

**Neurodegenerative Disorders Project - Report Number 3**

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

**CASE STUDIES**

**by**

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## **PROJECT REPORTS**

There are six reports and an Executive Summary 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

## **FURTHER INFORMATION**

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## 1 BACKGROUND

The project is an investigation of the home support needs of people in Western Australia with one of four neurodegenerative disorders – Multiple Sclerosis (MS), Motor Neurone Disease (MND)<sup>1</sup>, Parkinson's Disease (PD) and Huntington's Disease (HD). The project has a number of components including the development and analysis of a linked database of members of disorder-specific support agencies and clients of home care service providers, an analysis of member and client characteristics 1996 – 2006, a postal survey, interviews, case studies and projections of unmet needs for home care support.

The purpose of the project is to provide home and community care providers, planners and policymakers with information that will enable them to better understand the current and future home care support needs of individuals (and their families/carers) living with Neurodegenerative Disorders (NDD) in the community. To this end, the quantitative and qualitative outcomes from the analyses of the survey, interview and membership/client data are complemented with four examples of the lived experience of individuals with NDD. With an understanding of the key issues related to unmet needs, better funding and planning can eventuate.

This report presents the results of the case study (or vignette<sup>2</sup>) component of the project. Hughes (1998: 381) defines vignettes as “stories generated from a range of sources”. In this project, these case studies integrate the evidential material collected for analysis of the gaps in home care support for a sample of people with NDD. This process comprehends the argument by Hughes (1998: 383) that “no (single) research tool can truly reflect people's real life experiences”. Rather, a combination of tools (such as surveys, interviews and diaries or a series of consecutive interviews) can bring the researcher in closer contact with the reality of the lived experience. For example, Cornwall ((1984) cited in Hughes, 1998: 384), in her series of interviews about people's health, found that as “she got to know the people in her study ... later interviews contained more private accounts that reflect richer and more detailed descriptions of people's lives”. This was the experience of the research team for this project as the early survey responses from the four case study participants were followed up with semi-structured face-to-face interviews and, later, structured diary entries.

The vignettes presented in this report are thus illustrative of the home care support needs from the perspective of individuals and their carers. That is, they provide a snapshot of a range of experiences with attempting to live in the community whilst having, or caring for someone with, a neurodegenerative disorder. Vignettes have been used in other studies for similar reasons (see, for example, Cheek, *et al.*, 2005 in relation to the care transition experiences of older people and their families).

Unlike other studies that use vignettes (Hughes, 1998) or develop vignettes (Chesson, 2003), this project did not intend to directly obtain participants' perceptions, beliefs and attitudes. Indirectly, however, participants' assessments of their needs, the helpfulness of the care they receive from care workers as well as from carers, and their summation of their lived experience will be coloured by their values and opinions. However, discerning differences between participants based on these parameters is beyond the scope of this project.

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<sup>1</sup> In northern America, this disorder is known as Amyotrophic Lateral Sclerosis (ALS).

<sup>2</sup> The terms ‘case study’ and ‘vignette’ have been used interchangeably in this report.

The remainder of this report is structured as follows. Section 2 summarises a number of studies that use a case study approach, or similar, in the examination of the home care support needs of people with neurodegenerative disorders. Also referenced in Section 2 are some studies that examine event-affect congruence using event recording.

The process of developing the case studies from survey, interview and diary information is described in Section 3. Sections 4 to 7 present the four case studies. Note that in three of these, information from both clients and carers was used. One of the case study participants did not have a carer. A discussion of the case study information in Section 8 includes a comparison of the lived experiences of the four case study participants as well as reference to previous studies. The Conclusions in Section 9 suggest future research ensuing from this case study approach.

## **2 LITERATURE REVIEW**

In this section, two types of studies are summarised. The first of these are studies of the home support needs of people with neurodegenerative disorders, in particular, those studies that have included case studies of the lived experience of study participants. Section 2.1 summarises these studies. Note that there do not appear to be any studies of home support needs for people with any of the neurodegenerative disorders that develop case study summaries from participant diaries.

The second type of studies, discussed in Section 2.2, is those that refer to the methodology of event reporting and its usefulness in case study development. For this project, studies that compare diarised events and daily moods are especially informative.

### **2.1 Studies of Home Support Needs**

Studies in Australia and overseas of the home support needs of people with neurodegenerative disorders have collected data and information using a variety of methods. Some have used postal surveys (Black, Grant, Lapsley, & Rawson, 1994; Kristjanson, 2004; Krivickas, Shockley, & Mitsumoto, 1997; O'Hara, DeSouza, & Ide, 2004; Solari, Ferrari, & Radice, 2005). Other studies have made use of structured or semi-structured interviews of people, their carers and/or health professionals (Chesson, 2003; Dawson, Kristjanson, Toye, & Flett, 2004; Habbermann & Lindsey-Davis, 2005; Hughes, Sinha, Higginson, Down, & Leigh, 2005; Kersten, *et al.*, 2000; Kristjanson, 2003, 2004; McGarva, 2001; Skirton & Glendinning, 1997; Tribe, *et al.*, 2006; van Teijlingen, Friend, & Kamal, 2001). One study has used focus groups (Ward & Cavanagh, 1997). Only one of these studies (Chesson, 2003) has used information from participants to present detailed case studies.

In her study of carers of people with MS, Chesson (2003) used the information from semi-structured face-to-face interviews to present six case studies. Unlike the current project and its emphasis on identifying the gaps in home care support for people living at home, the Chesson study targeted only one type of support, social support, for one group of people, carers of people with MS. Nonetheless, Chesson's study provides some useful points of comparison with the current project. For example, Chesson found, in her small sample, an inverse law of care. That is, as need increased, support from family and friends decreased. She also reported lost friendships as both care recipients and carers became less able to socialise and wheelchair use prevented many social activities due to difficulties with access.

## 2.2 Studies Using Event Reporting Methodology

The use of event reporting methodology to shed light on event-affect congruence is discussed in Lawton, DeVoe and Parmelee's (1995) study of the lived experience of the elderly residents of a nursing home and congregate housing<sup>3</sup>. The authors argue that the recording of events is selective and not inclusive of all events and that this requires few cognitive demands (pg 470). This selection process is subjective in that usually only what the participant thinks is worth reporting is reported. Hence reported events are a subset of all events that occur in the day. Whilst not comprehensive, those events that are recorded provide valuable insights into the lived experience of the participants.

Event-affect congruence refers to the effect of relatively minor events on daily variations in mood. In their appraisal of previous research in this area, Lawton, *et al.* (1995) commented that there appear to be "selective congruence of positive events and positive mood and negative events and negative mood" (pg 469). Lawton and Simon ((1968) cited in Lawton, DeVoe, & Parmelee, 1995: 470) take this one step further, suggesting that, as personal competence decreases, event-affect congruence increases. That is, as health deteriorates, environmental effects on psychological well-being are stronger. Note that this hypothesis was not able to be confirmed by Lawton, *et al.* (1995).

There are a number of ways that study participants can record daily events, for example, in a diary or on a proforma. The latter approach has the advantage that participants are kept focused on the task at hand – recording the events of the day and their scores on various wellness or mood scales. Free flow diary entries on the other hand may be difficult to analyse if parameters of interest are not recorded each day.

## 3 METHODOLOGY

From the client and carer interviews (see NDP Report No 2 – Client and Carer Interviews) and in line with the project plan, the research team chose four people, one for each disorder, to be the case study participants. The main criteria for inclusion in the vignettes, were a high level of dependency (that is, needing help all the time with at least one of their activities of daily living) and a perception by the research team of the individual's or carer's ability to record the required information about their daily lives. In addition, the research team were keen to have different living circumstances as well as disorders represented. A summary of the characteristics of the case study participants and their living situations, derived from their responses in the postal survey, are shown in Table 1.

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<sup>3</sup> Congregate housing differs from nursing homes in that it doesn't include any major medical care which nursing homes offer and it offers a measure of privacy and independence that nursing homes cannot (Helpguide.org, 2001-2008). This type of housing is also referred to as supported accommodation. Residents tend to have their own rooms but share kitchen, dining and other communal facilities.

Table 1: Characteristics of Case Study Participants

Case Study Participant	Disorder	Age (years)	Carer	Age of Carer (years)	Time Since Diagnosis (years)	SEIFA <sup>a</sup>	Mobility
	(1)	(2)	(3)	(4)	(5)	(6)	(7)
Adela	MND	61	Daughter (lives elsewhere)	36	2	929.4	Use of wheelchair inside with use of arms
Beth	MS	59	No carer	n/a	15	1069.0	Use of wheelchair inside but little or not use of arms
Charles	PD	69	Wife	71	39	964.2	Trouble walking but no aids
David	HD	64	Wife	61	14	1165.1	Trouble walking but no aids

Notes: <sup>a</sup> Socio-Economic Indexes for Areas (SEIFA) is an Australian index of relative socio-economic disadvantage based on 2001 Census data. Values over 1000 represent areas (postcodes) of advantage relative to the mean and values under 1000 represent areas of disadvantage relative to the mean. Note that within areas (postcodes) there can be considerable variability in wealth, education and occupation. Hence the case study participants may not necessarily have the socio-economic characteristics of the SEIFA assigned to their area.

It can be seen in Table 1 that there are similarities and differences between the four case study participants who are all living in their own homes. For example, the average age of participants (column 2) ranges from 59 to 69 years (average age of 63.2 years) which is slightly older than the average age of survey respondents of 60.8 years. There are three different types of living arrangements (Column 3) – no carer, live-in carer and carer who lives elsewhere. The mean age of the carers (Column 4) is 56 years (n = 3) compared with the mean age of carers in the survey of 63.3 years (n = 493). These differences are for noting only as the choice of case study participants was not intended to be representative of survey respondents.

Table 1 also shows that time since diagnosis (Column 5) varies from 2 years for Adela who has MND to 39 years for Charles who has PD. As each of the participants is at the end stage of their disorder, time since diagnosis is close to the average diagnosis to death longevity for each of the disorders. In the case of Charles, who has PD, his symptoms commenced when he was at a young age - 29 years. It is rare for people with young-age onset of PD to live as long as he has. This is even more surprising given his co-morbidities of leukaemia and glaucoma.

Column 6 shows the values of the index of socio-economic disadvantage (SEIFA) for the suburbs in which the case study participants reside. It can be seen that two of the participants live in areas that are more disadvantaged than the average (SEIFA = 1000) and two live in suburbs that are classified as more advantaged. However, it should be noted that the index provides an average across the postcode area and is not necessarily a true reflection of the socioeconomic status of the participants themselves.

The final column in Table 1 shows that two of the four case study participants are in wheelchairs and two have trouble walking but are not using any walking aids (see Column 7). In the diaries, it can be seen that one of these participants has daily problems with falling and hence his carer is regularly called upon to help him to stand. The other participant usually spends the waking part of his day in a special chair which has modifications that provide him with postural assistance.

Each person or couple were given the diary (see Attachments A and B) in person by the research team. In one case, the participant was also sent, by email, an electronic copy as she was going to complete her diary on her computer. The research team read through the diary instructions with the participants and answered any questions about information to include in, and exclude from, the diary.

In two cases, the carers would be completing the diaries on behalf of the care recipients so some clarification of whose point of view would be recorded was necessary. In one of these cases, the care recipient asked that his carer exclude some information pertaining to his daily living from the diary entries.

The information to be collected in the diaries reflected concerns that were raised during interviews with clients and carers as well as issues that were raised in other similar studies. Three of these issues appeared to impact on the quality of life of people with NDD and their carers as they continued to live at home. First, a number of interview participants commented on the busyness of their days with the constant flow of care workers and other visitors. There was a sense in the interview comments that, whilst the help was welcome, the downside of this intrusion was reduced privacy, increased dependence and a loss of control.

A second issue raised in interviews was the routine and simplicity of daily life. Many individuals and carers seemed to set themselves small daily goals, the achievement of which gave them confidence and a sense of normality. Being unable to achieve even small goals appeared to be quite dispiriting. Finally, during interviews, participants often referred to 'good' and 'bad' days – a subjective account of their daily quality of life. One of the case study participants in Chesson (2003) reported that her daughter with MS appeared to have 'good and bad weeks' and 'good days and bad days'. Lawton *et al.* (1995) suggested that positive and negative affects can be linked to particular daily events.

The research team were interested in whether these three issues were linked. That is, does the flow of visitors to the home, some of whom may be new to the family, and the achievement or otherwise of small daily goals lead to a sense of a 'good' or 'bad' day? In addition, is the type of visitors important to the 'goodness' or otherwise of the day. For example, Larson, *et al.* (1986) in their study of the daily well-being of older adults concluded that the quality of time spent with friends was, on average, better than the quality of time spent with relatives.

To this end, the diary was designed so that each daily entry had three parts. The first part was a table listing visitors to the home – who came; whether they were care workers, relatives, friends, volunteers, or health or allied health professionals; when they came and how long they stayed; what they did while they were in the home; and whether they gave the help that was needed. The second part of the daily diary entry asked about the setting and achievement of daily goals – did you do what you had hoped to do today? The final part of the diary entry was for the individual (or carer in consultation with the individual) to summarise their day – was this a good day? If so, why? If not, why not?

The research team hypothesised that ‘good’ days may be defined by having a certain number of visitors who were known to the individual and gave the necessary help together with the achievement of small goals. ‘Bad’ days might reflect too many visitors to the home or not enough help as well as frustrated goals.

Each of the case studies to follow is written using data from three different collections – the postal survey (completed between March and May 2007), the face-to-face interview (held between July and September 2007) and diaries (about four consecutive weeks during November and December 2007). Follow up phone calls, face-to-face conversations or emails have also been used to clarify some of the information for some of the participants. The real names of the participants have not been used.

The four neurodegenerative disorders that are the focus of this project - MS, MND, PD and HD - influence daily living for both the person with the disorder and for the people with whom they share their lives. How each care recipient deals with this depends on whether or not they have a carer, live-in or not, what their home is like (have they made modifications or moved), what equipment they can access, whether they can travel outside the home, and what support they get from various sources, including home care service providers. The following sections present personal perspectives on this lived experience. Note that visits can be purely social or they can involve some help with one or more activities of daily living. Sometimes they are a combination of both.

#### 4 ADELA (MND)

Adela, 61 years, was diagnosed with MND in 2002 and needs help always with most activities of daily living. Adela lives alone and her carer is her adult daughter, Meghan, who lives nearby. Meghan is 36 years old. Adela lives in a southern Perth suburb. Meghan and the home care support provider, Perth Home Care, share care tasks such as personal care, meal preparation and social support. Adela completed the hard copy diary herself.

At the time of the survey (March 2007), Adela was using a wheelchair inside her home and had the use of her arms. Weakness in her arms was increasing however such that, by the time of interview (August 2007), she was less able to lift her arms, for example to reach grocery items at the supermarket and to hang washing. She was only able to do activities at ‘lap level’. Nonetheless, Adela was able to write Christmas cards and do some craft for Christmas gifts, which she noted in her diary (December 2007). One day she was able to clean her birdcage – “*(this) is getting harder but (I was) glad I could do it*”. Adela can still use the computer (laptop) and feels good about sending emails to friends.

Adela uses Department of Planning and Infrastructure (DPI) subsidised taxi services to go shopping, go to social engagements, to visit family and friends and to go to medical appointments. Due to upper limits on the subsidy<sup>4</sup>, Adela has had to pay up to \$300 for a one-way trip to the city to go to medical appointments at the tertiary hospital. She has no alternative transport arrangements.

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<sup>4</sup> Eligible users who use a wheelchair or scooter may be entitled to a 75% subsidy, up to a maximum of \$25 for each single trip (WA Department for Planning and Infrastructure, 2007).

Adela's chief concern is about how much longer she will be able to remain in her own home. The threshold for her moving into residential care will be determined by a need for 24 hour care and/or a need for better symptom management. Even if her current home care support regime is improved, the fact that she lives alone means that her needs will eventually increase beyond the scope of the community care system. Adela is on a waiting list for a place at a residential facility<sup>5</sup> and, whilst reluctant to leave the familiarity and privacy of her home, is aware of how her needs are continuing to increase. She has had some respite in residential facilities with varying degrees of satisfaction.

In her survey responses, Adela listed mild levels of difficulty with muscle spasms/tremors/involuntary movements, pain, sensitivity to cold, tearfulness, weight gain and eyesight. She had medium levels of difficulty related to fatigue/tiredness, sleep disturbance and swollen feet/hands. Adela also listed weak arms and/or legs as an extreme difficulty.

Adela's home care assistance at the time of the survey amounted to 18 hours per week and she did not think that, at that time, she needed more services. This had changed however by the time she completed the diary nine months later when she recorded that the home care service provider re-assessed her needs after her recent discharge from hospital and agreed to allocate her more time. In subsequent entries in the diary Adela recorded midday services being added to the morning and evening personal care Monday to Friday. Prior to this, in her diary, Adela expressed frustration at the care provider's reluctance to increase her service in response to the longer time it takes the care worker to do the showering, dressing and toileting as well as the extra tasks that Adela used to be able to do for herself – meal preparation and laundry.

In March 2007, Adela had no breathing difficulties. However, in the interview in August she revealed that she had started using a Variable Positive Airway Pressure (VPAP) machine to assist breathing at night. In her diary entries in December, Adela refers to numerous occasions of breathing difficulties – *“am finding it hard to cough up phlegm which makes me breathless from trying”*, *“coughing too much and trouble catching my breath”*, and *“I could hardly breathe and couldn't cough up much ... (which was) ... distressing”*. In early December, Adela was admitted with respiratory distress to the palliative care unit at Peel Hospital for four days and then transferred to the high dependency ward at Sir Charles Gairdner Hospital for a further five days. In her diary (which she continued to maintain throughout her hospitalisation) she writes that, as her condition deteriorated (pneumonia then a collapsed lung), she was *“frightened that I may not recover”* and *“doctors (were) very concerned”*. Within six days of her initial hospital admission, Adela started *“feeling I am getting better”* and was *“able to say a few words without becoming breathless”*. The day before her discharge she was able to *“sit up out of bed and cough independently”*.

Adela experienced mostly good days over the period of filling in her diary, excluding the first few days in hospital when her deteriorating condition made her feel frightened. On those days that some of her goals were not met, she was still able to record a good day because other goals were met or she was able to do something enjoyable like going to visit her daughter – *“change of environment”*. She recorded in the diary that all of her visitors provided her with the help she needed.

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<sup>5</sup> Adela went into residential respite two weeks after completing her diary entries. She was subsequently offered a permanent place which she accepted. She did not return home after respite and at the time of writing has been in the residential facility for four months.

Adela kept the diary for 37 days including the nine days she spent in hospital. In the 28 days she was at home, Adela was visited by 21 people representing 78 separate visits and between 2 and 3 people coming into her home each day. Only one of these people had not visited Adela previously. She had some extra visits in the few days immediately after her return home from hospital from palliative care team staff. Over Christmas, two of Adela's daughters who live interstate visited Perth. They visited Adela in her home and she was able to visit with them at her Perth-based daughter's home.

Forty five visits were from six care workers sent by the home care service provider. One of these care workers made 16 visits for personal care, the other five care workers made between 1 and 7 visits. Adela can thus rely on having a familiar face at least once per day. Adela's daughter/carer, Meghan, visited 15 times over the period, for night-time care on Fridays and some midday care (lunch preparation, etc) on some days.

Five staff from the palliative care service made 6 visits suggesting that palliative care workers are not allocated to regular clients. Neighbours and other family members visited Adela nine times over the period and would make a tea/coffee and sometimes do something specific for her. She also had three one-off visits - an OT, a computer technician and the Silver Chain researcher. On some days Adela went out shopping, to choir, to church, to functions at the retirement village and to visit family and friends.

## 5 BETH (MS)

Beth, 59 years, was diagnosed with MS in 1992. She lives in the metropolitan area and has no informal carer. Beth has a number of care workers from various home care support providers including Silver Chain, MSS WA, Care Options, The Carers and Stanhope Healthcare Services, who assist her during the day, 7 days a week. She has a high level of dependency, and uses an electric wheelchair operated with mouth controls as she has no use of her hands and arms. Beth is having a purpose built house built on land adjacent to her current home and is looking forward, when it is finished and she can move in, to having access to a garden again. Beth completed her diary using her computer.

In the survey, Beth reported that she had a mild level of difficulty with itching and muscle spasms/tremors/involuntary movements and a medium level of difficulty with balance, fatigue/tiredness, pain and swollen hands/feet. She also reported extreme sensitivity to cold and extreme weakness in arms and legs. She has no co-morbidities. Her mobility level is severe with very little physical movement. However, Beth can still converse and, with the aid of assistive technology, can use a computer for email, making Christmas cards, etc.

From the diary entries, Beth had 101 visits from 26 different people over an 18-day period in November/December 2007, averaging between 5 and 6 visitors per day. All of these people had been to see Beth previously. Fifty five of the visits were from six home care service providers, at least three visits per day, mainly for showering, toileting, feeding, medication and transferring.

A further 46 visits, or 2 to 3 visitors per day, were from family, friends or neighbours all of whom helped Beth with repositioning, shopping, laundry, phone calls, etc, or social support. In her diary, Beth reported that these visits were important to her – *“having a friend around is always a good feeling”* and *“(this was a good day because) ... I had a visit from my brother”*. In her interview, Beth had stated that, whilst she might need more care, she didn't really want more people in the house because it made her exhausted.

In the lead up to Christmas, some of her friends helped Beth with preparing Christmas cards which she was producing on the computer. It is likely that these visitors would still have visited during this period and helped with other activities or given social support.

In the survey, Beth had reported that she received about 48 hours of home care support each week and that this was sufficient. This amount of assistance didn't seem to have changed in the period between completing the survey and filling in the diary. As Beth cannot do anything for herself in relation to personal care, she needs a reasonable time allowance for all visits during the day. She needs help with getting out of bed in the morning using the hoist to transfer, showering, dressing and positioning comfortably in the wheelchair for breakfast. During the day, Beth gets help with lunch, including being fed, and toileting. In the evenings, she has help with supper, toileting, and putting to bed. In the survey, she commented that she was no longer getting the 1am visit from Silver Chain any more and misses that.

On good days, Beth reported that she felt well or relaxed. On those days she might have had a visit from a friend or her brother. On bad days she may have reported that she was tired. Some days were neither 'good' nor 'bad' which might also be related to her being tired or uncomfortable due to the weather, or being unable to fulfil some personal goals for the day – *"because I didn't get any work accomplished"*. In a separate conversation with the research team, Beth expressed her belief that emphasising the positive aspects of her life was important to her. She was particularly appreciative of living in Australia and being able to access the technology and devices that she uses.

## 6 CHARLES (PD)

Charles has PD and is 69 years. He and his wife, Nina, live in regional WA. Nina, who is Charles' carer, completed the hard copy diary for him. She is 71 years old. They are not receiving assistance other than cleaning from Silver Chain once a fortnight. Nina helps Charles always with all activities of daily living. At Charles' request, Nina has not sought help from a home care service provider, such as personal care, in-home respite and social support. One of Chesson's (2003) case study participants, Mrs Mitchell, suggested that, whilst "you should ask for help ... (but) sometimes it is very hard to accept" (pg 61). Charles did not use assistive devices such as walking and continence aids.

In the survey, Charles reported mild levels of difficulty with dizziness, hallucinations, irritability and tearfulness and medium levels of difficulty with balance, bladder incontinence, boredom, bowel problems, breathing, clumsiness, constipation, muscle spasms/tremors/involuntary movements, sleep disturbance, weak arms and/or legs and eyesight. Extreme difficulties for Charles related to communicating, expressing feelings, falling, fatigue/tiredness, lapses of concentration, remembering, responding appropriately to others, sensitivity to cold, speaking, swallowing and understanding or comprehending. In the interview, six months later, Nina commented that Charles' continence difficulties had worsened. As a result, she does a lot of washing. Charles did not use continence aids, although they had information on the federal-funded Continence Aids Assistance Scheme which provides financial help to people needing to purchase continence aids.

Charles was diagnosed with PD in 1968 and has two co-morbidities – leukaemia and glaucoma. Nina reported that it was difficult to distinguish between the symptoms of the leukaemia from the effects of the PD. In the diary, Nina reports that Charles is *"very tired at the end of the day"* and sleeps a lot during the day.

This often follows a busy day, for example, if they are away from the home during the day to go to medical appointments or to visit family or friends. Some days, Charles needs “*plenty of help all day*”. When his fatigue is so extreme, Charles is more prone to falling. One of the difficulties for Charles of having PD relates to his deteriorating posture. This has prevented him from easily reading the newspaper, for example.

During the 28 days of keeping the diary, Nina recorded that they had 16 visits from 10 people, averaging between none and one visitor per day. All visitors had visited Charles and Nina previously. Nine of these visitors were family or friends. One visitor was from the home care support provider for one and a half hours of housework per fortnight. Nina was ambivalent about the helpfulness of this cleaning for which they make a small co-payment. In the interview in August, Nina had mentioned that having the house cleaned was helpful. However, the cleaner they were allocated did not do a good job, particularly in the bathroom. Leaving the floors wet was dangerous for Charles with his balance and falling difficulties. Nina was stressed about this but did not want to report it to the provider. Following the interview, the research team gave general feedback to the provider but, without specific details, the provider could not follow up.

In addition to having friends and family visit, Nina noted in the diary that she and Charles had visited friends, attended functions at the retirement village and went to medical appointments. Charles still liked to do some gardening, including pulling weeds, pruning and watering. However, due to his balance and falling difficulties, he is sometimes unable to do these or attempts them but falls. If he is unable to do something, Charles feels “*annoyed*”. Sometimes, he starts doing something in the garden but is “*quickly exhausted*”. During the period of the diary, Nina wrote that Charles went for some walks, unaided, around the village.

One day, Nina notes in the diary that “*it was one of the worst days possible, (Charles) fell and slept a lot*”. On this day, the home help had been to clean which, as mentioned earlier, is always a stressful experience for Charles and Nina. In addition, they were unable to go to afternoon tea at the village club house due to Charles’ fatigue. Nina had mentioned at the interview in August that she did not like to leave Charles for any length of time because of his tendency to fall. Hence, if Charles wasn’t up to an outing then Nina would stay home also. The following day was “*much better than previous day*” and Nina and Charles were able to go to the village club house for morning tea. In the same week, they were able to attend a late afternoon wedding at the club house which was, Nina wrote, “*achieved ... without any problems, rare*”.

## **7 DAVID (HD)**

David, 64 years, has HD at a high level of dependency. He and his wife, Olwyn, receive considerable in-home support, including personal care, in-home respite and social support. David and Olwyn live in metropolitan Perth. David has regular respite in a residential facility. Olwyn completed the hard copy diary in consultation with David although she sometimes found it difficult to elicit his exact responses. Olwyn is 61 years old and is David’s carer.

David was symptomatic when he was diagnosed with HD in 1993. His family history showed that his grandmother, mother, uncle and two cousins had HD.

In the survey, Olwyn reported, on David's behalf, that he had mild levels of difficulty with irritability, lapses of concentration, responding appropriately to others and sleep disturbances. He had medium levels of difficulty with constipation, falling, heat intolerance, muscle spasms/tremors/involuntary movements, pain, remembering, sensitivity to cold and weak arms and/or legs. David had extreme difficulty with balance, bladder incontinence, bowel problems, clumsiness, communicating, expressing feelings, fatigue/tiredness, speaking, swallowing and weight loss.

David, at the time of the survey, was receiving 18 hours of home care support from Brightwater in a weekly package. This involved 10.5 hours of personal care and 7.5 hours of social support. According to his response in the survey, David did not need extra hours of care. However, in the carer section of the survey, Olwyn reported that she would like more assistance with providing personal care and minding, and with doing gardening and home maintenance. By the time of the interview, they were receiving some extra help with minding from the palliative care service. They were also about to have help with the housework.

David and Olwyn had used residential respite in an aged care facility two or three times a year for two weeks at a time. This is funded through the Commonwealth Respite and Carelink Centre. Olwyn noted on the survey, that they would like more respite "when needed" and in a respite house, preferably for younger people. Since completing the diary in December 2007, Olwyn has placed David's name on a waiting list for residential placement. The residential facility is one to which David has gone previously for respite – "*where he has been the most comfortable and well cared for*".

There were two key factors in the making and timing of Olwyn's decision. First, Olwyn had recently acknowledged her physical limitations in caring for David. Second, Olwyn was concerned that, should something happen to her, their daughters would have to step in to help and that this would be difficult.

*"I believe it's quite significant that the reason for my concern about the difficulties with our daughters being able to assist me to any great degree, is that our oldest daughter who lives opposite me, is already symptomatic with Huntington's disease and the younger daughter has the gene and will, at some stage, develop the illness. The fact that Huntington's Disease is a genetic disease causes a considerable degree of emotional problems for the whole family. As the prime carer, it's a constant balancing act to be of support to a number of people all at varying stages of the same disease while managing your own emotions. While carers are constantly urged to take time out and look after themselves, the amount of in-home support at this level of advanced care, is in no way adequate. Carers in the home are now well aware of the well-documented problems with on-going staff shortages and the expectations by service providers that the carer will manage, particularly when respite is referred to as a "non-essential" service."*

Olwyn recorded the diary for 25 days. During this time they had 108 visits, an average of 4 to 5 visitors per day, from 57 different people. Five of these people had not been to visit previously. Just under half of the visits were from three different home care support providers, two support organisations (AHDA and NSU) and two medical providers (a GP and a speech pathologist). The remaining visits were made by family and friends. These visits include two friends visiting Perth from interstate and overseas, respectively. One of the visits was for nursing care of a leg wound.

David usually had a regular care worker for his morning routine and other care workers from the home care support provider attending between one and five times over the period. Three different care workers from the palliative care team provided seven occasions of in-home respite. Family and friends visited between once and four times per day over the period. Whilst most of these visits provided both David and Olwyn with some social support, these visitors often provided food or cooked meals or helped with David's routine in some way.

One of the comments that Olwyn made at the conclusion of the survey was “*being mentally unprepared for the impact that the additional help and changes needing to be made in the home had on me*”. They had installed rails in the home and replaced the bath with a hobless shower. At the time of the survey, David did not have all the equipment he needed. Whilst these modification and equipment needs had been resolved by the time of the diary entries, it was no longer tenable for David to continue to remain at home.

## 8 DISCUSSION

The client and carer interviews highlighted a number of quality of life issues for people with neurodegenerative disorders. First, whether or not people had a good or bad day (Chesson, 2003 also referred to good and bad weeks) appeared to depend on whether or not they had achieved something on their ‘to do list’ during the day. These lists included activities which might prove challenging given their level of functioning, for example being able to go to choir practice and sing if they had respiratory or breathing difficulties, or everyday tasks that they wanted to keep doing, like washing the dishes, which required some adaptation and/or determination. The same applied to carers, especially those who felt that the caring role represented the totality of their life. Lawton, *et al.* (1995: 469) refer to available literature that confirms that, for older people, “daily variations in mood are related to relatively minor events”.

A second issue, that was more obvious for people who received many services than those who needed less help with activities of daily living, was the number of people visiting the home at any one time or over a period of time (eg, a day). Anecdotal evidence suggests that whilst the assistance is much appreciated, there is a downside to having so many visitors to the home, some of whom may be familiar faces – regular care workers, family or friends - or new faces – relief care workers, or locum health professionals. Deriving an optimum number of visitors to the home is not useful as individual circumstances on a day-by-day basis might suggest fewer or more visitors.

Unlike Chesson's (2003) study of carers of people with MS, an inverse law of care did not seem to apply for the case study participants in the current study. Perhaps for Charles and Nina there were not many family and friends visiting their home, but they were still able, at the time of filling in the diaries, to socialise at various events in their retirement village. Adela had fewer social visits but she had moved interstate to be closer to her daughter. However she had made friends within her retirement village and in social groups outside the village. Beth had many family and friend visitors who visited regularly, as did David and Olwyn.

The law of care is also not supported in this example from an interview earlier in the project, with the widow of a man with MND who had participated in the piloting of the postal survey. This carer said that after her husband's death she had little contact with the many friends who had, during her husband's illness, been regular visitors to their home. She felt that *"they must have been (his) friends"*. The nature of the disorders and the needs for practical and emotional support during the course of the illness are considerable for both the person being cared for and their carer. However, daily life for carers of people with neurodegenerative disorders after the death of their partner, family member or friend is not well documented. The termination of home care support services, the return of equipment and the dismantling of devices compounds the grief. The widow referred to above reported that trading in her purpose built wheelchair-friendly van for a small car was further confirmation of the huge loss she was feeling.

Quality of life can also be affected by the availability of practical support in the home. One of the case study participants referred to a reduction in service – Beth stated that the 1am visit from Silver Chain no longer occurred. Changes in services are not unusual. These may occur because providers withdraw services they can no longer staff or that they do not receive adequate funding for. Alternatively, the client may ask for a different service mix, for example, asking that more hours be allocated to showering and/or toileting or bedtime settling. In Beth's case, the 1am visit was withdrawn by the provider due to funding changes.

Concomitant with the intrusion, albeit helpful and encouraged, of so many visitors is a fourth issue related to the quantity and size of equipment, other adaptive devices and housing modifications. Generally, these are necessary trappings of a disabled life. Hence, they send specific signals about the person with the disorder and their level of functioning together with a very clear sense of the life-limiting nature of the disorder. Wheelchairs need to be stowed when not in use, bathrooms and bedrooms are cluttered with hoists and commode chairs. Comfortable bedding is replaced with a serviceable electric/hospital bed. Kitchens are turned into mini-pharmacies with prescription and over the counter medications, medication charts and, possibly, percutaneous endoscopic gastrostomy (PEG) feed equipment. Other devices such as blenders and tap-turners are also evident. Overall, lack of independence is clear.

In the case studies, the issues of equipment and transport are raised in relation to the lived experience of people and their carers. However, the equipment needs for people with neurodegenerative disorders were not specifically looked at in this project although the postal survey of clients and carers did ask if people had the equipment they needed and responses in the provider interviews included comments on equipment needs. Similarly, transport needs were touched on in the postal survey (see NDP Report No 1 – Client and carer survey results), the client and carer interviews (see NDP Report No 2 – Client and carer interviews) and the provider interviews (see NDP Report No 5 – Key issues and unmet need – health, allied health and service provider perspectives).

According to estimates based on survey information, none of the case study participants had any unmet needs for home care support. However, piecing together the information from the three sources – survey, interview and diary – revealed a different picture. For example, Beth missed her 1am visit from a home care service provider. For someone like Beth who lives alone and is quadriplegic, such a visit could have provided physical (for example, repositioning in bed) and social support.

Charles and Nina have a number of difficulties which could be alleviated by appropriate home care support. However, they are not asking for or accepting any help except for domestic assistance. David and Olwyn receive a considerable amount of support during the week, but Olwyn copes, in the main, on her own on weekends even though the needs on weekends are no different to care needs during the week. Finally, Adela has the appropriate types of care, but, as her condition has deteriorated since the survey, the levels of care (time allocated to different tasks such as toileting) are no longer sufficient. The service allocation is not flexible enough to be changed quickly to her new levels of dysfunction.

Chesson's (2003) case study participants talked around rather than directly about unmet needs for home care support. For example, Mr Duncan, who cared for his wife who had MS, needed respite as well as social support. He cited the Council's refusal to help as a source of frustration (pg 55). Another of Chesson's case study participants, Mrs Graham, also referred to lack of respite and that care workers and carers appeared to be substitutes and not complements – 'the more you do, the less help you get' (pg 58).

## **9 CONCLUSIONS**

In summary, some deterioration in functioning and increase in needs over the period of the study was apparent for three of the four people in the case studies; only Beth, who has MS, appeared to be clinically stable over the nine months of data collection. Adela and David had declining function over the same period and had more help by the end of the year. Charles also had more difficulties and some existing difficulties worsened over the period. However, he and Nina continued to manage on their own and not use a home care service provider for personal care or services other than domestic assistance. This deterioration is one of the salient features of neurodegenerative disorders.

The lived experience of the four case studies reported here are not dissimilar to the anecdotal evidence of the experiences of other people with neurodegenerative disorders (and their carers). Some are able to access and accept care arrangements with home care service providers; others are protective of their privacy and independence.

Investigations into equipment and transport needs, which were summarily touched on in this project, could be the focus of future research.

## REFERENCES

- Black, D., Grant, C., Lapsley, H., & Rawson, G. (1994). The Services and Social Needs of People with Multiple Sclerosis in New South Wales, Australia. *Journal of Rehabilitation, Oct/Nov/Dec*, 60 - 65.
- Cheek, J., Ballantyne, A., Gillham, D., Mussared, J., Flett, P., Lewin, G., et al. (2005). *Options, opportunities and older people: An exploration of care transitions of older people* (Report for the Australian Research Council (ARC) Linkage – Projects). Adelaide, SA: University of South Australia, ACH Group and Brightwater Collaborative (Brightwater Care Group, Silver Chain and Perth Home Care Services).
- Chesson. (2003). *Who's there for carers? The role of social support and social networks for carers of people with Multiple Sclerosis* (Report): Health Services Research Group The Robert Gordon University for MS Society Scotland.
- Dawson, S., Kristjanson, L., Toye, C., & Flett, P. (2004). Living with Huntington's Disease: Need for supportive care. *Nursing and Health Sciences*, 6, 123 - 130.
- Habbermann, B., & Lindsey-Davis, L. (2005). Caring for Family with Alzheimer's Disease and Parkinson's Disease: Needs, Challenges and Satisfactions. *Journal of Gerontological Nursing*, 31(6), 49 - 54.
- Helpguide.org. (2001-2008). Congregate housing for seniors. Rotary Club of Santa Monica and Wise and Healthy Aging Online.
- Hughes, R. (1998). Considering the vignette technique and its application to a study of drug injecting and HIV risk and safer behaviour. *Sociology of Health and Illness*, 20(3), 381 - 400.
- Hughes, R., Sinha, A., Higginson, I., Down, K., & Leigh, N. (2005). Living with Motor Neurone Disease: Lives, Experiences of Services and Suggestions for Change. *Health and Social Care in the Community*, 13(1), 64 - 74.
- Kersten, P., McLellan, D., Gross-Paju, K., Grigoriadis, N., Bencivenga, R., Beneton, C., et al. (2000). A Questionnaire Assessment of Unmet Needs for Rehabilitation Services and Resources for People with Multiple Sclerosis: Results of a Pilot Survey in Five European Countries. *Clinical Rehabilitation*, 14, 42 - 49.
- Kristjanson, L. (2003). *Assessing the Extent to which Existing Models of Supportive Care Service Delivery meet the Needs of People living with Multiple Sclerosis, Motor Neurone, Parkinson's and Huntington's Diseases and their Families* (Summary Report of Phase I). Perth, Western Australia: Edith Cowan University.
- Kristjanson, L. (2004). *Assessment of the Effectiveness of Australian Models of Palliative Care Delivery in Four Neurodegenerative Disorders* (Final report). Perth: Edith Cowan University.
- Krivickas, L., Shockley, L., & Mitsumoto, H. (1997). Home Care of Patients with Amyotrophic Lateral Sclerosis (ALS). *Journal of Neurological Sciences*, 152(Supp 1), S82 - S89.
- Larsen, R., Mannell, R., & Zuzanek, J. (1986). Daily well-being of older adults with friends and family. *Psychology and Aging*, 1, 117 - 126.
- Lawton, M. P., DeVoe, M. R., & Parmelee, P. (1995). Relationship of events and affect in the daily life of an elderly population. *Psychology and Aging*, 10(3), 469 - 477.
- McGarva, K. (2001). Huntington's Disease: Seldom Seen - Seldom Heard? *Health Bulletin*, 59(5).
- O'Hara, L., DeSouza, L., & Ide, L. (2004). The Nature of Care Giving in a Community Sample of People with Multiple Sclerosis. *Disability and Rehabilitation*, 26(24), 1401 - 1410.
- Skirton, H., & Glendinning, N. (1997). Using Research to Develop Care for Patients with Huntington's Disease. *British Journal of Nursing*, 6(2), 83 - 90.
- Solari, A., Ferrari, G., & Radice, D. (2005). A Longitudinal Survey of Self-Assessed Health Trends in a Community Cohort of People with Multiple Sclerosis and Their Significant Others. *Journal of the Neurological Sciences*, 243(1-2), 13 - 20.

- Tribe, K., Longley, W., Fulcher, G., Faine, R., Blagus, L., Pearce, G., et al. (2006). Living with Multiple Sclerosis in New South Wales, Australia, at the Beginning of the 21st Century: Impact of Mobility Disability. *International Journal of MS Care*, 8(1), 19 - 30.
- van Teijlingen, E., Friend, E., & Kamal, A. (2001). Service Use and Needs of People with Motor Neurone Disease and Their Carers in Scotland. *Health and Social Care in the Community*, 9(6), 397 - 403.
- WA Department for Planning and Infrastructure. (2007). Taxi and charter: Passenger subsidies. Retrieved 21 February, 2008, from [http://www.dpi.wa.gov.au/taxis/15155.asp#What\\_subsidy](http://www.dpi.wa.gov.au/taxis/15155.asp#What_subsidy)
- Ward, H., & Cavanagh, J. (1997). A Descriptive Study of the Self-Perceived Needs of Carers for Dependents with a Range of Long-Term Problems. *Journal of Public Health Medicine*, 19(3), 281 - 287.

## **ATTACHMENT A: DIARY INSTRUCTIONS**

### **Neuro Project: Diary Instructions**

**Name(s):** \_\_\_\_\_

**The diary has three parts.**

#### **Part A: Who came to visit or help you today?**

We are particularly interested in knowing who comes to help you during the day and whether they are paid carers, family, friends or volunteers. We would also like to know if these people are regular visitors or carers, or whether they are new.

You might like to fill this out during the day.

#### **Part B: How are you feeling today?**

We are also interested in knowing how you are managing on a daily basis. For example, have you achieved something you set out to do today? Have you been unable to do something today?

You might like to fill this out at the end of the day.

#### **Part C: Was this a good day?**

Here we are interested in how you felt at the end of the day.

If you have any questions about filling in this diary please feel free to call **Margaret Giles on 9242 0185 or Dawn Woods on 9201 6758.**

Thank you for helping with this project.

Date Diary Delivered: \_\_\_\_\_

Date Diary Picked Up: \_\_\_\_\_

**ATTACHMENT B: DIARY ENTRY**

Day: \_\_\_\_\_ Date: \_\_\_\_\_

**Part A: Who came to visit or help you today?**

First name	Are they <i>Family or Friend</i> or from an <i>Organisation</i> ?	Has this person been here before? Yes/No	What time did they arrive?	How long did they stay?	What did they do to help?	Did they give you the help you needed? Yes/No

**Part B: What goals did you have for today?**

Is there something you wanted to do today and were able to do it?		Was there something you wanted to do today but <u>were not</u> able to do it?		
What was it?	How do you feel about achieving this?	What was it?	How do you feel about not being able to do this?	Will you try again?

**Part C: Was this a good day?**  Yes  No  Uncertain (please tick your answer)

Why or why not? \_\_\_\_\_