

Neurodegenerative Disorders Project - Report Number 2

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

CLIENT AND CARER INTERVIEWS

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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 (NDD) – Multiple Sclerosis (MS), Motor Neurone Disease (MND)¹, Parkinson's Disease (PD) and Huntington's Disease (HD). There are a number of components in the project including the development and analysis of a linked database, a summary of the characteristics of participating organisations' members and clients 1996 – 2006, a postal survey of clients and carers, interviews with clients, carers and providers, client case studies and projections of the gaps in home care support for people with NDD as the Western Australian population increases and ages.

This report summarises the outcomes of interviews with members/clients and carers². In the remainder of this section, other studies that used interviews with patients with neurodegenerative disorders and their carers are summarised. The interview process, including sampling, is described in Section 2. The interview responses are summarised in terms of daily lives (Section 3), achievable and relinquished goals (Section 4), current home care support needs (Section 5) and future needs (Section 6). The Conclusions in Section 7 include discussion of the process for choosing people for the development of case studies.

A number of other Australian and overseas studies have also used interviews to obtain information on, *inter alia*, unmet home care support needs. In Australia, Dawson *et al.* (2004) and Kristjanson (2003; 2004) used semi-structured face-to-face interviews and Tribe *et al.* (2006) used phone interviews. Dawson *et al.*'s study of care needs recruited HD patients (n = 6) and carers (n = 19) as well as health care workers (n = 7). Their findings include "that palliative care services for people with Huntington's disease and their informal carers need to provide expert psychological and practical support and perhaps most importantly, be flexible, adequately planned and choreographed."

Kristjanson's (2003; 2004) interviews of people with MS, MND, PD and HD (n = 41), their carers (n = 70) and health care professionals (n = 24) was the first phase in a two part study of the effectiveness of Australian models of palliative care for people with these disorders. The second phase was a postal survey to patients and carers (Aoun, Kristjanson, & Oldham, 2006; Kristjanson, Aoun, & Oldham, 2006; Kristjanson, Aoun, & Yates, 2006). This has been discussed in NDP Report No 1. The aims of the first phase of the Kristjanson study were to assess the effectiveness of existing services in relation to the unique needs of each disorder and to summarise key issues raised by carers in relation to their care responsibilities.

In her conclusions regarding the phase 1 results, Kristjanson (2004) reported that individuals with neurodegenerative disorders and their carers preferred the option of home care for as long as possible, that carers needed support to be effective in their caring role, and that care in the home required a plethora of services including care workers, allied health professionals, general practitioners (GPs) and specialists, respite and palliative care. The interviews also raised the joint issues of high costs (in particular, medications, equipment, transport and home modifications) and reduced income (through loss of employment for the patient and often for the carer as well).

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

² NDP Report No 30 summarises key issues raised in interviews with health and allied health professionals and service providers.

MS patients (n = 2,525) and carers (n = 116) were interviewed by phone for the Tribe *et al.* study (2006) to determine factors affecting their living arrangements, employment rates and uptake of immunotherapy. In their conclusions, Tribe *et al.* stated that “essential medical care and personal support needs were mostly well met but less reliably so for the most severely disabled respondents and those living farther from major cities. The most frequently reported unmet needs were for breaks from home and employment support” (pg 19).

Three studies in England³ also used face-to-face semi-structured interviews to examine the needs of people living at home with MND (Hughes, Sinha, Higginson, Down, & Leigh, 2005), MS (Kersten, *et al.*, 2000) and HD (Skirton & Glendinning, 1997). Hughes *et al.* interviewed MND patients (n = 9), their carers (n = 5) and professionals (n = 15) regarding their lived experiences and their service needs. They concluded that meeting the myriad of health, social and palliative care needs for people with MND are best achieved through “improved sources of information, and improving the integration of health, social and palliative care policies and practices”.

Despite some limitations related to inconsistencies in interview techniques across countries⁴, Kersten *et al.* (2000: 48) reported that the interviews in London and elsewhere revealed that,

“as Maslow has suggested, there may be a model of hierarchy of need in which higher order needs emerge as lower ones are fairly well satisfied. Such a model would also explain why, in countries with higher provisions of services such as Belgium and the UK, so many needs for equipment and services including therapy and medical care were expressed. Alternatively, the provision of these services may have empowered disabled people and raised their expectations.”

The aim of the Skirton and Glendinning (1997) study in England was to examine the support and care provided for people with HD living in the largely rural county of Somerset and to identify unmet needs for home care support. They had two main conclusions. First, a coordinated proactive approach was more successful than a crisis management approach as is often the case. Second, each HD patient needs to be assigned a case manager or ‘key worker’. This would preferably be a district nurse or community psychiatric nurse. Importantly, the authors felt that these aspects of an effective model of care were also applicable to the home care support of other patients with a range of complex, long-term disabling conditions such as MS.

Two studies in Scotland used structured interviews with HD patients (n = 15) and their carers (n = 16) (McGarva, 2001) and with MND patients and their carers (n = 153) (van Teijlingen, Friend, & Kamal, 2001). Both studies were looking at home care support needs. Teijlingen *et al.* found that “the formal health and social care sectors in conjunction with voluntary organisations are only partially managing the trajectory of patients with a rare progressive degenerative disease” (pg 397).

³ The Kersten *et al.* study included interviews in Belgium, Estonia, Greece and Italy.

⁴ For example, “the large differences in service provision may also partly have been caused because some patients were interviewed whilst they were inpatients in a rehabilitation centre whilst others were interviewed at home where their last contact with a service provider may have been a long time ago.” (Kersten, *et al.*, 2000: 48)

McGarva (2001) found that “the burden of care is falling upon people who will themselves become increasingly less able as the person they care for becomes more dependent”. As with the Skirton and Glendinning (1997) study in the UK, McGarva argued for multi-disciplinary assessment and support as well as practical collaboration between agencies.

In the US, semi-structured interviews with carers of people with PD (n = 20) and Alzheimer’s Disease (n = 20) were intended to identify the types of assistance most helpful in caring for a family member at home (Habbermann & Lindsey-Davis, 2005). Habberman *et al.* concur with McGarva (2001) that the carers need information (and training) not only about how to care but also about how to care for themselves.

Pozzilli *et al.* (2002) interviewed MS patients (n = 201) in Italy to compare, *inter alia*, the cost effectiveness of home based care versus hospital care. In their conclusion they stated that “comprehensive planning of home based intervention implemented by an interdisciplinary team and designed specifically for people with multiple sclerosis may provide a cost-effective approach to management and improve the quality of life” (p. 250).

In summary, these studies, all of which use structured or semi-structured interviews with patients, carers and/or health professionals, found unmet needs for home care support of some degree and recommended a multi-faceted, case management approach to the care in the home of people with neurodegenerative disorders.

2 INTERVIEW PROCESS

In the postal survey which was conducted early on in this project (see NDP Report No 1 – Client and carer survey), respondents were asked to indicate whether or not they would be available for interview. Three quarters of survey respondents (n = 804) agreed to be interviewed and made this known by providing their name and contact phone number. However, only 48 people were to be selected for interview.

The selection of people for interview depended on their disorder, their living arrangements and their level of dependency. Table 1 shows frequencies of respondents agreeing to be interviewed in each sub-category. Respondents who are independent (n = 228) are excluded from Table 1.

Table 1: Matrix of Potential Interviewees: By Disorder, Living Arrangement and Level of Dependency

Disorder/Living Arrangement	Low Level Of Dependency	Medium Level Of Dependency	High Level Of Dependency	Total
MS				
No carer	131	26	21	178
Live-in carer	41	34	39	114
MND				
No carer	2	3	4	9
Live-in carer	0	8	19	27
PD				
No carer	56	11	10	77
Live-in carer	32	56	69	157
HD				
No carer	0	0	0	0
Live-in carer	6	4	4	14
All	268	142	166	576

The interviews were conducted between the end of July and mid-September 2007⁵. The final matrix of disorder, living arrangement and level of dependency in the interview sample is shown in Table 2. Forty nine interviews were subsequently undertaken.

Table 2: Matrix of Actual Interviewees: By Disorder, Living Arrangement and Level of Dependency

Disorder/Living Arrangement	Independent	Low Level Of Dependency	Medium Level Of Dependency	High Level Of Dependency	Total
MS					
No carer	1 ^b	3	1	3	8
Live-in carer	0	3	0	3	6
MND^a					
No carer	0	2	2	2	6
Live-in carer	0	0	3	4	7
PD					
No carer	0	2	2	3	7
Live-in carer	0	2	2	2	6
HD					
No carer	0	1	0	0	1
Live-in carer	0	3	2	3	8
All	1	16	12	20	49

Note: ^a Also interviewed was the widow of a member who had died earlier in the year. Her responses are included in the category of MND/high level of dependency/live-in carer. This couple had previously participated in the piloting of the survey. ^b This participant had survey responses that suggested a higher level of dependency which turned out not to be the case.

⁵ One interview was conducted in October 2007 because the survey respondent was going into respite in August. Then, due to complications related to changes in his medication regime, he had to stay in respite for a longer period.

In addition to asking for information that had not been asked for in the postal survey, the interview questionnaire asked for confirmation of information that had already been supplied in the completed survey. The main purpose of this was to check whether the person had altered needs between the date they completed the survey and the interview date. This enabled confirmation of their allocation to a particular category in the matrix.

In a handful of cases there had been changed needs – more or less help in the home. In some cases, the person with the disorder had experienced some deterioration since the survey date. In these cases, the person's profile belonged in a different category in the matrix - at a higher level of dependency. In other cases, some survey information was found to be incorrect. For example, a couple of people had misinterpreted the survey question on what help they received for activities of daily living. These people actually had a lower level of dependency than seemed to be the case from their survey responses. In both cases, the difference between the level of dependency reported in the survey and the actual level of dependency only became evident during the interview.

During the early weeks of the interviews, the research team were able to change the selection of people for interview in the later weeks to correct the imbalance in the interview matrix. However, Table 2 shows that, by the completion of the interviews, some categories still had either more or fewer people than expected.

For a number of categories of interviewees, there were either no survey respondents who fitted the attributes of the categories or some survey respondents who fitted the categories but did not agree to be interviewed. These categories are MND/low level of dependency/live-in carer, HD/medium level of dependency/no carer and HD/high level of dependency/no carer. In the case of the category of MS/medium level of dependency/live-in carer, also with no interviews conducted, two chosen survey respondents ended up belonging to other categories - neither had a medium level of dependency after comparing their survey and interview responses.

The four neurodegenerative disorders that are the focus of this project, Multiple Sclerosis, Motor Neurone Disease, Parkinson's Disease and Huntington's Disease, influence daily living for the person with the disorder and for the people with whom they share their lives. How each person 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 and what support they get from various sources, including home care service providers. The interview questionnaire (see Attachment A) is intended to explore these issues.

The questionnaire also included questions about short and long terms goals and how these might have changed in response to the progression of their disorder, and what they think might happen in the future. A final set of questions asks people to think about their future home care support needs and what they envisage they will need in order to remain at home. They were also asked if they had alternative plans if their current carer arrangements were suddenly unavailable.

The interviews were audio-taped and subsequently summarised, but not transcribed, by the research team. The summaries divulged common themes about current and future needs, revised life goals and other changes resulting from limitations imposed on patients by their disorder and on carers by the requirements of caring.

In some respects, the interview responses and survey responses together provided quasi-longitudinal data. That is, it was possible to see if difficulties and mobility had changed between the survey and interview dates and whether more home care support services were being reported in the interview compared with in the survey. In addition, there may have been changes in living arrangements, such as no carer at the time of the survey compared with having a carer at the time of the interview.

The percentages of survey respondents with carers in the survey population (n = 1,080) and in the interview sample (n = 49) are 43 per cent and 59 per cent, respectively. This difference is to be expected as the interview sample is not intended as representative of the survey respondents. As previously discussed, interviewees have been selected on the basis of specific criteria, one of which is whether or not they have a live-in carer. The intention was to interview equal numbers of individuals who did and did not have live-in carers. As mentioned, some individuals who had not reported having carers in the survey, did have live-in carers by the time of interview.

Some interviewees have carers who are either partners or adult or dependent children, and some people did not have carers. Those without carers may have been living alone or living with others. One person who lived alone had a carer who lived elsewhere. Some people without carers, who had considerable needs, were mostly assisted by care workers. Most people without carers still had someone in their lives who was helping them in a variety of ways either because they needed help or because the help had always been part of their living arrangements.

Table 3 summarise some of the socio-demographic characteristics of the interview sample (n = 48⁶). The discussion to follow will highlight any differences between the interview and survey samples⁷ in terms of these characteristics. Table 3 shows that interview participants are, on average, 61.7 years (n = 48). This is slightly older than the average age of survey respondents (n = 1,070⁸) which is 60.8 years. The age range of interview participants is 29 to 85 years and for all survey respondents is 18 to 93 years.

Table 3: Comparison of Interview Participants by Disorder: Age, Gender, Membership and Living Arrangements

Disorder	Number	Average Age (years)	Males (%)	Members (%)	Living Alone (%)	Live-in Carer (%)
MS	14	49.6	35.7	100.0	28.6	42.9
MND	12	63.5	50.0	83.3	50.0	41.7
PD	13	72.6	46.2	84.6	30.8	46.2
HD	9	62.1	55.6	77.8	11.1	88.9
All	48	61.7	45.8	87.5	31.2	52.1

⁶ One interview participant was the widow of a man who had died in early 2007 and so had not completed a survey. His details are not included in the survey dataset and therefore not available for the analysis reported in Table 3.

⁷ See NDP Report No 1 for comparable survey results.

⁸ Excluding respondents for whom age was not able to be calculated (eg year of birth was missing).

Whilst the average ages of interview participants with MND and PD are similar to the average ages of survey respondents with these disorders (about 64 and 72 years, respectively), interview participants with MS are younger (49.6 years) than survey respondents with MS (53.1 years). Interview participants with HD (62.1 years) are older than survey respondents with HD (58.2 years). These results follow from the high incidence of interview participants with MS and HD who are at a low level of dependency and therefore at an early stage of their disorder. For both groups, diagnosis is often at a younger age.

Males make up 37.4 per cent of survey respondents and 45.8 per cent of the interview participants. As the research team endeavoured to create a gender balance in the choice of interview participants, these differences in proportions are not unexpected. Across the four disorders, over half of the interview participants with HD are male as well as 50 per cent of those with MND, 46.2 per cent of those with PD and about 36 per cent of those with MS. The corresponding percentages of males in the sample of survey respondents are 52 per cent, 55.4 per cent, 58 per cent and 22 per cent, respectively.

The proportions of interview and survey samples who are support agency members are 87.5 and 91.5 per cent, respectively. Membership rates for interview participants range from 77.8 per cent for those with HD to 100.0 per cent for those with MS. The range of membership rates for the survey sample is from 68 per cent for those with HD to 96.2 per cent for those with MS.

One of the criteria for choosing interview participants was whether or not they had a carer. The final two columns of Table 3 provide proportions of interview participants who live alone or who live with their carer. Not included in the table are people who neither live alone nor live with their carer (that is, they live with others - partners, children and/or parents - who are not their carer). One female with MND has a carer who lives elsewhere.

Of those interview participants who live with their carers ($n = 25$), 23 live with their partner/carers and 2 live with their child/carers. One of these child/carers is aged 12 in the case of a single female with MS. The other is school-aged in the case of a single male, also with MS.

By comparison with the profile of survey respondents, interview participants are more likely to be living alone (31.2 per cent compared with 29.2 per cent of survey respondents) or living with their carer (52.1 per cent compared with 42.9 per cent of survey respondents). This may be as a result of the difficulty the research team had in recruiting interview participants who had no carer, particularly those who had HD (see Table 2 above).

In the following sections, the daily lives and current and future home support needs of people who were interviewed are discussed. Section 3 reports how people (and their carers) manage key aspects of their daily lives. For those with low levels of dependency, few changes to their daily routines are noticeable whereas, for those with high levels of dependency, their days are dictated by their functioning and the quality, quantity and timing of the formal and informal care they receive.

The goals of individuals and their carers are summarised in Section 4 with an emphasis on which goals were achievable and which goals have been set aside for reasons related to the impact of the disorder on their lives. In Section 5, current needs are reported and in Section 6, people and their carers reflect on their future needs, including whether or not they think they will continue to live out their lives at home.

3 DAILY LIVING WITH A NEURODEGENERATIVE DISORDER

Interview participants were asked to describe a typical day in their life (for example, the day before the interview) – what times they had their meals and medications, what activities and rest times they had, whether they went out during the day and, if so, how they managed this, and how this pattern of daily living was different to how they lived their lives before their symptoms started impacting on their functioning. Participants were also asked about their weekly (or, in some cases, fortnightly) routine. For those who were assisted by care workers in the home, the times and days of the visits were noted.

Some interview participants had no carer nor did they receive assistance from a home care support provider. Generally these participants had a low level of dependency and a high level of mobility. At the other extreme, a number of participants, some of whom lived alone, had considerable complexity in their care and received services from a variety of providers⁹.

3.1 Medication Routines

One of the key aspects of daily living reported by most interview participants is their medication regime and the impact this has on the timing of their meals and other activities. Some participants take medication¹⁰ for their neurodegenerative disorder as well as medication for other health issues, such as diabetes and insomnia.

People with PD are most reliant on strict adherence to the timing of their medications. A fifty four year old single woman with PD has recognised that her ability to lead a full and active life is dependent on taking her PD tablets at specific times during the day – 7 am, 11 am, 3 pm and 7 pm. The medication has to be taken one hour after eating. It allows her to stay engaged with what she is doing and she is very aware of how her functioning declines in the lead-up to her next dose. Whilst she has some trouble walking, this participant was not using any aids, was catching public transport to appointments and was active in a number of PD support groups. To deal with fatigue, she rests on alternate days.

Some individuals with MS need injections which are rotated around various sites on their bodies. Hence, even if they are able to give themselves the injections, they sometimes have their carer give them if a particular site is difficult to reach. There doesn't appear to be the decline in functioning related to the timing of medication with people with MS as there is for people with PD.

Medication for HD and MND appears to be symptom-specific. For example, some people with HD take medication to minimise the chorea associated with it. One lady with HD is taking medication to control the need to go to the toilet so often. Some individuals with MND take pain medication, in particular at night-time to help them sleep.

⁹ NDP Report No 4 – Data Linkage 2006, details the incidence of multiple service provision across ten organisations delivering home care support to members/clients of ten of the organisations involved in this study.

¹⁰ In the case of some people with MS, this can take the form of an injection.

3.2 Employment

Many of the interview participants had already retired either by the time they were diagnosed or when their symptoms began to interfere with their functioning. One 61 year old female with MND, who would have liked to keep working, reported discrimination in the workplace resulting in her early retirement. A 64 year old man was forced to take early retirement when the workplace-appointed medical assessment, instigated when he became symptomatic with HD, recommended against his continued employment. A female with MS resigned from her full-time job when she became too slow to respond to tasks.

Some interview participants are still working despite their symptoms. One 45 year old male with early stage MS is continuing to work within a fly in – fly out industry even though, on occasion, he is unwell during or after flights. He was expecting to retrain when his mobility and fatigue worsens.

3.3 Leisure

Whilst most interview participants are no longer working (all but one were dependent on others for at least one daily activity), many are trying to keep up some hobbies. These might be playing cards (a man with PD and his carer/wife play cards once a week at an organised activity in their retirement village), doing craft including sewing and knitting (two females at different stages of MS are continuing with their craft work)¹¹ and reading. However, one participant with late stage PD reported that reading the newspaper was no longer possible because his posture had deteriorated to the extent he couldn't hold his head up to read.

Most individuals spend some of their time watching free-to-air or cable television or DVDs/videos. Many also listen to the radio, including listening to 'talking books'. Wressle, *et al.* (2007), who used interviews in their study of patients with PD and their relatives in Sweden, found that even daily walks were limited and leisure activities such as bicycling decreased due to problems with balance.

3.4 Housing Modifications and Moves

Most interview participants have made changes to their housing either moving to more suitable housing or renovating their home or both. In general, the number of home modifications increases with deteriorating mobility with the most common modifications being changes to the bedroom and bathroom, installation of rails and ramps and modification to steps and split levels. The average number of home modifications rises from an average of 0.6 changes for people with a low level of dependency to 1.2 changes for those with a medium level of dependency to 1.5 changes for those with a high level of dependency. See NDP Report No 1 for further discussion of types of housing modifications and reasons for moving.

¹¹ In contrast, Wressle, *et al.* (2007) that some women with PD reported needlework "as a difficult task because of tremor and lack of initiative" (pg 134).

3.5 The Job of Caring

For many partners, caring has become a full-time job. As stated by one 69 year old partner/carer, whose wife, aged 67 years, had HD:

“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.”

This summary of the persistent nature of the caring role suggests that carers too need help in the home. As stated by Wressle, *et al.* (2007), “carers need recognition, information, honesty, someone that listens, practical and emotional help, time for themselves, good health and financial help” (pg 132).

In some cases, carers lives are complicated by more than just daily care of their partner or parent. For example, a 62 year old wife/carer of an 83 year old male with PD is coping daily with her role of caring not only for her husband but for her frail-aged mother, her daughter and new granddaughter. Intergenerational care needs of this kind are not uncommon. In his survey of carers in the UK using the first eight waves of the British Household Panel Survey (BHPS), Hirst (2001) was able to identify some cases with up to three care recipients in the carer’s household and up to seven or more in other households. Moreover, Hirst confirmed that the apparent trend of a decline in the number of multigenerational households “does not necessarily translate into a decrease in intergenerational care-giving” (pg 355).

An important issue arising from an interview with a 79 year old female with PD was that she did not consider her husband her ‘carer’. Similarly her husband, in his eighties, did not consider himself a ‘carer’. However, they were both caring for each other in a way that transcended their earlier married life. In this project, the role of carer has been linked to helping with activities of daily living so that, in this example, the perceptions of the female and her husband – not having or being a carer - were appropriate. Hirst (2001) referred to this issue in relation to the problem of identifying trends in carer prevalence. Specifically, he commented that care-giving is self-defined in most surveys and that this can lead to over-estimation of the amount of help provided by carers in both cross-sectional and longitudinal data.

4 SHORT AND LONG TERM GOALS

Whilst most interview participants were able to readily articulate their goals for the next 12 months or longer, some had no plans other than to cope with their disorder and the limitations imposed on their day-to-day living. In most cases the goals of individuals and their carers were identical. However, in some cases, the carer and the care recipient had goals that were quite different. In Section 4.1, the short and long term goals of individuals are summarised whilst in Section 4.2, the goals of carers are discussed.

4.1 The Goals of People with Neurodegenerative Disorders

Many of the interview participants had travel goals. Some had made plans to achieve these goals in the short term. Others had abandoned their goals in the face of difficulties imposed by their disorder on their functioning and needs. The travel goals included trips interstate to visit relatives or trips within Western Australia to see particular sights or to have particular experiences. Some would have liked to continue to travel but felt that they couldn’t plan beyond the next 12 months.

Some couples had had plans to be 'grey nomads' (Higgs & Quirk, 2007) in their retirement but the needs of the partner with the neurodegenerative disorder could not be accommodated by this sort of travel. For example, a couple living in a northern beachside suburb had retired early, moved into their 'dream home' and planned their caravan and car purchase in anticipation of driving/fishing trips in the north of WA or around Australia. Within two months of their retirement, his wife was diagnosed with rapid progression MND and her husband had become her full-time carer. The type of caravan that they would need to buy now would have to be self contained, at least having a shower and toilet. This would be more costly than if they had been able to use, as originally planned, on-site facilities at a caravan park. In addition, as his wife cannot be left alone for any length of time, her husband cannot indulge his passion for recreational fishing (long days at sea). Before her illness, this couple had led fairly independent lives. Now, they are together all day every day, which they have found difficult to get used to.

A man who is carer for his wife who has HD had already retired. They used to drive their caravan up north each winter but they cannot make plans to do this as his wife can no longer use the shower and toilet in the caravan.

One interview participant with early stage MS, whose level of dependency revealed he had no help with any activities of daily living and was therefore independent, was intending to bring forward family plans to travel overseas. They recognised that their future was uncertain and were hopeful to travel before his MS precluded this. Their situation was compounded by care issues for their son who had an intellectual disability.

4.2 The Goals of Carers

In the main, the goals of carers are similar to the goals of care recipients. Travel goals, both short term and long term, are the most common and these have either been simplified or abandoned. A 62 year old wife/carer of man aged 83 years who has had PD for over ten years, stated her short term goal was "*just to survive*" and, in the longer term, felt it would have been nice to have had "*a retirement together that included travelling around*".

The possibility of travelling without their partner has not been considered by partner/carers. For example, a couple aged 75 and 78 years had planned to travel around the eastern states in a van until he was diagnosed with Multiple System Atrophy (PD) over twenty years ago and is now bedridden. His wife/carer would also have liked to go back to Queensland for a visit as she had grown up there. She acknowledged that these plans would not be achieved now as her husband cannot travel and she is reluctant to leave him in respite for a long period.

Carers who are adult or dependent children of people with neurodegenerative disorders may or may not have thwarted plans. The 14 year old son of a woman, aged 39 years, who has MS and a high level of dependency, doesn't have many goals and those he has are related to his hobbies and future career. He thinks his mother's MS may prevent him from pursuing some of these goals, for example, not being able to get to training if he took up a new sport. His mother commenting on her own stymied goals, stated that she would probably not live to see her children grow up to be healthy and happy.

A 36 year old female, is carer to her mother, aged 61 years, who has MND. She lives nearby whilst her mother lives alone in an independent living unit in a retirement village. Her mother has morning and evening care from a home care service provider or from her daughter, under arrangement with the home care service provider. Her daughter has made changes to her employment, resulting in less rewarding work and a lower income, to ensure that she can provide support and care for her mother. She anticipates making further changes to her work to fit in with her mother's increasing needs. She has been unable to afford outfitting her new home as quickly as she had hoped because of her lower income. In addition, the daughter and her partner have delayed starting a family whilst her mother's care needs are paramount. This delay reflects more the reluctance of her partner in the face of uncertainty related to the mother's future needs and the daughter's further career and employment changes.

Another issue that has arisen in discussion of the responsibilities of caring is the health of carers and their goals related to this. A number of carers referred to delaying their elective surgeries because of anticipated recovery times and their unwillingness to temporarily (for respite) or permanently place the care recipient in a residential facility. Two examples are a daughter/carer indefinitely delaying her knee surgery and a wife/carer putting off her shoulder surgery.

5 CURRENT NEEDS

The interview questionnaire retraced answers from the postal survey regarding current home care needs – what these are, whether they have changed since the survey and, if so, how, what help care recipients and carers are getting and whether or not they need any more help, who could provide them with more help if necessary and what might prevent them getting the help they need.

As mentioned earlier, for some of the interviewees, their functioning had deteriorated since they had completed and returned their survey, to the extent that their level of dependency was higher. Concomitant with this change, were increases in needs that may or may not have been met by the time of the interview. In this section, discussions of the current needs of carer recipients and carers are summarised by level of dependency.

5.1 High Level of Dependency

Nineteen project participants with a high level of dependency were interviewed. Six of these had MS (four females and two males), 5 had PD (one female and four males), 5 had MND (three females and two males) and 3 had HD (one female and two males). Ten of these 19 interviewees had carers who they lived with and one had a carer who lived elsewhere. Six people lived alone and had no carer.

For care recipients who are receiving home care support from a provider, there are usually a set number of hours per week and specific tasks to be performed within the time allowed. For most care recipients, the delivery of this care is unsatisfactory for a number of reasons. One reason is that the amount of time may be too little. This can result in insufficient care or rushed care.

Another reason is the provider's use of relief or agency care workers, both of whom may be uninformed about the general needs of clients with neurodegenerative disorders or the specific needs of the clients they are scheduled to provide care for. Dissatisfaction with home care support from providers is also related to the timetable of care. Whilst some clients have some care at set times, some of their care is not delivered at specific times. The following examples highlight the type of care for individuals with a high level of dependency and the extent to which it is unsatisfactory.

A 61 year old female with MND, who lives alone, receives 18 hours of formal care. This time includes morning and evening shifts. In the mornings, she is helped out of bed, showered, toileted and given breakfast. In the evenings, she is prepared for and helped into bed. A hoist is used for transferring. She finds the time is barely adequate especially on those days that she is longer on the toilet. Her most important current care issue is the amount of time she is allocated. She is aware that the formal carers are timetabled to provide care for a number of people and that her extraordinary needs might result in delays for subsequent clients.

Another female, aged 81 years old, who lives alone and has Multifocal Motor Neuropathy (MND) has 14 hours of home care support from a provider each week. Whilst she generally has a regular care worker (45 minutes) in the mornings Monday to Thursday to help her get up, get showered and dressed and have breakfast, sometimes she has a relief care worker. The regular care worker always arrives between 8 and 8.30 am. However, if there is a relief care worker, they may arrive between 7 am and 9.30 am. She gets no notice of any changes. Because of the uncertainty of the timing of her morning care, this interview participant cannot book medical appointments in the mornings. She has care workers also in the middle of the day (45 minutes) to prepare lunch and in the evening (30 minutes). The midday care worker is organised by the provider but the care worker comes from an agency. These care workers can arrive at any time between 11.30 am and 2 pm and the client is not informed or consulted about the convenience of this. The evening care worker comes from the provider. Neither the midday nor the evening care workers are regular care workers for this client.

The two key issues for this care recipient are the timing of care worker visits and the familiarity of care workers. Regarding the first issue, she would prefer a more exact timetable of care or, at least, to be informed of changes in the times of visits. In terms of the second issue, she feels that care workers need more general training regarding the difficulties and care needs of people with neurodegenerative disorders, and all care workers need to be briefed on the care circumstances and needs of their specific clients.

Very few people with a high level of dependency do not have help from home care support providers. One 69 year old man with PD is managing at home because his wife/carers, who is 71 years old, is helping him with most activities of daily living, including showering, dressing, transferring and toileting, most of the time. His wife stated in the survey that her husband could not stay at home without her help and in the interview she raised concerns about the fragility of her own health. He has been assessed by the Aged Care Assessment Team (ACAT) as eligible for residential care in the event of needing placement in an emergency (for example, if something happens to his wife). The only assistance they receive is cleaning from a home care support provider. However, they are unhappy with this service (for which they make some financial contribution) but are reluctant to complain about it.

5.2 Medium Level of Dependency

The research team interviewed twelve people with a medium level of dependency. This group consisted of one female with MS, five people with MND (3 females and 2 males), four people with PD (3 females and 1 male) and two people with HD (1 female and 1 male). Seven of these people had carers. A further two lived with others but had no carer and the remainder lived alone and had no carer.

Interestingly, some interviewees needed less help at the time of interview compared with the help they were getting at the time of the survey. This appears to be related to three adjustments. The first of these relates to the acquisition of equipment and assistive devices that could have enabled the care recipient to undertake some daily activities that previously required help from a carer or partner. For example, railing and a shower chair could have temporarily enabled more independence in this middle stage of the disorder.

The second adjustment could be a delayed acceptance of a lower standard of activity or diminished activity at the later date. For example, someone who was used to moving within the home by themselves, may have initially requested help but later developed a means of helping themselves. The speed of the progression of neurodegenerative disorders for some people may have contributed to this apparent anomaly. That is, the suddenness of the loss of functioning may initially create dependence which later decreases as interventions are put in place.

Newcomer, *et al.* (2005), referring to the work of Lawton and Nahemow (1973), stated that “mismatches, where demands exceed capability, are thought to produce stress and inadequate performance. Demands below capability are thought to produce under-stimulation and even an erosion of ability” (pg S205). Thus it is possible that as people move from the early stage loss of functioning to the middle stage they may be more accepting of their condition, ask for less help and find ways of completing their daily activities by themselves.

Finally, medications and other treatments that become available as functioning deteriorates may enable someone to once again undertake some tasks without help. This may be the case if interventions reduce pain, tremor or fatigue. For example, someone with HD who may be at nutritional risk as symptoms worsen could find renewed vigour and need less help after accessing subsidised nutritional supplements.

Other people at the medium level of dependency stated they needed more help with tasks related, not to their personal care or needs, but to household tasks such as cleaning, gardening and home maintenance, and laundry. Some people recognised the importance of this extra help in reducing the physical burden for their carers. These needs were also expressed by some carers.

Many interviewees with a medium level of dependency were receiving enough help and didn't envisage needing more help. However, a number of interviewees needed more help but were unable, for various reasons, to obtain this extra help. One reason given by some people and/or their carers is a perception that the service providers can't provide more support due to staff constraints. For example, a 49 year old female with MS who lives alone and has no carer felt that care workers “*are in short supply and need to get paid more for what they do*”. A second reason for not being able to get more help is the financial burden on the family of treating the disorder and losing one or both incomes. The 37 year old wife/carer of a male with MND, aged 47 years, stated that the only thing preventing them from getting the extra help they needed was “*lack of funds*”.

Other project participants stated that their reluctance to seek extra help was personal. For example, a male with HD, aged 64 years, and his wife/carer, aged 58 years, reported they were not asking for help due to their “*own expectations*” about helping themselves versus accessing help from providers and others.

Another reason given by project participants for not accessing help or extra help was their ignorance about who they can ask for help if they think they need more help. For example, a 58 year old female with PD who has a 62 year old husband/carer thought they might be able to get help from the Neurological Council for social support (specifically, minding in the home). Other interviewees thought they might be able to ask a home care service provider or their Local Council for help.

A final reason for not seeking extra help is the interviewee’s perception of their need relative to the needs of others. One project participant with MND, aged 54 years, provided this explanation: “*Asking for help is difficult because ... there are people out there who are sicker*”. For someone at a medium level of dependency, there is probably knowledge of how their disorder is likely to progress and therefore some sense of comparative abilities and functioning. This observation is not unlike the perception versus observation dichotomy raised in clinical literature in relation to self-reported morbidity (see, for example, Sen, 2002).

5.3 Low Level of Dependency

Sixteen survey respondents with a low level of dependency were interviewed. Six of these had MS (4 females and 2 males), two males had MND, four people had PD (3 females and 1 male) and 4 had HD (2 females and 2 males). Eight of these interviewees lived with their carers. Three people lived with others and had no carer and five lived alone and had no carer.

As with interviewees with a medium level of dependency, some interviewees who need a minimum amount of help in the home also report that outside assistance would be welcome. However, often they do not know who to ask for this help. As stated by a female with MS, aged 38 years, who lives alone and has no carer, “*knowledge*” is preventing her from getting the help she needs, specifically, “*not knowing what you can get and how you go about getting it*”. Her needs included assistive devices and home modifications such as rails in the shower, as well as personal assistance, for example, someone giving her the daily injection and helping with the catheter. This project participant is a member of MSS WA and has received some of her injections there.

As with people with a medium level of dependency, many of the stated needs for people at a low level of dependence related to house and garden maintenance. For example, some interviewees commented on their inability to undertake annual tasks such as pruning bushes and roses, and cleaning the gutters

A 44 year old male, who has had MS for 18 years, was interviewed with his 17 year old son/carer. The father was concerned that his son was not getting the emotional support he needed. However, the son reported that he didn’t need any more support in caring for his father.

One project participant, a 68 year old male with MND, stated that he didn’t need more help in the home currently and, anyway, he “*likes to keep bureaucrats out of the house*”. Moreover, he felt that even if he was able to have some help from a home care service provider, he felt that this help would “*be cut back later on*”. He based this assumption on what he had “*seen happen to others*”.

Most people with few needs for help around the home state they are managing with their current level of assistance and don't have any reason to increase this level of assistance. This applies to people who have a carer as well as those who have no carer.

6 FUTURE NEEDS

In the interviews, survey respondents, and their carers if they had one, were asked to envisage their increasing needs for support in the home. For many, particularly those with a low level of dependency, responses reflected an unclear view of how their disorder would progress. This ambiguity was greater for people at lower level of dependency.

6.1 High Level of Dependency

Most interviewees with a high level of dependency affirmed that they wanted to stay living at home through the course of their disorder. However, some could not foresee the additional home care support or equipment that they would need even if they did agree that there may be a time when the help they would be getting would not be enough. None wanted to move into a residential facility in the future. However, a 50 year old man with PD talked about not dying at home. His preference was to move into a hospice at the end.

On the other hand, carers of people with a high level of dependency often had a good idea of the amount of support that might be needed and the possibility that the person they are caring for will not be able to continue living in the community. For example, the carer might see increased needs related to cleaning and meal preparation in the future, but their partner might think that the amount of current support is sufficient now and in the future. Some carers who were life partners mentioned that they might have to place their partner in a residential facility. A carer whose husband has PD has his name down at a respite facility in case of an emergency (herself having an accident or getting sick).

A female carer argued that it *"is totally wrong and immoral for couples to be separated when one of them goes to a nursing home"*. This issue was also raised during the survey process when the research team visited with an elderly lady to help her complete the survey. Her husband had recently been admitted to a residential facility and she had no way of visiting him – she could get a taxi to take her but her husband had been placed upstairs and there was no lift. She couldn't walk up the steep ramp and he could not be brought downstairs to see her.

A man with MS, aged 61 years, was cared for at home by his wife, aged 59 years. She also has a milder version of MS. He preferred not to think about additional home care support in the future. He stated,

"We want to live with a positive attitude and live in the now, as if nothing is going to change from that. If we start to think of what might be, it could be really disastrous, and so you live your life with fear."

A 48 year old woman with MS commented that, if she became bedridden, then she would probably go into a residential facility. She lived in Albany with her male carer. One lady, 61 years, with MND who lives alone has her name down at a facility of her choice. She chose to have some respite there to see what it was like.

Many carers cited their own health issues getting in the way of their ability to care. In some cases, carers had chronic illnesses such as a bad back or had been or were being treated for cancer. Most had not considered a 'Plan B' – what would happen if they were, without warning, unable to provide care.

Carers were often caught between their own life plans and the needs of caring. Three examples of this follow. The first example is a retired couple who live in the metropolitan area. He has MND and is 64 years. His wife, aged 57 years, is his carer. She has health issues which might prevent her continuing in her caring role. She would not like to see her husband go into residential care but they have no alternative arrangements for home care support. They spoke about an overseas trip she has delayed until her caring role is ended.

Another example is a Perth couple who are aged in their early forties. He has HD, having been diagnosed in 1999. She would like to be more available to help with the imminent arrival of a grandchild, but cannot do that whilst her husband remains at home. She feels she would be relinquishing her responsibilities by putting him in a nursing home. She summarised this inability to know what to do and to make plans – *“Everything revolves around him.”*

This was echoed by another male carer, aged 69 years, in relation to his 67 year old wife who has HD. They live in a southern Perth suburb. He commented that he had been taking care of his wife for so long (16 years) that he would not know what to do with himself if he was not caring. They know no-one else with HD so don't know what home care support they will need in the future.

Some carers talk about elective surgery that they are delaying because of their care responsibilities. The wife of a man with PD is putting off hip and shoulder surgery and a hysterectomy. The daughter/carer of a lady with MND is postponing having knee surgery. The wife of a man with MND has MS and is aware that it could get worse. However, she felt that her husband's disorder would escalate much more rapidly than her own so catering to his needs was their first priority.

Most people with HD and their carers talked about the lack of residential facilities for younger people with HD. There is one 12 bed Brightwater facility but generally people with HD, who are unsafe in the community, have limited choices. Often they are placed at the State government psychiatric facility at Graylands or in dementia hostels. In both cases, staff appear to have little training or knowledge of HD and the clinical and behavioural issues involved in the treatment of some people with HD.

Some people with a high level of dependency are managing in the community without a carer. Four interviewees were in this category. Two of the four people in this category stated unequivocally that they wanted to stay living at home. One man, aged 66 years, who has had PD for nine years, wants to stay living at home as long as he can. He has been in a nursing home before and found it inadequate for his disorder. He feels he gets better care in his own home which is less noisy, and he is not restricted by nursing staff or other patients. A lady with MND, aged 81 years, who said, after having one week of respite, she cannot see herself living in a residential facility – *“it was too depressing”*.

Not all individuals were unhappy at the thought of moving into a residential facility. For example, a 79 year old female with PD who did not have a carer thought that if she needed more help, such as personal care and social support, she would go into a residential facility. This interviewee had many years experience as a volunteer in nursing homes and hospitals.

Only one of the ten survey respondents with HD who had a high level of dependency did not have a carer. This man, aged 51 years, had recently moved into HD-specific residential care and did not want to be interviewed. Many people with HD become alienated from families and friends because of their anti-social behaviours so tend to be without a carer. Interestingly, behaviour takes a backseat to physical difficulties as a determinant of whether or not these individuals move to residential care. Wheelock *et al.* (2003:) used both cross-sectional and longitudinal analyses of a database of people with HD in Rochester New York, to determine predictors of nursing home placement for people with HD. They found that whilst, “institutionalized patients with HD are more motorically, psychiatrically, and behaviorally impaired than their counterparts living at home ... motor variables alone predicted institutionalization.”

6.2 Medium Level of Dependency

Six people were in the category of medium level of dependency with a live-in carer. As shown in Table 2, none of these people had MS. In the main, there were few differences in the responses given by these people to their future home care needs compared to people with high levels of dependency and their carers. All wanted to continue living at home and this depended, primarily, on the continuing good health of their carers.

The precise nature of alternative arrangements for home care support in the event that their current care arrangement could not continue had not been thought about by most of these couples. For example, a female carer and wife, aged 62, of an 85 year old man with PD admitted to not having alternative arrangements for her husband in place and that they “*would deal with it when (if) it happens*”. At the conclusion of the interview, the husband thanked the research team for raising the issue of having a ‘Plan B’. A husband and carer, aged 60 years, of a woman with HD similarly confided that no other plans were in place for his 57 year old wife.

A female, 37 years, who was the wife and carer of a 47 year old man with MND stated that although her husband wanted to stay at home, she didn’t think it would be possible.

“It would not be in my best interests to be stuck in the house taking care of (him) during the end stages ... I need to think of my future and where I want to go. I also have to think about the children as it won’t be healthy for them to live in that situation 24 hours a day.”

Her husband agreed with this appraisal.

The 62 year old husband and carer of a woman with PD, 58 years, stated that he wanted to make alternative arrangements but didn’t know how best to do this. The wife/carer, 58 years, of a man with HD, 64 years, said that their adult daughter could temporarily replace her mother’s care role. This couple also commented about the lack of young age facilities for people with HD. His wife commented that it is “*a very depressing future without residential care specific to HD*”.

For people without carers, all want to stay living at home. Only one, a female with PD, could articulate her future home care needs – meal preparation, personal care and housework. Some interviewees have unmet home care needs at present such as needing more time from the home help and needing help with gardening and home maintenance.

A female with MND who is 54 years old would like more social support although her friends have “*been great*”. She stated that “*asking for help is difficult because I know that there are people out there who are sicker*”. A 49 year old female with MS felt that she would get better and therefore she would continue to get all the help she needs.

6.3 Low Level of Dependency

For people with few current difficulties and needs, “*it is difficult to see what the future will bring*” as stated by a couple in which the wife has HD and the husband is her carer. They are 63 years and 67 years, respectively, and live in metropolitan Perth. Most of the couples in this category don’t have alternative arrangements nor have they thought about what they would do in the case of the carer either temporarily or permanently being unable to care. As a woman with MS commented:

“I don’t think about these things because I don’t want to, and that’s the best way of handling the situation.”

A 54 year old single mother with PD whose carer is her own mother, sees the need for additional home care support as dependent on her mother’s health and the rate of degeneration of her PD. Another single woman with PD hopes that she stays as she is all the time. She is 73 years. Both women live in the metropolitan area.

A 45 year old single male with MS stated that any home care support he might need in the future will depend on how the MS progresses. His remark reflects a comment made by one of the survey respondents in relation to unmet needs – “*I don’t have a crystal ball!*” A lady in Bunbury with MS said that she was continually changing her lifestyle – slowing down and not doing so much – and that this was arresting the progression of her MS. As a result she couldn’t perceive of a time when she wouldn’t be able to live in her own home. She was 45 years old and lived with her husband who was retired.

An eighty year old male, who has lived alone since the death of his wife, has had MND for over 20 years. He states that his symptoms have not worsened over that time so he cannot see a time when the help he is getting (for some of his shopping) will not be enough. He still does most of his own shopping and meal preparation.

Only one person with a low level of dependency mentioned the possibility of residential care being required if insufficient support was available at home. This male with MS, 44 years, stated he would kill himself before going into a nursing home because he would not be able to handle it at his age – he is “*too young*”. His nineteen year old son is his carer.

Some people with a low level of dependency who reported not having a carer in the survey or the interview were living with other people who provide some help. For example, a female with HD who is 72 years old has a son who often helps. Her need for home care support into the future “*will all depend on how far (she) deteriorates, which will happen eventually*”. A female in Albany who has PD and is 77 years doesn’t want to think ahead. She says she “*just wants to live each day*” and not worry about the future.

7 CONCLUSIONS

The interviews have provided richer detail about daily living, the choreography of care and plans and goals for people with neurodegenerative disorders whose living arrangements vary.

A final question in the interview was about how people would manage at home if their informal carer or their support network was no longer able to provide them with the assistance they needed. Bruera (2006: 1029), in his editorial comments on research into treatment choices by cancer patients as their conditions deteriorate, refers to this as 'having a plan B'. He states:

“patients and their families are familiar with the importance of having a plan B in case catastrophic events occurred in their lives (eg, car insurance, trust funds for the education of children, and so on), even though the hope these events will not happen” (pg 1029).

He then suggests that these patients would be able to effectively plan for enhanced treatments in the event of their cancer progressing and their symptoms worsening even if they are also hoping for better outcomes.

Most participants in the current project had no 'Plan B'. As Dawson *et al.* (2004) in their study of the gaps in home support for people with HD conclude, with reference to Zarit (2001), *“it is often difficult for families to talk about the ‘what ifs’, yet if these conversations do not take place, a fragile system will crumble in the face of health threats. Ideally, the window of opportunity early in the ... disease trajectory would not be neglected”*. Nonetheless, Wressle, *et al.* (2007) state that *“living for today is a coping strategy to temporarily set aside ... fears”* (pg 136).

The interviews were specifically focussed on how people and their families are coping at home so it was to be expected that the tone of interview summaries is mostly sombre and sometimes desperate. In spite of this, as many interviewees added during the interview or in subsequent contact¹², there are other dimensions to their lived experiences that may contribute to a more balanced picture of their lives. These dimensions have to do with the strength and commitment in relationships between lifetime partners, the depth of involvement with others - families and friends, faith and spirituality, and personal resources. For some, a life limiting illness represents an opportunity for personal growth. Exploration of these and other issues, however, are beyond the scope of the current project.

From these interviews, the research team decided to choose four people, one for each disorder, to provide case studies. It was also decided to choose people who had a high level of dependency. The following case studies were selected:

- A 61 year old lady with MND with a high level of dependency. Her carer is her adult daughter who lives nearby. She lives in a southern Perth suburb. She was able to complete the hard copy diary herself.

¹² Interview summaries were sent out to all those who were interviewed with a request for comments or changes. Fourteen participants (individuals and/or their carers) subsequently responded either in writing or over the phone.

- A man with PD who lives in Bunbury. His wife, who is his carer, completed the hard copy diary for him.
- A lady with MS who lives in the metropolitan area and has no carer. She has a high level of dependency, uses a wheelchair and has no use of her hands and arms. She completed her diary¹³ using her computer.
- A man with HD who has a high level of dependency and receives considerable in-home support. He and his wife/carer live in Perth. He has weekly in-home respite as well as regular respite in a residential facility. His wife completed the hard copy diary for him.

¹³ The diary was created in MS Word (landscape) and printed and bound for the three participants completing it in hard copy. For the electronic version the MS Word document had added formatting to allow easy movement (tabulation) through the document.

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ATTACHMENT A: INTERVIEW QUESTIONNAIRE

Name of Client: _____ Carer: _____

Address: _____ Postcode: _____

Phone Number: _____

Name of Interviewer: _____

**** TURN RECORDER ON ****

Before we start the interview, have you read the information sheet? In particular, counselling is available if you need it.

Are you ready to sign the consent form?

****Note that the carer has no legal right or obligation to sign on behalf of the care recipient****

Thank you for completing the survey earlier this year and offering to be interviewed. In this interview, I will refer to answers you gave in that survey and ask some additional questions.

As I explained to you on the phone, this interview will take about an hour and a half.

The interview has four parts.

The first part is an opportunity for you to provide an overview of **your life/your lives** with **Multiple Sclerosis/Motor Neurone Disease/Parkinson's Disease/Huntington's Disease**. I will also ask you about **your goals/your shared and individual goals**.

The second part of the interview asks you to explain the limitations to daily living you have experienced in the past and changes you have made to fit in with these limitations. These changes may relate to your home, your work and your other activities.

The third part of the interview asks you about your current needs and the help you are currently getting.

The fourth and final part of the interview refers to issues you, **and your carer**, raised in the survey about your, **and their**, needs in the future.

Part A:

First, I am going to ask you some general questions about your life with **MS/MND/PD/HD** and how your goals have changed because of this.

Care recipient questions:

- 1 Could you describe how your day to day life is affected by **MS/MND/PD/HD**?
- 2 a Are there things you would like to do in the near future?
 - b Have you made any plans to do these?
 - c Would anything prevent you from doing these things?

- 3 a Did you have any goals or plans that you are now unable to achieve?
b What was the key reason for these plans not happening?

Carer questions:

- 4 How has your daily life changed with the responsibility of caring?
- 5 a Do you have any short term goals or plans?
b What might prevent you from achieving or doing these?
- 6 a Did you have any goals or plans that you are now unable to achieve?
b What was the key reason for these plans not happening?

Part B:

Now, I'm going to ask you about your house, your work and your leisure time. Firstly, I'm going to ask **you/you both** about your home.

- 7 In the survey you said that you have made modifications to your house/moved house/moved house and made modifications/neither moved house nor made modifications.

What was the key reason for making these changes/not making any changes?

Do you think you will need to make further modifications/move again?

If so, why? If not, why not?

Now I am going to ask **you/you both** about your work.

Care recipient questions

- 8 a Did you change career or give up your job because of your condition?
If yes, can you explain what work you were doing and what prompted the change?
b Would changes made to the workplace have enabled you to stay in your job?
c Do you expect to make further changes in your job or career?

Carer questions:

- 9 a Did you change career or give up your job because of your caring responsibilities?
If yes, can you explain what work you were doing and what prompted the change?
b Would changes made to the workplace have enabled you to stay in your job?
c Do you expect to make further changes in your job or career?

Now I will ask **you/you both** about your leisure.

Care recipient questions:

10 a Have you given up sporting or leisure activities because of your condition?

If yes, what were these activities and why did you have to give them up?

Carer questions:

11 a Have you given up sporting or leisure activities because of your caring responsibilities?

If yes, what were these activities and why did you have to give them up?

Part C:

Now I am going to ask you about your home care needs.

Care recipient questions:

12 In the survey you said you get help with.....from.....

You also said you needed no help with.....

a Has this amount and type of help changed since you filled out the survey? How?

b Is there anything you think you need more help with and who could give this help?

c Is anything preventing you from getting the help you need?

13 Do you think your **carer** needs more support to help care for you?

What type of support?

Who could provide this support?

What might be stopping **him/her** from getting this?

Carer questions:

14 The survey said that you help with.....

a Has this amount and type of help changed?

b Is there anything you think you need more help with?

c Who do you need more help from?

d Is anything preventing you from getting the help you need?

Part D:

This is the last part of the interview and I will be asking you about your future home care needs.

Care recipient questions:

15 Do you want to stay living at home?

16 What additional home care support do you think you might need in order to continue to live at home?

17 Do you see a time when the help you are getting won't be enough?

Carer questions

18 In the survey, you said that could not stay at home without your help.

What might prevent you from helping?

19 Have you planned alternative arrangements for home care support for?

That is the end of my questions for you. Do you have anything else you would like to share?

If you think of anything else you would like to add, you can phone me. My phone number is on the information sheet.

****TURN RECORDER OFF****

Thank you for allowing me to interview **you/you both**.

Would you like to see the interview summary so that you can check that I have accurately recorded your experiences and comments? **Y/N**

Would you be interested in participating in the development of a detailed case study of your experience? You could describe the history of your condition in more detail. You could also explain how your need for support has impacted on the whole of your life and the lives of your family and friends. A useful way for you to do this would be for **you/you both** to keep a diary of your needs and the home care services you receive over the next three months. Would you be willing and able to participate with this? **Y/N**

I will contact you with the interview summary shortly and let you know if your circumstances have been chosen as a case study.

Another part of this project will involve talking with health professionals and service providers. Are you willing for us to talk with those professionals and providers who you see? If so, what are their names?

GP _____

Neurologist _____

Other medical specialists _____

Allied health professionals _____

Service providers _____

It will take about 12 to 15 months after the conclusion of this project for its recommendations to result in changes to the provision of home care services to people with neurodegenerative disorders. These changes are most likely to affect the amount and timing of services.

ATTACHMENT B: INTERVIEW INFORMATION SHEET

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

A Lotterywest-funded research project involving the Cross Agency Provider Group, support agencies, Edith Cowan University and the Neurosciences Unit of the WA Department of Health

You are being asked to participate in a research study. Please take your time to read this information statement and the attached consent form, which you will be asked to sign when a member of the research team visits your home. Please discuss any questions you may have about the project with that researcher.

What is this study about?

Many people living with neurodegenerative diseases need support to remain living in the community. This study will examine the current provision of home care services to these individuals. This will help health care planners, policy makers and providers like Silver Chain better understand the needs of individuals and families living with these diseases, and how they may be assisted to live well at home.

Who is invited to participate in an interview?

You have recently completed a survey which asked you to describe how you are managing at home and a little about yourself and your condition. When you returned the survey you indicated that we could contact you seeking your participation in an interview.

What will the interview involve?

The interview will take place in your home, or in another place of your choice. It is expected to last about an hour and a half. The questions we will ask will be about your experience of the disease and the support you have received, and the impact of the disorder on your own and your family's life. If you have a carer and you agree, we would like to ask them similar questions. If you agree, we would also like to ask, at a later date, similar questions of any health professionals or service providers that you see.

How will your privacy be protected?

If you decide to participate in an interview, you will be asked whether the interview can be tape recorded to allow the researcher to go through the tape later and ensure that the essence of everything you have said is included in the interview summary. You will not be identified by name on the tape, on the interview summary, or on any other information collected about you. Anonymity and confidentiality will be maintained at all times. In accordance with national research guidelines, all study records will be stored for five years by the Research Department in a secure location and then destroyed.

Voluntary Participation

It is important for you to know that you do not have to take part in this project and if you decide not to be involved, the services provided to you by any support group or service provider will not be affected now, or in the future.

If, after agreeing to participate, you later change your mind, you may withdraw your consent at any time simply by phoning Dawn Woods, the Research Support Officer at Silver Chain, on 9201 6758. We would then destroy any project records containing your information.

Risks and Discomfort

As a result of hearing or responding to questions in the interview, you may experience some stirring of emotions and feelings that you may wish to discuss further. The interviewer can refer you to a counsellor at no cost to you and anything you discuss with the counsellor will remain confidential and will not be included in this study.

What if you have any concerns or a complaint about how the study is conducted?

Approval for this study and its procedures have been given by the Silver Chain Human Research Ethics Committee and the ethics and research committees of collaborating agencies and providers. Any concerns or complaints about the conduct of the study should be directed to the Chairperson of the Ethics Committee at Silver Chain on 9242 0242.

Who to contact if you have any questions about the study?

If you have any questions about this study please discuss them with the member of the research team when they visit you. Should you still wish to ask any further questions please feel free to call Margaret Giles on 9242 0185 or Dawn Woods on 9201 6758.

Thank you for taking the time to read this statement.

Cross agency provider group, support agencies and collaborative partners:

Alzheimer's Assoc of WA	Multiple Sclerosis Society of WA
Australian Huntington's Disease Association WA	Neurological Council of WA
Brightwater Care Group	Parkinson's Western Australia Inc
Edith Cowan University	Perth Home Care Services
Mercy Aged Care	Silver Chain
Motor Neurone Disease Association of WA	WA Department of Health (Neurosciences Unit)