

**AN INVESTIGATION INTO THE HOME SUPPORT NEEDS OF
ADULTS LIVING WITH MULTIPLE SCLEROSIS,
HUNTINGTON'S, PARKINSON'S AND
MOTOR NEURONE DISEASES**

EXECUTIVE SUMMARY

by

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Collaborative research partners:

Australian Huntington's Disease Association WA
Brightwater Care Group
Curtin University of Technology
Disability Services Commission
Mercy Aged Care
Motor Neurone Disease Association of WA

Multiple Sclerosis Society of WA
Neurological Council of WA
Parkinson's Western Australia Inc
Perth Home Care Services
Silver Chain
WA Department of Health
(Neurosciences Unit)

This is an updated version to the original document dated 25 September 2008.

FOREWORD

As a person suffering from Motor Neurone disease I was delighted to participate in this important report, because my needs in the home have increased as my disease worsens. The number of health related agencies involved in this report, deserve praise for addressing this long overdue issue. More needs to be done by health professionals and allied staff in homes, to take the pressure off spouses and children.

The recommendations in this report must be taken seriously by Governments and senior health bureaucrats to ensure people living with life threatening neurological diseases can receive proper home care, in order to live happy and dignified lives, which is a right every human being deserves.

Robert Haynes (Project participant with Motor Neurone Disease, 51 years, metropolitan Perth)

Suffering on your own is not much fun. My first experience of it was in New Guinea during World War II when I lay on a stretcher in a field hospital whose walls were mainly hessian. Dengue had me in its feverish grip. I didn't care who won in the Pacific. I just wanted my Mum, Cottesloe Beach, the Saturday afternoon flicks and clean socks. My only regular visitor was a surly male nurse who paused briefly on his rounds to ask: "Are you still breathing?"

But the war was won and things have changed for the better. Yet much more needs to be done for the sick and the lonely, as this thorough going report makes clear. At 84 I'm home and still breathing, even though a long-term victim of Parkinson's Disease. I'm lucky enough to have a compassionate carer (my wife) and can call on a number of organisations formed to support those with neurodegenerative diseases. In WA there are nearly 8,000 of us at home trying to cope with Multiple Sclerosis, Huntington's and Motor Neurone diseases as well as Parkinson's. They're all nasty and the sufferers are stuck with them. That number will grow as the population (particularly the aged part) grows. More people will be needed in the areas of personal care, domestic help, social support, gardening and home maintenance.

Australians are well-known for their generosity to those in need. This quality is also obvious in the work professionals and others have done to prepare this report. Their expertise, experience and concern lead them to conclude that home care should be recognised as a vital element of health policy. It needs to be rationalised, adequately funded and made flexible enough to meet the special needs of every sufferer. And the need is urgent. Not only would there be less pressure on hospital beds but hard-pressed carers (especially partners) might find the time to go to Cottesloe Beach or even the Saturday afternoon flicks.

Athol Thomas (Project participant with Parkinson's Disease, 84 years, metropolitan Perth)

PROJECT TEAM

Professor Gill Lewin, Research Director, Silver Chain and
Professor of Ageing, Curtin University of Technology
Dr Margaret Giles, Project Co-ordinator, Silver Chain
Mr Dave Harrison, Research Assistant, Silver Chain
Ms Boshra Yazahmeidi, Research Assistant, Silver Chain
Ms Candice Patterson, Research Assistant, Silver Chain

STEERING GROUP

Professor Gill Lewin, Chair and Project Manager
Dr Margaret Giles, Project Co-ordinator
Prof Samar Aoun, Curtin University of Technology
Mrs Carole Bain, Silver Chain
Mr Jim Benson, Motor Neurone Disease Association of WA
Dr Carmela Connor, WA Department of Health (Neurosciences Unit)
Ms Meredith Doyle, Australian Huntington's Disease Association WA
Ms Georgie Hunter, Mercy Aged Care
Ms Sandy Komen, Brightwater Care Group
Dr Anne Mathews, Disability Services Commission
Ms Brenda Matthews, Parkinson's Western Australia Inc
Ms Sue Shapland, Multiple Sclerosis Society of WA (Inc)
Ms Marita Walker, Perth Home Care Services
Ms Karen Westmacott, Neurological Council of WA

The Steering Group developed the research plan, supervised the conduct of the research, co-ordinated their own organisation's involvement in the project, reviewed project progress and documentation and disseminated project progress and research findings to members/clients. The group met fourteen times between July 2006 and June 2008.

STATE ADVISORY PANEL

Professor Gill Lewin, Chair and Project Manager
Dr Margaret Giles, Project Co-ordinator
Ms Carole Bain, Silver Chain and Steering Group representative
Dr Bill Carroll, Consultant Neurologist
Dr Robert Edis, Consultant Neurologist / Neuro-rehabilitation Specialist
Dr Penny Flett, Brightwater / State Aged Care Advisory Committee
Mr Stephen French, Commonwealth Department of Health and Ageing
Ms Lois Gatley, Consumer representative
Ms Jenni Perkins, Disability Services Commission
Ms Sue Shapland, Multiple Sclerosis Society of WA (Inc) and Steering Group representative
Mr Rob Wilday, Aged and Continuing Care, WA Department of Health

The panel endorsed the research plan and resulting reports, extracted the policy implications of the research findings, advised on methods to disseminate findings including to their own constituencies, assisted in promoting the credibility of the project, fostered broad interest in project activities, and provided information to the project team on reports, planning and policy developments of relevance to the project. The panel met four times during the course of the project.

ACKNOWLEDGEMENTS

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THE PURPOSE OF THE PROJECT

The Neurodegenerative Disorders Project (NDP) was an investigation into the home support needs of adults living with one of four neurodegenerative disorders (NDD) – Multiple Sclerosis (MS), Motor Neurone Disease (MND), Parkinson's Disease (PD) and Huntington's Disease (HD). The purpose of the project was to provide home and community care providers, planners and policymakers with information that would enable them to better understand the current and future home care support needs of individuals (and their families/carers) living with NDD in the community in Western Australia. It was also expected that an understanding of the key issues related to the gaps in home care support would enable providers, planners and policymakers to make more effective funding and planning decisions in relation to this group of people.

ETHICS

The Silver Chain Human Research Ethics Committee approved the project. In keeping with the Guidelines approved under Section 95A of the Privacy Act 1998 (NHMRC, 2001), principles protecting participants (informed consent, self-determination, confidentiality of information and anonymity, protection from harm) and governing the storage, access and disposal of files were adhered to throughout the study. In addition, ethics clearance was gained from each of the participating organisations at the commencement of the project.

DESIGN

The project had six components, each reported separately:

- A postal survey of members of disorder-specific support agencies and clients of home care support organisations, 2007 (NDP Report No 1),
- Interviews with clients and members and their carers, 2007 (NDP Report No 2),
- Case studies, 2007 (NDP Report No 3),
- Summaries, 1996 to 2006, and linkage, 2006 of member and client data, (NDP Report No 4),
- Interviews with health and allied health professionals and care workers of home care support organisations, 2008 (NDP Report No 5), and
- Projections of the gaps in home care support (NDP Report No 6).

The contributing reports to this Executive Summary provide summaries of information collected during this project and reference to other similar Australian and overseas studies. Reference to this other literature is not made in this Executive Summary.

NEURODEGENERATIVE DISORDERS

Neurodegenerative disorders are characterised by a number of symptomatic difficulties which usually worsen significantly over the course of the disorder. However, they are not universal symptoms and can affect some people and not others with the same disorder. They are variable and can affect some people acutely and others less so. For example, this project has found that:

- Nine in ten people with NDD experience fatigue/tiredness,
- Seven in every ten have muscle spasms, tremors or involuntary movements,
- Three in every four have some degree of weakness in their arms and/or legs,
- About half have difficulty with their eyesight,
- Four in every five have compromised balance,
- Two in every three tend to be increasingly clumsy,
- Most people with MS, and about half of people with other NDD, experience heat intolerance,
- Over half suffer lapses of concentration,
- Three in every five had difficulty remembering,
- Three in every five report sleep disturbance,
- Over half experience some degree of pain, and
- About half have bladder incontinence.

These symptoms can appear early on in the disorder or be late onset. They may present slowly or become suddenly apparent. The manifestation of these and other symptoms may be complicated by co-morbidities, such as diabetes (present in over 12 per cent of those with co-morbidities) and high blood pressure (in 19 per cent), or by functional decline related to ageing (the median age of survey respondents in this project is 61 years and over 10 per cent of all respondents are aged at least 80 years).

In addition to symptomatic difficulties, the four disorders of interest in the project are similar in a number of other respects:

- They can reduce lifespan as well as decrease health-related quality of life;
- They cause deterioration in functioning and mobility to the extent that patients may need help with all activities of daily living, particularly towards the end of life. This help can be provided by carers, including family and friends, and/or by care workers from home care support service providers; and
- They require varying levels of clinical care in the home. Other than for brief stays related to symptom management and other health issues including infections, there is no need for people with NDD to spend time in hospital.

Increasingly, people express a desire to remain in their homes for as long as possible, often up to the time of their death. They are supported in this desire by health and allied health professionals and service providers.

“It is usually preferable for patients to try to avoid a public hospital death.” (Health professional, 2008)

ADULTS WITH NEURODEGENERATIVE DISORDERS

Despite similarities in symptoms, there are obvious differences both between people with the four different disorders and within the groups. These include differences related to age, gender and living arrangements as follows:

- Whilst overall the average age of adults with NDD is 61 years, adults with MS and HD have lower average ages, 53 and 58 years, respectively, and those with MND have a higher average age of 64 years. People with PD had the highest average age, 72 years.
- Under forty per cent of adults with NDD are male. There is a definite gender bias for those with MS (one in five adults with MS is male) and PD (three in five adults with PD are male). MND and HD affect men and women at the same rate.
- Adults with NDD may live alone or live with others. In either case they may or may not have carers. For example, only 12 per cent of adults with MND live alone and have no carers compared with 34 per cent of those with MS. Over 76 per cent of adults with MND live with family members who are their carers, compared with 30 per cent of people with MS and 84 per cent of those with HD.

In 2007, there were an estimated 7,600 adults with a NDD living at home in Western Australia. Of these, the biggest group is adults with PD (74 per cent). Adults with MS comprise 22 per cent of this estimated population. Less than four per cent of the NDD population living at home have either HD or MND.

By 2021, the number of adults with NDD will have grown to about 9,600 adults. This growth reflects an increase in the size of the WA population and assumes that prevalence rates applicable in 2007 apply also in 2021. If incidence rates for MS and PD increase, and prevalence rates for MND increase, then the 2021 population of West Australians with NDD living at home could be as high as 14,000.

HOME CARE SUPPORT SERVICES

Four main categories of home care support¹ – personal care, domestic assistance, social support and gardening and home maintenance – were examined in the project. In 2007, at least 25% of adults living with a NDD at home required these types of home care support services, although this ranged from about 15 per cent of males with MS to 44 per cent of females with MND. That is, about 1,900 adults accessed support in the home, such as personal care, cleaning, social support and gardening and home maintenance, in 2007.

In the postal survey, it was found that the amount of personal care services received by adults with NDD averaged 5.2 hours per week but the average hours of personal care described as needed in the home was 6.5 hours per week. These gaps in personal care services were identified for 25 per cent, 45 per cent and 18 per cent of people with MND, MS and PD who reported current and/or needed hours of service, respectively. These gaps ranged in size from 1.5 to 4 hours for those with MND, 1 to 27 hours per week for those with MS and 1.5 to 7 hours per week for those with PD.

Housework is another home care service received by adults with NDD but gaps were evident for between 30 per cent and 40 per cent of people with MND, MS and PD and for 20 per cent of people with HD. The gaps ranged from 0.25 hours per week to 6.25 hours per week for people with PD. Gaps for people with other NDD were at least 0.5 hours per week and at most 4.5 hours per week. The average gap for all people using this service was a half hour per week.

Another service commonly provided to people with NDD living at home is social support. Up to 60 per cent of people with PD reported needing between 0.25 and 4 hours extra of social support per week. Twenty five per cent of people with HD said they needed about four hours more per week. Two in every five people with MS need as much as 11 extra hours per week of social support. No respondents with MND needed extra social support. Despite this, the average gap identified in social support services was for 1.3 hours a week, thus equalling personal care in terms of the size of the average gap between the services received and the services needed.

The amount of gardening or home maintenance received by adults with NDD averaged 0.5 hours per week. However, it was reported that this type of home care support was needed for, on average, 1.3 hours per week. Gaps in gardening and home maintenance services were common – 50 per cent of adults with MND had gaps of between 1 and 2 hours per week, 65 per cent of those with PD reported gaps ranging from ten hours per year to 3 hours per week, and 74 per cent of adults with MS said they needed between 4 hours per year and 4.5 hours per week more assistance of this type. No respondents with HD reported needing additional hours per week of gardening and home maintenance services.

¹ Other types of home care support are in-home respite, meals-on-wheels and transport. Nursing and allied health services might also be provided.

It is predicted that, by 2021, the number of adults with NDD living at home and needing support will be at least 2,388 (assuming constant prevalence rates and constant proportions of the population needing homecare) or 3,600 (with expected changes to prevalence rates). Unmet need for home care support for this group of people is projected to rise from a total of 115,000 hours per year in 2007 at an annual cost of about \$3.5 million (in 2007 dollars) in 2007, to 211,000 hours per year in 2021 at a total cost of, at most, \$9.8 million (\$6.5 million in 2007 dollars). This represents about 2.3 per cent of the total WA Home and Community Care² (HACC) 2007/2008 budget of \$153 million (WA Department of Health, 2007a).

In summary, the total cost of home care support for people with NDD is about 3.4 times the cost of the gap or unmet need. In 2007, the total cost of HACC-type support to people with NDD living at home is estimated at around \$12 million. This is 7.8 per cent of the HACC budget for WA in 2007.

² “The HACC program is a key provider of community care services to frail aged and younger people with disabilities and their carers. The HACC program is a joint Commonwealth State and Territory initiative under the auspices of the Home and Community Care Act 1985. It provides services to support people who live at home whose capacity for independent living is at risk” (WA Department of Health, 2007b: 43). “The Australian Government also jointly funds community care with the states and territories through the Home and Community Care program (HACC) which provides services to people with disabilities, as well as to older people. HACC services for older people generally assist people with lower levels of care needs than those who receive residential care and community care packages. HACC assists older people to defer or avoid the need for residential care or community care packages” (Department of Health and Ageing, 2006: 3).

IMPLICATIONS

1 Current Funding and Models of Care

Home care support is currently funded by a combination of Federal and State aged, disability and health care programs. Generally, HACC and care packages are available for the aged with a variety of disability programs for the young and those with reasonably stable conditions, either physical or intellectual. The difficulty for people with NDD is that they are usually too young to be eligible for the aged care type support and their conditions are degenerative which makes disability type support inadequate. Moreover there is no seamless transition from one type of service to another and the interface with the health sector is also complicated. Thus, the overall home care support system is complex and the level of misunderstanding among providers and individuals accessing the system is widespread. The lack of consistent application of funding guidelines across agencies and geographical locations is also a source of frustration.

In the main, health and allied health professionals and home care service providers feel that it is the inflexibility of the current funding assistance structure that is most to blame for gaps (unmet needs) in home care support. There is no single bucket of funds and assistance.

“Home care support criteria are too limiting for, and means testing should not apply to, people with MND. That is, (these) people should be able to access whatever is necessary in a timely fashion.” (Health professional, 2008)

Provision of home care support for people with NDD and their families within the existing framework of disability and aged care funding and resources is seen as inadequate and often also inappropriate. As a result, providers often report being frustrated in their attempts to do their jobs well, and are concerned that the well-being of carers and the maintenance of quality of life for care recipients are compromised.

2 Individualised Care – Flexible, Timely and Appropriate

People with NDD are a small group with specific, complex and individual needs that require timely, appropriate and increasing levels of care as their conditions deteriorate. Timely, appropriate care is particularly important for those with high care needs – about one third of this group. For individuals and their carers, the burden of caring at home can be considerable. However, the alternative of residential care is, in some cases, not appropriate or, in many cases, not available.

“Home care support services must be flexible to accommodate the unpredictable course and the complexity and uniqueness of each individual’s experience.” (Home care service provider, 2008)

The key difficulty in meeting the needs for this group of people is that their conditions are not stable and can be unpredictable. They need ongoing assessment related to:

- clinical management of their disorder and its symptoms (and any other health issues);
- home support (including services, transport, equipment, housing modifications and assistive devices); and
- access to suitable respite, both in and out of home (irrespective of whether or not they have a carer).

Obtaining services in the first instance or obtaining assessments of revised circumstances require some deft navigation of the community and health care systems. However, adults with NDD have varying competencies in relation to accessing these systems. At one extreme are people living alone who have few financial resources, no family or social networks, and reduced or no ability to know where to start to negotiate the application processes for home care support, including interpreting the eligibility rules.

At the other extreme are resourceful individuals who are good with problem solving. In some cases, it is the carers (often life partners) who have these skills. In these cases, care recipients or carers can coordinate many sources of support. In the case of people with few resources, it is support agencies or service providers who tend to take the lead in coordinating avenues of home care support. Indeed many care workers are de facto case managers.

Whilst some generalisations can be made about home care support needs for people with varying levels of mobility or difficulties, these are not useful for defining the delivery of specific services, etc, to particular clients in the home. Not only can disorder-related physical, psychological/psychiatric and cognitive difficulties vary, but individuals can also differ in terms of pre-morbid personalities, co-morbidities, their experiences with the health and community care systems, and their support networks of carers, family and friends. Also, the stage they are at in the progression of their disorder provides another difference. In summary, a one-size-fits-all approach to providing a 'choreography of care' for individuals with NDD is not effective or appropriate.

3 Access to Respite

Health and allied health professionals and home care service providers argue that different types of respite, catering to different needs, should be readily available to individuals with NDD and their families. These types of respite are:

- Overnight respite in the home: This type of respite would allow the carer to have a good night's sleep whilst the care recipient remains safe, with toileting and other night-time care needs met.

- Short and long term residential respite: Short term (less than one week) planned respite in an appropriate residential facility would allow the carer the opportunity to spend some time in the home, or away from their home, without caring responsibilities and providing an opportunity to refresh. Longer term (more than one week) planned respite in a suitable residential facility is also needed. This might enable the individual to have their care plan refined, their symptoms to be stabilised and their clinical treatment plan to be evaluated and revised. It can also allow the carer the opportunity to have a much needed break thereby reducing the risk of carer burn-out.
- Emergency respite in an appropriate residential facility: This type of respite is needed if the carer is suddenly and temporarily, through ill health or stress, unable to provide the level of care required.

“The use of hospital high care beds for respite is inappropriate. These beds should be allocated to emergency patients.” (Health professional, 2008)

Some individuals resist accessing respite. The individual with a NDD may not want to go to residential respite because of a fear of being institutionalised or not receiving the appropriate care, or a misapprehension about the stage they are at in their disorder. Many do not like leaving their familiar surroundings.

“Some clients won’t accept strangers caring for them.” (Home care service provider, 2008)

Similarly, some carers are reluctant to make use of respite for either their own sake or the needs of the care recipient. They may feel that accessing respite is an admission of their inability to cope with their caring role.

“No-one can care as well as I can.” (Carer, 2007)

Currently, suitable respite for people with NDD is difficult to obtain in the metropolitan area and rare in the country.

4 Disorder-specific Residential Facilities for Permanent Placement and Respite

There are only two dedicated facilities in WA – the Multiple Sclerosis Society of Western Australia (MSS WA) metropolitan respite facility which caters to people with MS and some others with neurological conditions and similar care needs, and the Brightwater residential facility for young people with HD, Ellison House. This is also located in the metropolitan area. However, The MSS facility has only 6 respite (including one emergency) beds and Ellison House has 12 permanent beds and no respite. Both facilities appear to have long waiting lists.

Usually, care workers at residential facilities, especially in aged care settings, are unlikely to be knowledgeable about either NDD or the care needs of people with NDD. This is not unexpected due to the low incidence of these disorders. That is, it is difficult to gain experience if the caseload is primarily people who do not have a NDD. Whilst efforts are made to provide professional development (related to symptoms, medications and care needs) to care workers in a variety of settings, most service providers acknowledge that high staff turnover and absenteeism can disrupt the continuity of appropriate care for any one individual.

Permanent placement in residential facilities is generally unnecessary for people with NDD. Instead, with more support in the home, such as social support and in-home respite, service providers envisage that families can manage at home for much longer. If families can be encouraged to access more home care support, then providers feel the demand (and unmet need) for beds, whether respite or permanent, in residential facilities would reduce. However for those who require 24 hour supported living, age appropriate options, with disorder specific expertise, are needed to ensure quality of life and care, for example, HD and MS clients with high support needs as well as cognitive or behavioural problems.

5 Carers

Carers with good communication skills are the exception and not the rule in the lives of people with NDD. Yet, current funding models for in home care support tend to assume that people with NDD who are living at home have either the resources to organise their own support or a carer who is willing and able to do this for them.

“The key to successful home management of the needs of patients ... is having a competent and physically and mentally fit carer as well as living within a geographical area that has sufficient access to services including good palliative care support. In this case, (the patient's) desire to remain at home throughout the course of their disorder can be achieved.” (Health professional, 2008)

Most carers take up their caring role by default. For example, the person with NDD may be their child, their parent or their life partner. The normal familial relationship becomes, over a period of time, usurped by a new relationship characterised by dependency and considerable physical, emotional and social demands, resulting in changed roles within the relationship and the added distress of watching a loved one deteriorate. This change may be subtle and over a long period of time, or it could occur markedly and within a short period.

“I spend most of my day going backwards and forwards ... I just do a job, that's what it is, and it doesn't matter how many days, how many hours, or what time of the day or what time of the night, you've got to go to work.” (Carer, aged 69 years, referring to his wife, aged 67 years, who has HD, 2007)

SUMMATION

People with neurodegenerative disorders need timely access to their own individualised package of care support that is funded appropriately with eligibility criteria that suits their circumstances (where they live, whether they have a carer who lives with them, what type of housing they live in, etc) but is not means-tested. It needs to be flexible in the quantity and type of services provided at any one time allowing an increase over time as required and including an allocation for case coordination. Some capacity to purchase services would also be helpful. Such care support will allow people with neurodegenerative disorders access to resources from a range of health, disability and aged care funding sources.

Total home care support for people with neurodegenerative disorders has to be both quantitatively increased (by about \$1,800 per person in 2007) and qualitatively enhanced and these improvements need to happen with haste. Without these improvements, people with NDD and their families experience progressive reduction in their quality of life. Importantly, the need for this essential support will increase in the future as a result of overall population increases as well increased longevity due to improved treatments for NDD and changes to the age profile of the population.

Filling the gaps in home care support for people with neurodegenerative disorders is likely to increase the current (Home and Community Care (HACC)) budget by about 2 per cent per year, assuming that this budget is progressively increased by cost inflation appropriate to community care expenditure items. Compared with options for residential care and hospitalisation, neither of which are necessary or satisfactory, increasing support in the home in a flexible and timely manner is preferred by carers and the professionals and care workers that support them. In addition, personal dignity and quality of life are thought, by people, their carers and their health and care workers, to be best preserved in the home.

In addition to the four neurodegenerative disorders that have been examined in this project, there are many other acquired and degenerative disorders, neurological and otherwise, that impact a similar younger target group. For individuals within this group, their increasing home care needs also lead to growing service gaps. These gaps may arise as well in relation to access to equipment. It would seem to be appropriate for policymakers and planners to encourage further examination of this broader group with a view to more effective targeting of ageing, health and disability resources.

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FURTHER INFORMATION

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PROJECT REPORTS

There are six reports for this project:

- Report 1: Client and Carer Survey Results
- Report 2: Client and Carer Interviews
- Report 3: Case Studies
- Report 4: Data Linkage 2006
- Report 5: Key Issues and Unmet Needs - Health, Allied Health and Service Provider Perspectives
- Report 6: Projections of Unmet Needs