also reduce their relevance or usefulness to carers of people with mental illness. Staff in generic services often do not have the skills to engage with people with mental illness and to inspire confidence by the consumer and carer that relevant services will be provided.

- **Systemic and programmatic barriers**

Barriers of a systemic or programmatic nature can arise from a range of factors including eligibility criteria, program priorities and related assessment measures that discriminate against people with mental illness, their families and carers. Family and carers encounter difficulties in accessing in-home and outreach support programs, such as Home and Community Care and disability services funded under the Commonwealth State and Territory Disability Agreement, and Centrelink benefits.

- **Indirect vs direct respite**

Many of the services that are helpful to families and carers of people with mental health issues are classified as indirect funding and as such, according are often not a priority for funding. This presents a barrier to service delivery.

- **Complex issues**

Some respite and support services either cater for or are perceived to target a specific illness group and to exclude others. Families, carers and consumers experiencing a range of complex problems such as mental illness and intellectual disability of mental illness and substance abuse often fare poorly.

### *Priorities for action*

- Increased provision of community based psychosocial rehabilitation and recovery services for consumers
- Provision of respite services that enhance and facilitate consumer recovery.
- Development of support and respite services to meet the needs of the whole family, not just the primary carer. This is particularly the case in indigenous and CALD communities
- Development of support and respite services responsive to the needs of young carers
- Development of service delivery models that are flexible and responsive to the changing needs of the consumer and the carer and facilitate access into the service delivery system
- Development of service delivery systems that promote and enhance relationships between the mental health respite and support system, other components of mental health system and primary health and community care systems
- Workforce development of generic respite and support system to better respond to the needs of consumers and families and carers of people with mental health issues

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### **Parkinson's NSW**

Parkinson's NSW have raised the following specific issues for carers for people living with Parkinson's Disease:

Carers require specific information about Parkinson's Disease, including:

- symptoms of Parkinson's Disease
- mental health issues in Parkinson's Disease, eg anxiety, depression, paranoia, obsessive compulsive behaviours
- medication

Carers accessing respite need to have the confidence in the person providing the respite that they have an understanding of Parkinson's Disease, in particular that medication is required on time, correct dose, every time to maximise the person's "ons" (time where symptoms are least pronounced) and to minimise "offs" (time where symptoms are most pronounced).

Care workers need to take the time necessary when assisting the person living with Parkinson's, eg to communicate, to eat and drink, to rise from a chair and not to rush the person.

People living with Parkinson's and their carers can become very isolated due to Parkinson's. They need support and encouragement to continue to interact with the wider community. This might include access to appropriate community transport or centres where they will not feel embarrassed due to the illness.

Hidden carers of people living with Parkinson's have responded well to public information seminars on Parkinson's advertised in the local media. Carers may consider accessing information seminars as less threatening than other services. Once the carers have been identified through their attendance at such seminars additional support can be offered.

Another approach to reaching out to hidden carers of people living with Parkinson's is to disseminate information through pharmacists.

Carers of people living with Parkinson's, of course, face all the general issues associated with caring including low income and limited resources.

Support programs to break down isolation and encourage a sense of wellbeing would be very welcomed.

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### **Alzheimer's Australia NSW (AANSW)**

#### Carers of people with dementia

The 2003 Access Economics report commissioned by Alzheimer's Australia, *The Dementia Epidemic – Positive Solutions for Australia*, found that dementia will overtake depression as the leading cause of disability burden by 2016. One in three Australians with dementia live in NSW (about 76,200 in 2006) and by 2050 this number is set to quadruple to more than 227,000. With total expenditure for dementia projected to increase by 225 per cent between 2003 and 2030 Australia wide, both commonwealth and state governments will need to make a commitment to support annual growth of aged and disability services to meet demand and keep pace with the demographic shift. Many of these new services will need to focus on supporting the predicted four-fold increase in numbers of people with dementia and their carers over this period.

The Australian Institute of Health and Welfare Report *Dementia in Australia* tells us that informal sources of care provide much of the assistance received by people with dementia who are still living at home. The majority of people with dementia at home have a carer, particularly those with a more severe level of disability or dependency. In addition, those with dementia are more likely to have a carer than those without dementia. (Australian Institute of Health and Welfare, 2007)

According to the 2003 Survey of Disability, Ageing and carers (SDAC) there are approximately 35,900 carers of people with dementia in Australia, according to the Australian Bureau of Statistics (ABS) definition of a carer. However, this number probably underestimates the real numbers of carers of people with dementia, as many are often reluctant to step forward and seek access to help and services.

Available data tells us that carers of people with dementia are either not working or have reduced their hours of work. This reflects partially the age of carers and partly the demands associated with caring for someone with dementia. Almost half the carers of people with dementia reported they did not have a fall-back carer and 52 per cent of carers reported needing or wanting an improvement or more support in areas such as respite care, financial assistance, physical assistance, emotional support, improvement in their own health or other areas of assistance.

Certainly many of the issues identified by carers of people with dementia they share in common with other groups. However, there are some issues that appear unique to carers of people with dementia. Those issues are associated with the unpredictability of the disease and physical and emotional demands of living day-to-day with a person with dementia. There are also important issues for carers of people with younger onset dementia that often go unrecognised.

Alzheimer's Australia NSW support group research conducted in 2006 yielded strong evidence based recommendations around the needs of carers of people with dementia. The research also demonstrated the important role support groups play in providing a model of mutual aid for carers of people with dementia. There had been anecdotal research, but no systematic study of the operation of, or the experience of belonging to, ongoing support groups for dementia carers in NSW until the Alzheimer's Australia NSW study provided evidence of the unique issues of carers of people with dementia. (Brown 2007)

### *Recommendations*

1. AANSW research found that stigma was a major factor that prevented carers from accessing support and assistance from service providers and support groups. Not only are GPs reluctant to make a diagnosis of dementia research also found that community attitudes needed to change. If the community were more aware and accepting of dementia, then carers of people with dementia would be readily acknowledged and supported.
2. AANSW research clearly demonstrates the ongoing value of support groups for carers of people with dementia to ensure their ongoing physical and emotional well being. On the basis of the evidence, AANSW recommends the ongoing funding of support groups for carers of people with dementia.
3. The research also found that carers of people with dementia are stressed – particularly emotionally stressed. In fact, research suggests says that carers of people with dementia are more emotionally stressed than physically stressed, and that most of the stress is based around issues of grief and loss which are not always recognised, acknowledged or dealt with appropriately. Jacqueline Frank's research (Frank 2008) replicates these results. Frank says that grief and loss issues are the main barrier to effective care giving, not the hands on day-to-day physically exhausting work. Once again, the mutual aid that carers receive from each other in ongoing support groups was found to relieve stress and attendance at support groups provides good ongoing socio-emotional support for carers.
4. There is a profound lack of respite and other services for carers of people with younger onset dementia because they often fall into service gaps because they neither fit 'disability' or 'ageing' criteria. The lack of respite services for carers of people with dementia often stops carers of people with dementia from attending support groups which have been shown to ease social isolation and emotional stress.
5. Carers of people with younger onset dementia often have dual caring responsibilities. They may be caring for a partner with younger onset dementia and for older parents as well. In addition, teenagers of parents with younger onset dementia are often dealing with a person with both mental and physical challenges and inconsistent behaviour and needs. The unique needs and stress on carers of people with younger onset dementia needs to be recognised.
6. Caring demands can change with the unpredictability of dementia. Unlike a physical disability, dementia can mean a person's behaviour can change from day to day, week to week - so there is often no consistency for the carer. It requires carers of people with dementia to be super flexible and to be able to adapt to changing circumstances. This can cause added stress and often makes it difficult to plan ahead for things like respite.
7. The issue of wandering or 'walking' can create added stress for carers of people with dementia, as they need to be constantly vigilant about keeping track of loved ones.

Supporting carers with programs such as *Safely Home*, and ensuring access to home modification and maintenance benefits to ensure that a carer's home is secure, and encouraging the use of various forms of assistive technology should all be considered as ways to support the carer. Carers tell AANSW that they support further investigation of tracking and tagging technology to keep their loved ones safe.

8. Challenging behaviours related to dementia limit respite and care options and create added stress for the carer. Carers of people with dementia, particularly people with dementia with challenging behaviours, should be given priority access to specialty respite.
9. Lack of timely assessment and diagnosis of dementia affects carers. Because GPs are often reluctant to diagnose dementia, carers cannot gain access appropriate support services. Early diagnosis can help ensure carers are linked to appropriate support services sooner, rather than later.

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#### **Motor Neurone Disease Association NSW**

##### *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 1,300 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 spiralling series of losses, which pose:

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

#### *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 wellbeing.

#### *Barriers to social and economic participation for carers*

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 national 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

*Extra strategies to facilitate opportunities, choice and transition for carers*

1. Counselling
2. Bereavement support
3. Involvement in Advanced Care Planning
4. 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.

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