

Neurodegenerative Disorders Project - Report Number 1

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

CLIENT AND CARER SURVEY RESULTS

by

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

Multiple Sclerosis Society of WA
Neurological Council of WA
Parkinson's Western Australia Inc
Perth Home Care Services
Silver Chain
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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

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1 INTRODUCTION AND LITERATURE REVIEW

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)¹, Parkinson's Disease (PD) and Huntington's Disease (HD). There are a number of components to the project including the development and analysis of a linked database, an analysis of member and client characteristics 1996 – 2006, a postal survey of members, clients and carers², interviews with members, clients and carers as well as with health and allied health professionals and service providers, case studies, and estimations of unmet need for home support in 2007 and projections of unmet need in 2021.

This report summarises the results of the postal survey component of the project. In the remainder of this section, literature referring to the use of postal surveys with individuals having any or all of these disorders is summarised. In Section 2, the process of developing and conducting the survey used for this project is described. Response rates are reported in this Section. Survey results are presented in Section 3. Many survey respondents agreed to participate in follow-up interviews hence the conclusions in Section 4 summarise the contribution of the surveys to the interview process.

Few postal surveys have been conducted with people diagnosed with one or all of the disorders of interest to examine their use of, and need for, home support services. Most studies making this comparison, or an assessment of either services provided or services needed, have used face-to-face interviews with individuals and/or their carers and/or health professionals managing their cases.

There are two main reasons for the lack of postal surveys and the popularity of face-to-face interviews. First, the heterogeneity of the difficulties associated with these disorders and the resultant complexity of home support needs complicates survey design. Interviews, on the other hand, can be less generic and more cognisant of the individual's precise circumstances and symptoms, together with their home support use and needs. Second, by their nature these neurodegenerative disorders can be characterised by cognitive impairment, particularly in the later stages. This can compromise both the response rate and the accuracy of self report postal surveys. See Solari, Ferrari and Radice (2005: 19) for a summary of these limitations.

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

² See Appendix A for the legislation related to carers in Western Australia. Importantly, in this report and the other reports in the Neurodegenerative Disorders Report series including the Executive Summary, 'carer' means family or friend who assists the care recipient in the home. This assistance may include personal care, social support or minding. 'Care worker' means someone who is paid by either a disorder support agency, a home care service provider or some other organisation to provide care in the home. Types of care provided by care workers include advice, case management, showering, cleaning, gardening and counselling. See NDP Report No 4 for information about the services to support people in the home provided by the organisations involved in this project. See NDP Report No 5 for a summary of key issues related to the delivery of this support.

As mentioned above, very few studies in Australia and overseas analysed the home support needs of people with any or all of the four neurodegenerative disorders using data compiled from responses to a postal survey. These studies were by Black (1994), O'Hara, DeSouza, and Ide (2004) and Solari, Ferrari & Radice (2005) for people with MS, Krivickas, Shockley and Mitsumoto (1997) for people with MND and Kristjanson (2004)³ for people with MS, MND, PD and HD and their carers.

The Black, *et al* (1994) study, despite being over a decade old and specific to NSW, provides a useful comparative methodology of a postal survey of unmet needs for one group of people with neurodegenerative disorders who were living in the community. The data from this survey were used to derive a detailed demographic and socioeconomic profile of people with MS in New South Wales (NSW). Black's survey, which had been piloted, achieved a 71 per cent response rate (n = 1,143). Unmet needs included support for family members (over 40 per cent of respondents), respite services (about thirty per cent) and household services (ten per cent). Personal care needs appeared to be well met with less than five per cent of respondents stating unmet needs in this area.

In the US, a study by Krivickas, *et al* (1997) used a postal survey⁴ to members of the Cleveland Clinic and Eastern Ohio Chapter of the MND support organisation to assess the utilization, availability and types of home care services for persons with the disorder, and the impact of home care availability on the patients' carers. The response rate was 30 per cent (n = 98). However some of the non-respondents did not have the disorder and some individuals on the mailing list had died. The study did not report either the adjusted response rate (greater than 30 per cent) or the year of the survey (circa 1996). Follow-up interviews with nineteen individuals and their carers were also conducted. The study found some unmet needs for home care services and that the gap between services received and services required widened as individuals' functionality decreased. The authors conclude that this gap is due to both the inadequacy of home care service provision *per se* together with delays in matching services in response to ever-increasing needs for help in the home.

O'Hara, *et al* (2004) investigated the nature of informal and professional care in a community population of individuals with MS in the UK. Their postal survey⁵ was sent to 278 individuals recruited by voluntary community-based organisations. The response rate was 61 per cent (n = 169). Home care services (housework) were required by up to three quarters of respondents. Some people required support with transport (37 per cent), personal care (36 per cent), leisure (34 per cent) and/or employment (8 per cent). Seventy per cent of respondents considered their current provision of home support as essential. However, no estimation or discussion of a needs gap was included in the investigation.

³ The Kristjanson study has been published subsequently in Aoun, Kristjanson and Oldham (2006), Kristjanson, Aoun and Yates (2006) and Kristjanson, Aoun and Oldham (2006).

⁴ Krivickas, Shockley and Mitsumoto (1997) did not specifically state that they piloted their survey. However, their questionnaire was mailed out to the same people twice. The first mail-out could be returned anonymously. The second mail-out required respondents to identify themselves for follow-up telephone interviews. The questionnaire used in the second mail-out was similar to that used in the first mail-out with "slight rewording of some items to clarify the question or simplify data coding" (page 583). The authors did not report the time interval between the two mail-outs.

⁵ No mention is made of pilot testing this survey.

A study of MS patients in the Lombardy region of Italy (Solari, *et al.*, 2005) included initial and follow-up postal surveys⁶ to 400 individuals. The response rates were 65 per cent (n = 261) for the initial survey in March – June 1999 and 82 per cent (n = 205⁷) for the follow-up survey in March – June 2004. A comparison of needs identified in the initial and follow-up surveys showed that the proportion of people requiring daily home assistance had increased over the period from 19 per cent to 28 per cent. As expected, this comparison confirmed the progression of the disorder for some individuals. As with the O'Hara, DeSouza and Ide (2004) study, Solari, *et al* (2005) did not report gaps in home care service needs.

In Australia, a project on the palliative care needs of people with the four neurodegenerative disorders and their carers comprised two phases. The first phase involved semi-structured interviews with individuals (n = 41) and their carers (n = 70). Participants from Western Australia, Queensland and Victoria were recruited from advertisements in support agency newsletters as well as snowballing. Specialist clinicians, general practitioners and other health professionals with a particular interest in the four disease groups were recruited directly (n = 24). Phase I results, published in Kristjanson (2003), were used to inform the second and more comprehensive phase of the study. In this second phase, Kristjanson used a postal survey. This was pilot-tested in early 2003, then finalised and distributed to 1,962 members (individuals and carers) of support agencies in May 2003. Completed questionnaires by individuals and carers were returned in separate envelopes. This precluded linking individual and carer information, so concordance of responses could not be checked even though the two questionnaires included similar questions. The survey had a response rate of 26 per cent (n = 503) for individuals and 19 per cent (n = 373) for carers (Kristjanson, Aoun, & Oldham, 2006).

One of the limitations of the Kristjanson, Aoun and Oldham (2006) study was that, for ethical considerations, people considered too sick or incapacitated were excluded from agency mailing lists. This meant an absence of respondents in the late stage of their disorder and hence little information on the home care support needs of these people. Nonetheless, Kristjanson, Aoun and Oldham concluded that people in their sample needed most assistance with transport and social support. These activities, however, focus more on accessing community activities rather than receiving care support services in the home. The study also revealed that a carer's ability to cope, both mentally and physically, with the role of caring was fundamental to a care recipient remaining at home.

Finally, Aoun, Kristjanson and Oldham (2006) argued that service provision models of supportive care to people with these diseases should be tailored to their specific needs. This implies that 'a one size fits all' model of home care service provision is less than ideal "This study highlighted the need for improved coordination of care between service providers ... (including) home care agencies ... The findings highlighted the need for a partnership between the organisations involved in service provision (both government and volunteer) for the effective planning, delivery and monitoring of supportive and palliative care" (page 20). Importantly, the Kristjanson study provided a basis for the development of the research questions underpinning this current study.

⁶ See footnote 3.

⁷ Ten completed surveys were subsequently removed from the sample on the basis of exclusion criteria.

2 METHODOLOGY

In the current study, a postal survey was designed to provide an overview of the demographic and disease characteristics of people with the four neurodegenerative disorders of interest. It was also intended to estimate the extent and type of gaps in home care service provision. A single questionnaire was used to survey individuals and carers wherever they lived in metropolitan or country Western Australia.. Some survey respondents subsequently agreed to be interviewed. As with other studies (for example, Barrett, 2005: 44), it was thought that the interviews would add clarification, colour and depth to the survey responses. The outcomes of the interviews are reported in NDP Report No 2 – Client and carer interviews.

2.1 Pilot Survey

The survey was piloted in January 2007 with seven individuals who didn't have a carer and nine individuals with their carers. The individuals were contacted firstly by their support agency or service provider. They were asked if they would participate in the piloting of the survey. The names and contact phone numbers of those that agreed were then provided to the research team to set-up the piloting schedule. The project co-ordinator visited these people and answered questions as they went through the survey. All but two couples were able to complete the pilot survey during the project co-ordinator's visit. One couple mailed back the pilot survey after the visit as they needed more time to go through it and their daily programme of care was very busy. The second couple did not return the survey.

A number of issues were raised during the piloting of the survey. These related mainly to either the wording of the questions or the valid response categories. A number of questions required rewording. For example, the request for details of respondents' current and preferred home care services, which was a single question in the piloted questionnaire, required disaggregation into four separate questions. It also required streaming of responses into two categories - those respondents receiving care packages and those receiving unpackaged care services.

Another question requiring rewording, as well as changes to some of the response categories, was the question 'Do you currently have difficulties with the following?' The list of difficulties was alphabetically sorted. The difficulties were intended to be a comprehensive summary of symptoms across all four disorders and for all stages of each disorder. The labels for each of the difficulties were agreed by representatives of the support agencies as recognisable. The response categories were 'Yes' and 'No'. Whilst there is some merit in grouping symptoms by disorder, there was considerable concurrence of symptoms between two or more disorders. Therefore, it was decided to leave the difficulties in alphabetical order, rather than direct respondents to disease-specific symptoms.

Another issue with the difficulties question was that some pilot survey respondents queried some of the difficulties which clearly did not apply to their disease or their stage or experience of the disease. Also, in some cases where the carer was completing the survey, the presence or not of a difficulty was unclear. Finally, it was realised that current difficulties are sometimes confounded by medication, equipment or aids. For example, some respondents reported no balance or falling difficulties because they were in wheelchairs.

Three changes were subsequently made to the difficulties question to minimise respondent confusion or error. First, a mobility question was inserted prior to the difficulties question. Second, the difficulties question was rewritten with a caption 'You may currently be taking medication ... and/or using equipment ... or aids. However, you may still be having some difficulties.' Both the mobility question and the caption to the difficulties question was intended to reduce the uncertainty for the respondent deciding about how to record the presence or otherwise of their difficulties. The mobility question was designed to provide a categorical control variable in the analyses of differences in difficulties and day to day activities. It was also used to partition estimates of met and unmet home care support needs.

Some respondents during the pilot survey queried the differences between tiredness and fatigue and between tremors, involuntary movements and muscle spasms. After discussion with clinicians and consideration of the statistical analyses to follow, it was decided to group these two sets of difficulties.

The pilot survey highlighted another issue, namely whether the person completing the questionnaire was the care recipient or the carer. Concerns that this might make a difference to the validity of the responses were raised. However, only two studies in the literature had findings related to differences in viewpoints. The study by Finlayson, Van Denend and Shevil (2003) of the health service needs of older adults with MS compared responses made by carers/clients with those from health professionals and found differences in perceptions of health/medical status. McGarva's (2001) investigation of the needs of people with HD compared clients with carers in terms of perceptions of problems. McGarva found that clients had a bleaker picture than carers in relation to anxiety and social/outings, and carers perceived more problems than clients in relation to memory, emotional problems, worries about the disease and temper control. The differences in the Finlayson, Van Denend and Shevil (2003) and McGarva (2001) studies were not tested for statistical significance.

It was decided to address the issue of identifying responses from the point of view of the person with the disorder in two ways. First, the revised questionnaire was divided into three sections. Section A invited responses from people with the disorders of interest. Section B asked questions to do with respite so could be answered by the person and their carer if they had one. The final part of the survey, Section C, had questions for the carer and could be left blank if the respondent had no carer. A comparison of responses in Sections A and C, in particular in relation to home care assistance, is discussed in Section 3.4 of this report.

The second approach to identifying the responses from the viewpoint of the person with the disorder was to ask directly 'who completed this survey?'. After discussion with the survey designer, it was decided that this question be included at the end of the first section.

In addition to the assistance of respondents to the pilot survey, a number of other people were asked to provide feedback on the survey instrument. These included members of the project Steering Group, Dr Rex Simmons, Project Manager of the Australian MS Longitudinal Study at Canberra Hospital, and Mr Phil Stanwell, Silver Chain Volunteer Co-ordinator. The penultimate version of the survey was proof-read by three members of the Silver Chain research department who had prior editing and proof-reading experience.

2.2 Main Survey and Response Rates

The revised survey was mailed out in early March 2007 to clients of Silver Chain, Brightwater, Mercy Aged Care, Perth Home Care and the Neurological Council, who were identified by the agency as having a diagnosis of one of the NDDs of interest, and to members of the Multiple Sclerosis Society of WA, the Motor Neurone Disease Association of WA and Parkinson's Western Australia. Members and/or clients of Australian Huntington's Disease Association (WA) and the Neurosciences Unit of the WA Department of Health were mailed to in May⁸. The covering letter to the survey and the survey⁹ itself are included as Attachments A and B, respectively. Table 1 summarises the size of the survey population and the number of respondents.

A total of 2,939 surveys were mailed to clients and members. As an ethics requirement, surveys were mailed from the relevant organisations using their own mailing lists. This enabled confidentiality and covering letters to be personalised by each organisation. It also meant that some individuals received more than one copy of the survey as the mailing lists were not merged. For example, a Silver Chain client with MND might also have received surveys from Brightwater and MNDAWA. From the analysis of the linked dataset (see NDP Report No 4 - Data Linkage 2006) it appears that the overlap in the mailing lists was not small – unique individuals represented about 69 per cent of the linked dataset.

Some of the surveys were not completed because the recipients received more than one copy, or the individual's address was no longer current, or the recipient had died or moved into an aged care residential facility. In some of these cases the research team was notified by phone or received uncompleted surplus surveys in the mail with completed surveys.

A number of people phoned the research team requesting help to fill in the form or asking for clarification of their suitability for the survey. Some of these people agreed to complete the survey without further help. In other cases, a member of the research team visited the respondent and their carer, if they had one, to help complete the survey. In one case, the client had completed and returned the survey but was phoned to clarify answers to some questions.

⁸ As many AHDA members are also clients of NSU, it was decided to minimise double posting of the survey by merging mailing lists from these two groups. This process together with the need to update the NSU mailing list resulted in delays in posting the survey to people with Huntington's Disease. As this is a fairly stable population in terms of incidence profiles at various stages of the disease, the delay is not thought to compromise the results, particularly the comparisons of home care service needs across disease types. Two people who responded to the March mail-out also responded to the AHDA/NSU mail-out. Only one of their completed surveys was included in the dataset and in calculations of returns and response rates.

⁹ This is the version of the main survey used in the mail-out in March 2007. Many changes were made to the questionnaire after the pilot survey. Names of individuals who participated in the pilot survey were not excluded from the mailing lists for the main survey. Hence, completed questionnaires from the pilot survey were not encoded.

The response rate at the aggregate level, shown in the last row of Table 1, is 54.0 per cent¹⁰. This is a pleasing result for two reasons. First, the survey is quite long and some questions require respondents to give considerable detail. Second, the target population has physical and cognitive disabilities to varying degrees so that, whilst they may be helped with the survey by, for example, their carer, the process of responding could have been tiring and/or onerous.

Table 1: Survey Population and Response Rates

Support Agency Or Service Provider	Number Of Posted Surveys	Number Of Returned Surveys	Response Rate (%)
Australian Huntington's Disease Association WA (AHDA) and WA Department of Health (Neurosciences Unit) (NSU) ^a	84	19	22.6
Motor Neurone Disease Association of WA (MNDAWA)	110	50	45.4
Multiple Sclerosis Society of WA (MSS WA)	1,567	590	37.6
Parkinson's Western Australia Inc (PWA)	689	343	49.8
Subtotal	2,450	1,002	40.9
Others ^b	489	93	19.0
Total	2,939	1,095	37.3
Adjusted^c Total	2,028	1,095	54.0

Notes: ^a Mailing lists for these two organisations were merged. ^b 'Others' includes the Neurological Council, Silver Chain, Brightwater, Perth Home Care and Mercy Aged Care. ^c The number of postal surveys has been adjusted by the extent of the overlap in mailing lists. Refer to footnote 11. Fifteen returned surveys were subsequently excluded for various reasons – see Section 3.

Both survey length and difficulty - referred in the health outcome literature as 'respondent burden'¹¹ - were obvious during the pilot survey and, although, the revised survey hoped to minimise this burden, it is not known the extent to which this was achieved. In summary, it is likely that non-response could be attributed, to some extent, to either or both of these features of the survey design.

Response rates by organisation are shown in Table 1 to range from 19.0 per cent to 49.8 per cent. One of the difficulties in determining response rates at the disaggregate level is matching returned surveys to the organisation from which they were sent. A basic rule of thumb, adopted for the compilation of Table 1, was that if a respondent answers that they are a member of a particular support agency, then that survey is attributed to the mail-out from that agency. However, this respondent may have received surveys from both a support agency and a service provider. Three of the service providers had very small mailing lists ($n < 20$). The possibility of identifying individuals contradicted ethics requirements regarding anonymity, hence respondents were not asked to name their service provider(s).

¹⁰ The linkage process identified 2,550 unique individuals (69.0 per cent) in the linked dataset of 3,695 observations (see NDP Report No 4). If this percentage is applied to the 2,939 posted surveys, then the number of unique individuals across all mailing lists is 2,028. Thus, the adjusted response rate becomes $1,095/2,028 = 0.540$ or 54.0 per cent.

¹¹ See Saleh, *et al* (2002) for a helpful description of respondent burden and how this is only one of the limitations of self-administered postal surveys.

If the respondent did not indicate membership of a support agency, then it was assumed that the survey had been mailed out from a service provider. These are included in Table 1 as 'Others'.

The Kristjanson study (2004) surveyed subsets of support agency members and their carers. A response rate of 25.6 per cent (n = 503) was achieved from the mailout to 1,962 members. The equivalent response rate in the current study is 40.9 per cent without adjustment for multiple mailings. Inclusive of respondents categorised as 'Others', the (adjusted) response rate is 54.0 per cent.

The higher response rate in this project's survey can probably be attributed to two influences. First, multiple mailings from, for example, a support agency and a home care service provider, might encourage care recipients of the importance of their completing the survey. Second, unlike the survey instrument used by Kristjanson (2004), this project's survey asked respondents specific questions about the actual hours of home care support currently received and estimates of hours of support currently needed. Hence, some respondents may erroneously link completion of the survey to immediate and specific improvements in their home care support.

Table 1 also shows that the response rates varied between support agencies. The response rate from PWA members was highest at 49.8 per cent. Whilst Kristjanson, Aoun and Oldham (2006) reported proportionately more completed returns from members with PD, it is unclear whether this represents a higher response rate or that proportionately more surveys were mailed out by the three PD support agencies. The lowest response rate in the current study, 22.6 per cent, was for people with HD who were mailed surveys from either AHDA or NSU. In the Kristjanson study (2004), the proportion of completed surveys by people with HD was lowest, at 10 per cent, reflecting that the proportion of surveys mailed to AHDA members was small in relation to the proportions of surveys mailed to members of the other support agencies.

Note that, of the 1,095 completed and returned surveys, fifteen surveys had either a high proportion of missing values or were completed by people who did not have one of the four disorders or were completed by people who were living in residential care facilities. For the analyses to follow, these surveys were excluded. Hence, the modified dataset of survey responses contains 1,080 observations and 429 variables, many of which are categorical or dummy variables.

Before introducing the results, it is useful to reconcile the profile of respondents with the profile of people to whom the surveys were sent. If these profiles are similar, then conclusions can be generalised to reflect the total membership.

Table 2 shows the average age and the proportion of males in the linked datasets¹² (called here 'Population') together with the statistics from the corresponding survey respondent cohort. As the mailing lists and organisation datasets from which the linked dataset was compiled were generated at different times, concordance between these population parameters and the parameters for the mail-out population is not expected to be exact. For example, members may have died in the period between generating the agency dataset used for the linkage and compiling the agency mailing list.

¹² See NDP Report No 4 – Data Linkage 2006.

The profiles of survey respondents and support agency members are similar. For example, the profile of AHDA(WA) members in the survey dataset is similar to their profile in the AHDA/NSU dataset – about 50 per cent are men and their average age is mid 50s. The average age for MNDAWA members is about the same in the survey and agency datasets – early 60s. The proportion of male MNDAWA members responding to the survey is the same as the proportion of males in the MNDAWA member dataset – 60 per cent. The profiles of MSSWA members and survey respondents who reported membership of MSSWA are similar – average ages of 52 and 53 years and proportions of males of 24 and 22 per cent, respectively.

Table 2: Comparison of Population and Survey Respondent Profiles: Average Age and Proportion of Males

Organisation	Population		Survey Respondents	
	Average Age (Years) (N)	Percentage of Males	Average Age (Years) (N)	Percentage of Males
Australian Huntington's Disease Association WA (AHDA) and WA Department of Health (Neurosciences Unit) (NSU) ^a	52.4 (101)	49.1 (114)	54.6 (18)	50.0 (18)
Motor Neurone Disease Association of WA (MNDAWA)	64.5 (96)	59.6 (114)	62.4 (47)	59.6 (47)
Multiple Sclerosis Society of WA (MSS WA)	52.3 (2,170)	24.4 (2,217)	53.0 (580)	21.6 (584)
Parkinson's Western Australia Inc (PWA)	n.a.	n.a.	71.7 (334)	59.7 (335)
All Support Agencies	n.a.	n.a.	59.8 (979)	36.9 (984)
Other Organisations	53.8 (1,249)	27.8 (1,250)	71.3 (81)	43.9 (82)
All Organisations	n.a.	n.a.	60.8 (1,070 ^c)	37.4 (1,076 ^d)

Notes: ^a Combining AHDA and NSU datasets for population parameters; AHDA dataset for survey statistics. ^b PWA dataset to calculate population parameters was not available to the project. ^c Ten survey respondents did not report their year of birth. ^d Four survey respondents either did not report their gender or their gender could not be determined from other information in their completed survey.

Of note in Table 2 are differences in age and gender between survey respondents who are members of support agencies and those who are non-members. The latter tend to be about ten years older on average. Also there is a higher proportion of males who are non-members, 44 per cent, compared to members, 37 per cent in the sample of survey respondents.

There does not appear to be any unexpected gender bias in the profile of respondents although slightly more women with MS responded to the survey. Cull, *et al* (2005), in a study of age and gender bias in responses to surveys of paediatricians in the United States, found that respondents were more likely to be female, and that this bias was higher the lower the survey response rate. Nonetheless, Cull, *et al* concluded that this bias never exceeded 5 per cent.

It should be noted that whilst the analyses to follow can be generalised to agency memberships, they cannot be generalised to the populations of people with these disorders. It is likely that, due to biases related to age, education, income and gender, agency members may be non-random subsets of these populations. See NDP Report No 6 for a comparison of the estimated disorder population profiles for 2007 based on prevalence rates and the survey respondent profiles.

3 RESULTS

The results are presented for care recipients in Sections 3.1 to 3.3 and for carers in Section 4. Section 3.1 reports socio-demographic characteristics of respondents. Section 3.2 presents dependency and disease profiles, and Section 3.3 summarises the current use and gaps in home care support services from the viewpoint of the care recipient. Section 3.4 summarises characteristics, and home care assistance needs, of carers and compares these with the responses about care needs from care recipients. In Section 3.5, the matrix of selection criteria for choosing interviewees from among those respondents who agreed to be interviewed is presented. Section 4 concludes this report with a summary of how the postal survey objectives and results meet the overall project goals and how the survey complements other components of the project.

The survey instrument allowed both explicit and open-ended responses. For the latter, meaningful sets of codes were developed, once the completed questionnaires were returned. These codes are shown in Attachment C. Most of the responses to the survey questions have been coded as categorical variables, for example gender and level of mobility. Some responses have been included in the dataset as continuous variables, such as client or carer year of birth and hours of home care services currently received. To test for differences between respondents based on combinations of categorical variables (shown in two-way cross-tabulations), chi square tests have been used. Both chi square results and p values are reported. For differences in sub-sample means of continuous variables, F-tests have been used.

It should be noted that the survey was to be mailed to people living at home. In fifteen cases, the survey was returned by people living in nursing homes. This may be the result of mailing lists being slightly out of date. Alternately, some people may have moved between when the mailing lists were being compiled and when the surveys were sent out. This is possible as long waiting lists at nursing homes result in vacancies being quickly filled. The base dataset for the results to follow is thus 1,080 individuals. Where the sample size for a particular table is less than this, notes to the table provide clarification.

Table 3: Who Completed the Survey by Level of Dependency

Who Completed Section A	Level of Dependency				
	Independent	Low	Medium	High	All
Client	239	298	101	57	695
Client and Carer	8	37	85	120	250
Carer	0	5	14	57	76
Others ^a	4	13	11	13	41
All^b	251	353	211	247	1,062
Chi square = 425.8928; p = 0.000					

Note: ^a These include care workers, family members, friends or unknown. ^b Eighteen individuals provided insufficient information for level of dependency to be calculated.

As mentioned in Section 2.1, the survey asked the question ‘Who completed this questionnaire?’ Table 3 shows the breakdown of response to this question by the level of dependency of the person with the disorder.

For respondents who need no help with activities of daily living (that is, they are independent), most (95.2 per cent) completed Section A of the survey by themselves. As level of dependency increases, a smaller proportion of respondents completed Section A by themselves. For example, whilst just under half of those respondents with medium level of dependency completed Section A by themselves, only one quarter of those with high level of dependency were able to do so. Thus, dependency level and who completed the survey are dependent and this result is statistically significant at the 1 per cent level.

When the figures in Table 3 are disaggregated by disorder, the results¹³ are similar for people with MS (chi square = 208.9876; p = 0.000) and PD (chi square = 160.2371; p = 0.000). For people with HD, 15 of 25 surveys were completed by the carer or with the carer and the difference is statistically significant at the 10 per cent level (chi square = 12.0875; p = 0.060). For people with MND, the proportionate difference in who completes the survey at each level of dependency is also statistically significant at the 10 per cent level (chi square = 24.1633; p = 0.062).

3.1 Socio-demographic Characteristics of Respondents by Disorder

A number of socio-demographic characteristics were included in Section A of the survey. Results are presented here in aggregate and in terms of disorder.

The average age of respondents, shown in Table 4, is about 61 years. Respondents with MS and HD have lower average ages, 53.2 and 57.9 years, respectively, and respondents with MND have a higher average age of 64.5 years. Survey respondents with PD had the highest average age, 72.4 years. These average ages are not dissimilar to the results of other studies of people with these neurodegenerative disorders.

¹³ Results by disorder are available from the authors.

Table 4: Comparison of Survey Respondents by Disorder: Age, Gender, Membership and Living Arrangements

Disorder	N ^a	Average Age (Years)	Males (%)	Members (%)	Living Alone (%)	Lives With Others (%)
MS	608	53.1	22.0	97.3	33.7	66.3
MND ^b	56	63.8	55.4	87.5	17.9	82.1
PD ^c	391	72.3	58.0	86.8	24.6	75.4
HD	25	58.3	52.0	68.0	16.0	84.0
All^d	1,080	60.8	37.4	92.3	29.2	70.8

Notes: ^a The sample sizes for each of the statistics in Columns 2 to 6 may be slightly less than N if there are missing values in the data. ^b Two respondents with MND reported membership of PWA not MNDAWA. ^c Two respondents with PD reported membership of MSS WA and one, membership of AHDA. ^d As this table provides statistics by disorder, the figures differ from those in Table 2 which provides statistics by support agency.

With MS being the most common cause of neurological disability in young and middle-aged adults (Solari, *et al.*, 2005), the relatively low average age of respondents is not surprising. This figure is comparable to other studies where the mean age has ranged from 46.9 to 51.3 years (Black, *et al.*, 1994; Kersten, *et al.*, 2000; Kristjanson, 2004; O'Hara, *et al.*, 2004; Solari, *et al.*, 2005; Tribe, *et al.*, 2006).

The survey results show a slightly lower average age for respondents with MND than the average age of 65 years for respondents with MND in the Kristjanson, Aoun and Oldham (2006) study. Two other studies of people with MND reported higher average ages. Hughes, *et al.* (2005) found that two thirds of their sample was at least 70 years and van Teijlingen, Friend & Kamal (2001) reported that half of their survey respondents were over 64 years.

Data from a variety of studies on people living with Parkinson's disease (PD) has shown the average age of PD sufferers to be in the late 60s or early 70s (De Boer, Sprangers, Speelman, & de Haes, 1999; Fukunaga, Kasai, & Yoshidome, 1997; Jarman, Hurwitz, Cook, Bajekal, & Lee, 2002; Karlsen, Larsen, Tandberg, & Maeland, 1999; Kristjanson, Aoun, & Oldham, 2006). One Australian study reported most of its PD participants to be between the ages of 51 and 60 years. However, this study had a small sample size of 8 participants (Hudson, Toye, & Kristjanson, 2006).

Table 4 shows that the average age of respondents with HD is 58 years. The study by Kristjanson, Aoun and Oldham (2006) reported a mean age, 56.8 years, for its HD sample. Additionally, the study by Skirton & Glendinning (1997) had 64 per cent of its sample over 50 years and Dawson, Kristjanson, Toye, & Flett (2004) reported most of their sample to be between 51 and 60 years of age.

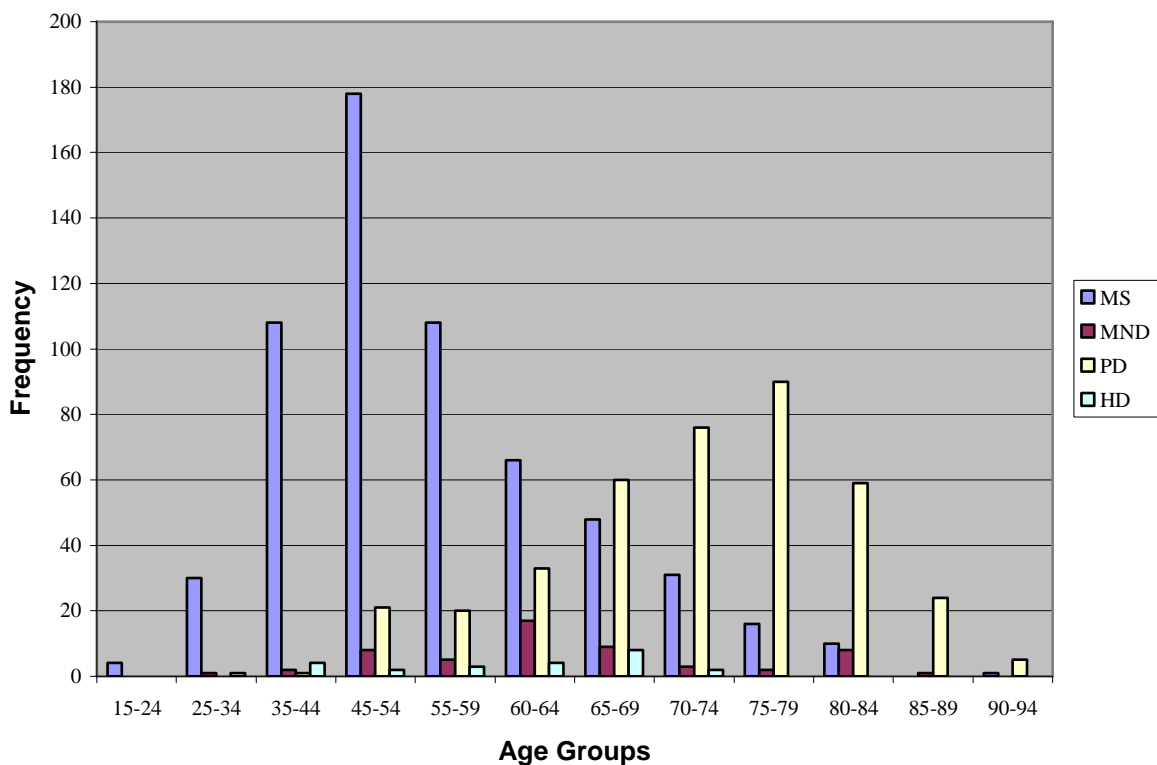
Figure 1 shows the distribution of ages of survey respondents for each disorder. It can be seen that the age distribution of respondents with MS is positively skewed ($k = 2.7956$) and the modal age category for MS is 45 to 54 years. For survey respondents with PD, the age distribution is negatively skewed ($k = 2.9469$) and the modal age category is 75 to 79 years.

The numbers of survey respondents who have either MND or HD are relatively low, hence their frequencies in each age category are overwhelmed by the larger frequencies for respondents with MS and PD. Nonetheless it is still possible to discern that the age distribution for respondents with MND peaks at age 60 to 64 years and for respondents with HD, at 65 to 69 years. The age distributions for respondents with HD and MND are negatively skewed ($k = 2.6018$ and $k = 3.4521$, respectively).

Under forty per cent of all respondents are male. When disaggregated by disorder, Table 4 shows that 22 per cent, 55.4 per cent, 58.0 per cent and 52.0 per cent of respondents with MS, MND, PD and HD are male, respectively. The corresponding gender ratios are 1:3.5 for MS, 1.2:1 for MND, 1.4:1 for PD and 1:1.1 for HD. These gender ratios are similar to those reported in other Australian and overseas studies. For example, studies conducted on people with MS in Australia showed male to female ratios of 1:3.2 (Kristjanson, 2004), 1:3 (Tribe, *et al.*, 2006), 1:2.7 (Black, *et al.*, 1994), and 1:2.6 (Simmons, *et al.*, 2001). Previous studies of people with MND reported male to female ratios ranging from 1.3:1 reported in van Teijlingen, *et al* (2001) in Scotland to 2.0:1 (Hughes, *et al.*, 2005) in London. The Australian study by Kristjanson (2004) had a male to female ratio for people with MND of roughly 1:1.

Results from Australian studies of people with PD showed proportions of men ranging from 59.5 per cent (Katsikitis, Davis, & Burrow, 1996) to 65 per cent (Kristjanson, Aoun, & Oldham, 2006). Much of the literature on people with Huntington’s disease (HD) has shown the gender distribution to be similar with males being only slightly less represented than females in most cases (Foroud, Gray, Ivashina, & Conneally, 1999; Kirkwood, Su, Conneally, & Foroud, 2001; Kristjanson, Aoun, & Oldham, 2005; Skirton & Glendinning, 1997; US-Venezuela Collaborative Research Project & Wexler, 2004).

Figure 1: Age Distributions of Survey Respondents by Disorder



Over 90 per cent of respondents reported membership of a support agency for their disorder. Respondents with MS reported the highest membership (96.2 per cent). People with HD reported the lowest rate of membership with 68 per cent being members of their disorder-specific support group, AHDA. This result is not surprising as NSU is often the first port of call for people with family histories of HD. NSU provides, *inter alia*, gene testing, counselling and social work services. In these respects, NSU is a substitute for the role of AHDA. Nonetheless, seven in ten respondents with HD were members of AHDA. There are no similar government agencies for people with MS, MND and PD.

Finally, Table 4 shows that one third of survey respondents live alone and about 70 per cent live with others which may include their carer. There are some differences in these proportions in terms of disorder. For example, only 18 per cent of respondents with MND live alone compared with 34 per cent of those with MS. Eighty-two per cent of respondents with MND live with others compared with 66 per cent of people with MS and 84 per cent of respondents with HD.

3.2 Symptomatic Difficulties and Levels of Dependency by Disorder

There are two ways to examine the need for services in the home by people with neurodegenerative diseases. One way is to look at symptomatic difficulties they may be experiencing and draw inferences about how these difficulties may be impacting on their mobility and their ability to stay living at home. This is an indirect approach. Table 5 shows the numbers of respondents at each level of mobility, by disorder.

Table 5: Level of Mobility by Disorder

Disorder	Level Of Mobility						All (n)
	No Trouble Walking	Trouble Walking But Use No Aids	No Aid Inside The Home But Aid Outside	Aid Inside The Home	Use Wheelchair Inside With Use Of Arms	Use Wheelchair Inside But Little Or No Use Of Arms, Or Bedridden	
MS	32.6	24.8	15.2	11.3	10.3	5.9	593
MND	14.8	16.7	16.7	22.2	7.4	22.2	54
PD	27.1	29.0	14.9	21.5	2.9	4.5	376
HD	40.0	32.0	24.0	0.0	4.0	0.0	25
All^a	313	273	161	160	77	64	1,048
Chi square = 77.2252 p = 0.000							

Note: ^a Missing values on level of mobility are excluded (n = 32).

The mobility scale is similar to mobility scales reported in other literature (Jones, 2004; Tribe, *et al.*, 2006). In Table 5 the scale is shown to range from the highest level of mobility (Column 1) – no trouble walking – to the least mobile (Column 6) – using a wheelchair with limited or no use of arms or bedridden¹⁴. Aids for walking include walking sticks and walking frames. Wheelchairs may be manual or electric.

¹⁴ The categories of 'using a wheelchair with limited or no use of arms' and 'being bedridden' (which were offered in the postal survey) are included, for analysis purposes, in the one category as the sample size for the 'being bedridden' category is small (n = 5). Note also that, for some individuals, the wheelchair is used at night-time as well as during the day.

Table 5 shows that, overall, the proportions of respondents decrease as mobility worsens. That is, whilst 30 per cent of respondents have no trouble walking (n = 313), at the other end of the mobility scale, about 6 per cent are bedridden or quadriplegic (n = 64). In some respects this skewed distribution reflects selection bias in the respondent sample. That is, people with greater mobility probably have fewer difficulties overall and would find responding to the survey less onerous. People whose mobility is severely compromised may be less likely to respond to the survey. However, the alternative explanation for this skewed distribution is attrition. That is, as the neurodegenerative disorder progresses, the survival rate (staying alive and at home) at consecutive stages of the disorder diminishes. People may die or move to assisted living environments or hospital for reasons other than restricted mobility. In these cases they would not be in the catchment for this study (living at home). The extent to which selection bias and/or attrition are influencing the distribution of respondents in Table 5 is unclear.

Interestingly, whilst it appears that overall proportions of respondents decrease with a decline in mobility, when disaggregated by disorder the pattern is less obvious. For example, one third of respondents with MS have no trouble walking and this proportion falls as mobility diminishes, with 6 per cent of MS respondents using wheelchairs and having little or no use of their arms or being bedridden. This is similar to the pattern for all respondents. This is not surprising as Table 5 shows that 57 per cent of respondents who reported their level of mobility have MS.

For respondents with MND, there are two modal categories for level of mobility – using aids inside the home and, the least mobile, using a wheelchair inside the home with little or no use of arms or being bedridden. Proportions in these categories are each about 22 per cent.

For respondents with PD, around 27 per cent have no trouble walking, a further 29 per cent have a bit of trouble walking but don't use aids. Most of the remaining PD respondents use walking sticks or frames outside their home or both inside and outside the home. Few respondents with PD, 7.4 per cent, are in the lowest two categories of mobility.

Most of the respondents with HD use no aids or only use aids outside the home. At lower levels of mobility (using a wheelchair or being bedridden), most people with HD have co-morbidities that generally result in them being unable to remain in the community. Hence few respondents with HD are shown in Table 5 in these mobility categories.

In addition to asking about their mobility, respondents were asked to confirm whether or not they had each of a list of forty difficulties that may be associated with any of the disorders. Then, for each of the difficulties confirmed, respondents were asked to rank the level of difficulty. Table 6 shows the proportions of respondents in each of the difficulty categories.

Table 6: Symptomatic Difficulties

Current Difficulties	Level of Difficulty				Total (n)
	None	Mild	Medium	Extreme	
Balance ^a (%)	22.0	35.9	29.1	13.1	984
Bladder incontinence ^b (%)	50.7	25.9	15.9	7.6	989
Boredom (%)	75.4	11.6	9.2	3.7	941
Bowel problems (%)	54.2	22.0	16.9	6.9	982
Breathing (%)	81.2	10.5	7.0	1.3	977
Clumsiness ^a (%)	33.5	40.0	21.2	5.5	943
Communicating (%)	67.9	18.4	9.6	4.2	959
Constipation (%)	53.8	22.3	18.1	5.7	977
Depression (%)	55.4	25.4	14.8	4.3	929
Dizziness (%)	59.8	30.3	8.1	1.9	954
Expressing feelings (%)	72.7	14.5	9.5	3.3	917
Falling (%)	53.3	23.6	15.9	7.1	973
Fatigue/tiredness ^a (%)	10.7	26.3	41.1	21.9	997
Hallucinations (%)	90.4	5.3	3.2	1.1	970
Hearing (%)	70.8	15.7	11.4	2.1	1,001
Heat intolerance ^a (%)	29.9	21.6	25.4	23.1	990
Hunger (%)	91.0	4.8	3.1	1.1	990
Irritability (%)	59.2	27.0	10.8	3.0	943
Itching (%)	72.2	18.5	7.6	1.7	989
Lapses of concentration ^a (%)	42.7	34.4	19.0	3.9	958
Loneliness (%)	76.4	13.5	7.4	2.7	966
Muscle spasms/tremors/ involuntary movements ^a (%)	27.5	39.0	25.7	7.7	984
Nausea (%)	85.5	10.6	3.6	0.3	985
Pain ^b (%)	48.5	20.6	22.6	8.3	990
Remembering ^a (%)	40.0	36.9	18.6	4.6	963
Responding appropriately to others (%)	80.3	12.4	6.1	1.3	922
Sensitivity to cold (%)	56.4	20.4	15.5	7.6	969
Sleep disturbance ^a (%)	37.8	25.7	26.3	10.3	982
Speaking (%)	64.5	20.3	10.1	5.1	977
Swallowing (%)	69.6	17.6	10.0	2.9	980
Swollen feet/hands (%)	66.7	18.4	11.0	3.9	994
Tearfulness (%)	69.7	19.0	9.4	1.9	963
Uncontrollable anger or aggression (%)	87.5	8.5	3.1	0.9	989
Uncontrollable laughter (%)	97.3	2.3	0.3	0.1	998
Understanding or comprehending (%)	80.5	13.6	4.6	1.2	961
Weak arms and/or legs ^a (%)	25.1	29.1	30.8	15.0	976
Weight gain (%)	73.2	13.3	10.0	3.5	982
Weight loss (%)	82.9	8.7	5.8	2.5	984
Your eyesight ^a (%)	43.8	30.4	20.3	5.5	970
Your teeth and/or mouth (%)	76.2	11.9	9.2	2.8	960

Notes: ^a These difficulties affect over half of the respondents. ^b These difficulties affect about half of respondents.

A number of symptomatic difficulties are experienced by most respondents, ranging from 89.3 per cent of respondents having difficulty with fatigue/tiredness to 56.2 per cent having difficulty with their eyesight. Other difficulties affecting most respondents are related to balance, clumsiness, heat intolerance, lapses of concentration, muscle spasms/tremors/involuntary movements, remembering, sleep disturbance, weak arms and/or legs and eyesight. Many respondents also have difficulty with pain (51.5 per cent of respondents) and bladder incontinence (49.3 per cent of respondents).

Table 7 disaggregates responses to those symptomatic difficulties experienced by most respondents, by disorder. Of particular note are the differences between disorders for difficulties with heat intolerance, remembering, sleep disturbance and weak arms and/or legs. Eighty-five per cent of respondents with MS are affected by heat intolerance compared with about half of respondents with other disorders. Respondents with MND are least affected by difficulties with remembering, about 35 per cent compared with around 60 per cent for those with other disorders. A greater proportion of respondents with MND and PD have problems with sleep disturbance compared with respondents with MS and HD. The proportions of respondents affected by sleep disturbance ranged from 56 per cent for respondents with HD to 70 per cent for respondents with MND or PD. Most respondents with MND suffer weak arms and/or legs whereas few respondents with HD have these difficulties. Muscle spasms, tremors or involuntary movements are experienced by 72 per cent of respondents but this is much higher for people with PD, 83 per cent.

Table 7: Select Symptomatic Difficulties by Disorder

Current Difficulties	Level Of Difficulty				Total (n)
	None	Mild	Medium	Extreme	
Balance (%)					
- MS	20.7	37.6	30.0	11.7	564
- MND	16.7	22.2	27.8	33.3	54
- PD	24.6	36.0	27.8	11.7	342
- HD	25.0	25.0	29.2	20.8	24
Clumsiness (%)					
- MS	32.8	42.6	20.2	4.4	540
- MND	20.0	38.0	30.0	12.0	50
- PD	37.3	37.0	20.6	5.2	330
- HD	26.1	17.4	34.8	21.7	23
Fatigue/tiredness (%)					
- MS	8.2	25.4	42.9	23.5	574
- MND	6.0	32.0	38.0	24.0	50
- PD	14.6	27.4	39.4	18.6	350
- HD	26.1	17.4	30.4	26.1	23
Heat intolerance (%)					
- MS	15.0	23.6	28.3	33.0	572
- MND	50.9	18.9	26.4	3.8	53
- PD	50.7	18.5	20.5	10.3	341
- HD	41.7	25.0	20.8	12.5	24
Lapses of concentration (%)					
- MS	43.7	37.1	16.5	2.7	552
- MND	60.0	26.0	12.0	2.0	50
- PD	39.5	31.6	23.8	5.1	332
- HD	29.2	29.2	25.0	16.7	24
Muscle spasms/tremors /involuntary movements (%)					
- MS	37.0	37.9	19.9	5.2	552
- MND	19.2	30.8	38.5	11.5	52
- PD	14.9	43.3	32.0	9.8	356
- HD	16.7	20.8	37.5	25.0	24
Remembering (%)					
- MS	39.3	40.1	16.2	4.4	544
- MND	64.8	18.5	13.0	3.7	54
- PD	37.0	35.8	22.3	5.0	341
- HD	41.7	20.8	33.3	4.2	24
Sleep disturbance (%)					
- MS	42.9	26.9	22.8	7.4	557
- MND	29.4	25.5	29.4	15.7	51
- PD	30.5	23.9	31.6	14.0	351
- HD	43.5	21.7	21.7	13.0	23
Weak arms and/or legs (%)					
- MS	23.1	31.6	28.9	16.4	554
- MND	5.7	11.3	41.5	41.5	53
- PD	28.2	29.4	32.8	9.5	347
- HD	72.7	4.6	22.7	0.0	22
Eyesight (%)					
- MS	44.4	32.3	16.6	6.7	554
- MND	64.7	19.6	15.7	0.0	51
- PD	39.8	29.2	26.6	4.4	342
- HD	43.5	26.1	26.1	4.4	23

In the survey, respondents were asked to identify the year they were diagnosed and this, together with their date of birth, has been used to calculate their age at diagnosis. Table 8 summarises age at diagnosis by disorder and gender.

Table 8: Age at Diagnosis by Disorder and Gender

Disorder	Number	Mean (Years)	95% Confidence Interval	
MS	579	40.8	39.9	41.6
Male	131	41.9	40.1	43.7
Female	448	40.4	39.4	41.4
MND	52	57.1	53.5	60.7
Male	30	57.1	53.4	60.9
Female	22	57.0	49.7	64.3
PD	359	63.5	62.4	64.7
Male	214	62.9	61.4	64.4
Female	145	64.5	62.7	66.2
HD	23	52.6	47.1	58.2
Male	11	53.9	45.0	62.8
Female	12	51.5	43.4	59.6
Total	1,013 ^a	49.9	49.0	50.9
Male	386	55.1	53.6	56.5
Female	627	46.8	45.6	48.0

Note: ^a Sixty seven respondents did not provide year of diagnosis and/or year of birth information.

As shown in Table 8, people with MS are generally diagnosed at earlier ages and people with PD at older ages. Men tend to be diagnosed at older ages, on average at 55 years, compared with women at 47 years. This result is influenced by the large number of respondents with MS, 77 per cent of whom are women¹⁵. When disaggregated by disorder, however, Table 8 shows that men with PD are diagnosed at a younger average age, 62.9 years, compared with women with PD who are diagnosed at 64.5 years on average.

Columns 4 and 5 of Table 8 show the 95 per cent confidence intervals for age at diagnosis by disorder and gender. Confidence intervals are narrow for adults with MS and PD and wider for people with MND and HD.

Time between experiencing symptoms for the first time and being diagnosed differs by disorder, as shown in Table 9. This difference is statistically significant at the 5 per cent level ($F = 17.93, p = 0.0000$)¹⁶. People with MS are diagnosed within 4.5 years on average whilst people with MND and PD are diagnosed within 1.8 and 1.6 years, respectively. The sample size for respondents with HD is too small to draw general conclusions. However, Table 9 shows that the average time between symptoms appearing and diagnosis being made for the sample of sixteen respondents with HD is about 2.4 years.

¹⁵ Table 4 reports that 78 per cent of MS respondents are female. The difference between this proportion and the proportion reported in Table 8 results from the effects of missing values.

¹⁶ Excluding the small sample of HD respondents, the average times between having symptoms for the first time and being diagnosed differs for the remaining disorders and this difference is statistically significant at the 5 per cent level ($F = 26.41, p = 0.0000$).

There is a small gender difference in years between first experiencing symptoms and being diagnosed and this is statistically significant at the 10 per cent level ($F = 3.04$, $p = 0.0816$). On average male respondents are diagnosed in less than 3 years and females within 3.5 years. For respondents with MS, there is more variability for males (95 per cent confidence interval of 3.50 to 6.33 years) compared with females (95 per cent confidence interval of 3.64 to 5.05 years), between the year that symptoms first appear and the year they are subsequently diagnosed. Similarly for females (95 per cent confidence interval of 0.73 to 3.57 years) with MND compared with males (95 per cent confidence interval of 0.74 to 2.26 years).

On average, males with PD take longer to be diagnosed (1.7 years) than females (1.3 years). However, males and females with PD have the same amount of variability in years between symptoms and diagnosis (less than one year). Males with HD are, on average, diagnosed within 2.8 years of symptoms first appearing whilst females with HD are diagnosed within 2.1 years. Unlike respondents with PD, there is more variability in time between symptoms first appearing and diagnosis for males with HD (95 per cent confidence interval of 0 to 6.04 years) compared with females with HD (95 per cent confidence interval of 0 to 4.76 years).

Table 9: Average Time Between First Symptoms and Diagnosis by Disorder

Disorder	Number	Mean ^b (Years)	95% Confidence Interval	
MS^a	496	4.5	3.85	5.11
Male	113	4.9	3.50	6.33
Female	381	4.3	3.64	5.05
MND	48	1.8	1.06	2.48
Male	28	1.5	0.74	2.26
Female	20	2.2	0.73	3.57
PD	298	1.6	1.28	1.83
Male	178	1.7	1.30	2.11
Female	120	1.3	1.00	1.65
HD	16	2.4	0.56	4.19
Male	6	2.8	0 ^c	6.04
Female	10	2.1	0 ^c	4.76
Total^a	858	3.3	2.88	3.66
Male	325	2.8	2.26	3.39
Female	531	3.5	3.01	4.06

Note: ^a Includes 2 observations where gender was unspecified. ^b Often people who have been told they are gene positive for HD are symptom free at the time of testing, hence the 'diagnosis' precedes the symptoms. This appears to be the case for one person with HD. Another respondent with MS also reported being symptom free at the time of diagnosis. In both these cases, the gap between date of diagnosis and date of first symptoms has been set to 0 (instead of -1 or -2, respectively) so that confidence intervals can be calculated. ^c The distributions of time between HD symptoms first appearing and an HD diagnosis being made are skewed so that the actual lower bounds for respondents with HD are -0.38 for males ($k = 2.249022$) and -0.41 for females ($k = 6.517231$). For the purposes of the discussion these negative lower bounds have been rounded up to 0 in both cases.

The symptomatic difficulties shown in Table 7 may influence the type and level of support needed by people with neurodegenerative disorders. More directly, questions relating to current help received with activities of daily living could provide a better means of examining the levels of dependence of people with neurodegenerative disorders in the home setting. These activities range from help with using the telephone to assistance in getting into and out of bed. Currently this help may be from a home care service provider, from partner, family or friends, or from volunteers or others. The survey asked respondents to indicate whether or not they received any help around the home currently in relation to twenty of these everyday activities. Responses were used to construct a level of dependency variable as described in Attachment D.

There are four levels of dependency. Respondents were classified as independent if they did not receive any help with any activities in the home. Respondents with a low level of dependency needed help with instrumental activities of daily living (IADL), such as using the telephone or preparing food, but needed no help with activities of daily living (ADL) which include showering, dressing or moving about the house. A medium level of dependency is attributed to respondents who need help occasionally with any of the ADL activities and a high level of dependency is ascribed to respondents receiving help all the time for any ADL activity.

In Table 10, the percentages of respondents at each level of dependency are shown by type of disorder. The cell percentages pertain to the row totals in Column 5. For example, two thirds of respondents with MS are either independent or need very little help at home. Similarly, 46 per cent of respondents with PD need little or no help with activities of daily living. In contrast, around 11 per cent of MND respondents are independent or have a low level of dependency. Almost two thirds of respondents with MND have a high level of dependency which means that for some or all daily activities, such as showering, dressing, going to the toilet and getting in and out of bed, these people require assistance. Differences are statistically significant at the 1 per cent level.

Thirty-six per cent of the HD respondents have a high level of dependency and 44 per cent have a low level of dependency. Whilst this suggests a bimodal distribution of needs for people with HD, the sample size of 25 respondents is too small to be definitive on this issue. Very few of those respondents with HD or MND can be considered independent – 8.00 per cent and 5.56 per cent, respectively. Unpublished results using the data from the Kristjanson (2004) study also concluded that level of dependency differs by disorder and that this difference is statistically significant at the 1 per cent level.

Table 10: Comparison of Survey Respondents by Disorder and Levels of Dependency

Disorder	Levels Of Dependency				All (n)
	Independent	Low	Medium	High	
MS (%)	28.88	39.57	15.36	16.19	599
MND (%)	5.56	5.56	25.93	62.96	54
PD (%)	19.01	26.56	26.56	27.86	384
HD (%)	8.00	44.00	12.00	36.00	25
All^a (n)	251	353	211	247	1,062
Chi square = 117.4617; p = 0.000					

Note: ^a Eighteen respondents could not be categorised by level of dependency.

The survey data show whether or not respondents have a carer and, if they do, whether or not the carer lives with them. The data also show whether people are living alone or not. These characteristics are thought to be important predictors of the ability of people with neurodegenerative disorders to continue to live at home. Table 11 summarises these aspects of respondents' living arrangements. Cell percentages are related to row totals in Column 5.

Table 11 shows that most respondents who live alone and have no carer need little help (are independent or at a low level of dependency) at home (85.26 per cent). A similar pattern applies to respondents who are living with others but have no carer (82.7 per cent). The proportion of people who live with their carer increases as level of dependency increases – from 3.28 per cent of respondents who are independent to 20.74 per cent, 32.75 per cent and 43.23 per cent for those who have low, medium and high levels of dependency, respectively. The remaining categories in Table 11 are respondents who live with people other than their carers (n =6) and respondents who live alone but have carers who live elsewhere (n = 24). In neither category is there a consistent pattern in relation to increasing level of dependency.

The overall results in Table 11 confirm that people who need help attending to daily activities are unlikely to be living alone and the probability of living alone decreases the less able these people are to look after themselves. This difference is statistically significant at the 1 per cent level. Respondents with medium or high levels of dependency are more likely to have carers and are also more likely to live with these carers. In most cases, the carer is a spouse or partner. In some cases the carer is a parent or a child of the person with the neurodegenerative disorder.

Table 11: Living Arrangements by Levels of Dependency

Living Arrangement/ Carer Status	Level of Dependency				All (n)
	Independent	Low	Medium	High	
Lives alone and has no carer (%)	47.72	37.54	7.37	7.37	285
Lives alone and carer lives elsewhere (%)	0.00	37.50	16.67	45.83	24
Lives with others and has no carer (%)	34.26	48.44	12.11	5.19	289
Lives with others excluding carer (%)	16.67	33.33	16.67	33.33	6
Lives with carer (%)	3.28	20.74	32.75	43.23	458
All^a (n)	251	353	211	247	1,062
Chi square = 438.3617; p = 0.000					

Note: ^a For 18 respondents, there was insufficient information to determine their level of dependency.

There is a statistically significant gender difference in terms of levels of dependency. Table 12 shows that the proportion of female respondents who are living independently (that is, with no help with daily activities) and the proportion of male respondents who do not receive any help at home are about the same, 23 to 24 per cent. An interesting but not unexpected gender difference can be found in the category for low level of dependence. Here, the proportion of women is 16 percentage points higher than the proportion of men in this category.

The high incidence of female respondents with early stage MS in the survey sample is most likely to be contributing to this difference. In the medium and high levels of dependency categories, the proportions of males are about nine and seven percentage points higher, respectively, than the proportions of women in these categories.

Table 12: Levels of Dependency by Gender

Gender	Independent	Low Level of Dependency	Medium Level of Dependency	High Level of Dependency	Total (n) ^a
Female (%)	23.18	39.24	16.67	20.91	660
Male (%)	24.37	23.12	25.38	27.14	398
All (n)^a	250	351	211	246	1,058
Chi square = 33.1971; p = 0.000					

Note: ^a For 18 respondents, there was insufficient information to determine their level of dependency. Gender was unknown for 4 respondents

Gender differences also occur in relation to living arrangements and these are summarised in Table 13. These differences are statistically significant at the 1 per cent level. Cell percentages are related to Column totals in the final row. For example, about 63 per cent of female respondents live alone and a further 34 per cent live with a carer. For male respondents, 40 per cent live alone and 58 per cent live with a carer. About 37 per cent of female respondents live with other people compared with 60 per cent of male respondents.

Table 13: Living Arrangements by Gender

Living Arrangement/Carer Status	Female	Male	All (n)
Lives alone and has no carer (%)	31.05	20.10	290
Lives alone and carer lives elsewhere (%)	31.65	20.10	294
Lives with others and has no carer (%)	2.53	1.49	23
Lives with others excluding carer (%)	0.89	0.00	6
Lives with carer (%)	33.88	58.31	463
All (n)	673	403	1,076
Chi square = 63.3676; p = 0.000			

Note: ^a Gender was unknown for 4 respondents.

Table 14 presents transport information by disorder, levels of dependency and living arrangement. Cell frequencies are not additive as multiple responses to the 'transport used' question were permitted.

Table 14: Transport Used by Respondents by Disorder, Levels of Dependency and Living Arrangement

	Transport Type Used (n)								
	Drive self	Family drives	HACC or council bus	Bus or train	HACC taxi	DPI taxi	Other taxi	Other	Don't go out
Disorder									
MS (n = 605)	423	244	25	51	37	101	24	11	16
MND (n = 56)	17	35	1	6	6	11	1	1	0
PD (n = 386)	177	250	30	56	21	66	24	24	17
HD (n = 25)	7	17	1	4	2	2	0	0	1
Total (n = 1,072)	624	546	57	117	66	180	49	36	34
Level of Dependency									
Independent (n = 249)	235	33	3	33	3	6	3	0	0
Low (n = 351)	250	166	15	47	19	43	19	12	6
Medium (n = 209)	95	153	11	16	17	44	13	5	11
High (n = 245)	32	188	26	19	25	84	12	18	17
Total (n = 1,054)	612	540	55	115	64	177	47	35	34
Living Arrangement									
Lives alone (n = 315)	219	95	18	46	24	57	23	16	12
Doesn't live alone (n = 765)	405	451	39	71	42	123	26	20	22
Total (n = 1,080)	624	546	57	117	66	180	49	36	34

Most respondents are either continuing to drive themselves or being driven by family members. Some use public transport (buses and/or trains) or subsidised taxi services. Very few respondents do not go out at all. These results are consistent across disorders (top third of Table 14).

However, when transport type is examined in terms of level of dependency (middle third of Table 14), it is apparent that as the need for help in the home increases, the ability of respondents to continue to go out decreases. For example, no respondents are restricted from going out if they have no need for help in the home (that is, they are independent). As level of dependency increases, the number of respondents who no longer go out also increases. Seven per cent of respondents who have the highest level of dependency no longer go out.

This trend has a parallel in the declining number of respondents who can continue to drive themselves as their level of dependency increases. For respondents who are independent, 94 per cent drive themselves. For respondents who are least able to help themselves in the home (that is, their level of dependency is high), 13 per cent can continue to transport themselves, mostly by gopher rather than a car.

As dependency increases, respondents were relying increasingly on family for transport. Thirteen per cent of respondents who are independent were obtaining transport assistance from family members. This compares with 77 per cent of people with a high level of dependency who were transported by family members. Reliance on subsidised taxis, including multi-purpose taxis, increases also as level of dependency increases. For example, DPI taxi usage increased from 6 respondents who are independent to 84 respondents who have the highest level of dependency. Similarly usage of HACC taxis increases as level of dependency increases.

As expected, the use public transport decreases as respondents need more help and become less able to ingress or egress trains and buses. These respondents live in either metropolitan or country areas. They include people who live alone and those who live with others as well as people with carers and those without carers. Whether or not people have different modes of transport depending on whether they live alone or not is shown in the final third of Table 14. For example, 53 per cent of respondents who live with others continue to drive themselves compared with 70 per cent of respondents who live alone. Respondents who live alone are less likely to be transported by family members (30.2 per cent) compared with those who live with others (59.0 per cent).

In a subsequent question in the survey, respondents were asked if their current transport arrangements were satisfactory. Over 90 per cent agreed that their current transport arrangements did meet their needs. Of those who felt their needs were not met, about half cited the impracticality of the type of transport they were using and one quarter did not like having to rely on other people for transport.

Another issue touched on in the survey¹⁷ was whether or not people had the equipment that they needed. Table 15 disaggregates equipment needs by both disorder and level of dependency. Excluding those who have no need for equipment (about 46 per cent of respondents), most people have the equipment they need (86.4 per cent). Respondents with a medium level of dependency have greater unmet need for equipment than respondents at lower or higher levels of dependency. This result may reflect that the provision of appropriate equipment for this group of people as their mobility and functioning deteriorate is less timely.

¹⁷ More questions on equipment were not asked in the postal survey for the current project as the research team was aware of other studies on equipment that were underway at the same time.

Table 15: Equipment Needs of Respondents by Disorder and Level of Dependency

	Have Equipment Needed		Don't Have Equipment Needed		Total Who Need Equipment
	Number	%	Number	%	
Disorder					
MS (n = 608)	242	84.9	43	15.1	285
MND (n = 56)	37	86.0	6	14.0	43
PD (n = 391)	209	88.6	27	11.4	236
HD (n = 25)	12	80.0	3	20.0	15
Total (n = 1,080)	500	86.4	79	13.6	579
Level of Dependency					
Independent (n = 250)	43	87.8	6	12.2	49
Low (n = 350)	133	87.5	19	12.5	152
Medium (n = 216)	129	83.8	25	16.2	154
High (n = 245)	189	87.5	27	12.5	216
Total (n = 1,080)	494	86.5	77	13.5	571

The types of homes that respondents reported varied from houses (85 per cent) to rooms in boarding houses or rooms in hostels in retirement villages (0.2 per cent). Table 16 illustrates that proportionately more people with MS live in houses (87.4 per cent) and proportionately more people with PD live in various types of units (17.9 per cent). The result for respondents with PD is not surprising given that these are, on average, older people who may have already downsized their home in retirement before being diagnosed with PD. Similarly the result for respondents with MS is to be expected as these are younger people for whom houses are the normal type of home. The differences in types of home by disorder are statistically significant at the 5 per cent level.

Many people with neurodegenerative disorders are finding that their existing housing is less than appropriate or adequate, particularly as their functioning deteriorates (Karol & Giles, 2008). Respondents with MS, for example, may move to cooler climates or install air conditioning. Respondents with any of the four disorders might move closer to family or services, downsize their homes or install rails and ramps and other fittings to their existing homes. Tables 17 to 20 summarise these housing moves or modifications by disorder and level of dependency.

Table 16: Type of Home by Disorder

Disorder	Type Of Home						All (n)
	House	Room in boarding house/hostel	Independent living unit	Other unit or flat	Hostel in a retirement village	Caravan park (caravan or mobile home)	
MS (%)	87.4	0.2	3.0	8.3	0.0	1.2	605
MND (%)	85.7	0.0	7.1	7.1	0.0	0.0	56
PD (%)	81.0	0.3	9.1	8.8	0.5	0.3	385
HD (%)	84.0	0.0	0.0	12.0	0.0	4.0	25
All^a	85.0	0.2	5.3	8.5	0.2	0.8	1,071
Chi square = 29.4737 p = 0.014							

Note: ^a Nine respondents did not specify type of home.

The top half of Table 17 shows that 46 per cent of respondents have made changes to their home and that this is more common for respondents with MND and less common for respondents with MS.

Table 17: Changes Made to the Existing Home by Disorder and Levels of Dependency

	Made Changes (%)		All (n)
	Yes	No	
Disorder			
MS	38.8	61.2	598
MND	71.4	28.6	56
PD	53.3	46.7	383
HD	52.0	48.0	25
All ^a (n)	489	573	1,062
Chi square = 35.5627; p = 0.000			
Level of Dependency			
Independent	12.6	87.4	246
Low	32.7	67.3	346
Medium	66.0	34.0	209
High	82.4	17.6	244
All ^b (n)	483	562	1,045
Chi square = 298.7697; p = 0.000			

Notes: ^a Eighteen respondents did not report whether or not they had made changes to their home.
^b For 36 respondents there was insufficient information to determine level of dependency and/or home modifications.

The bottom half of Table 17 shows that as dependency level increases, the proportion of respondents making changes to their homes increases from 13 per cent (respondents who are independent) to 82 per cent (respondents with a high level of dependency). This result is intuitively appealing. For example, as mobility decreases, individuals will start using aids inside the home such as walking frames and wheelchairs. Steps to sunken lounges and sliding door tracks which prevent easy access into and inside homes will need to be adapted with ramps and rails. Showers with hobs will be difficult to use with shower chairs. Hence, the survey found that the three most prevalent changes to the home were the installation of rails and ramps as well as bathroom/shower renovations including removing hobs from shower recesses.

About 40 per cent of respondents who have modified their homes received a subsidy to do this. In some cases, the modifications were organised and undertaken by a provider. For example, a public hospital may arrange installation of hand rails in the shower recess following an inpatient or outpatient assessment.

On average, one in five respondents has moved house because of their disorder (see Table 18). However, this proportion is not constant across disorders, with two in five people with HD having moved as well as one in four respondents with MND. However, this result is not statistically significant. Less than three per cent of respondents who moved were subsidised to do so. Approximately 80 per cent of people who moved continued to live with the same people.

Table 18: Moving to a New Home by Disorder and Levels of Dependency

	Moved House (%)		All (n)
	Yes	No	
Disorder			
MS	19.7	80.3	598
MND	25.0	75.0	56
PD	18.6	81.4	376
HD	33.3	66.7	24
All ^a (n)	210	844	1,054
Chi square = 4.0256 p = 0.259			
Level of Dependency			
Independent	9.4	90.6	246
Low	18.0	82.0	345
Medium	24.2	75.8	207
High	30.5	69.5	239
All ^b (n)	208	829	1,037
Chi square = 37.0850 p = 0.000			

Notes: ^a Missing information on house moves for 26 respondents. ^b For 44 respondents there was insufficient information to determine level of dependency and/or whether or not they had moved house.

There are a variety of specific reasons why people decided to move in response to changes to their mobility and functioning as their condition deteriorated. These are shown in Table 19. Multiple responses were permitted so the cell frequencies are not additive. In some cases, they chose to move to bigger homes that had wider doorways or more space for their equipment such as the hoist. About one quarter of people who moved chose smaller homes. This downsizing was a response to their need to minimise their household management and reduce their costs. Having smaller gardens and less maintenance were priorities for some respondents.

Almost half of the respondents who moved did so because the new home was more accessible. This includes fewer or no steps or being single storey. Some people were able to move to disability housing or other housing that was more suitable for manoeuvring wheelchairs. Having less gardening and home maintenance was important to proportionately more respondents with MND and PD than those with MS or HD. Access to services, including health services and community care, was an important issue for some respondents.

Table 19: Features of the New Home for Respondents Who Moved Because of Their Condition by Disorder

Disorder	Bigger	Smaller	Different size, unspecified	More accessible	Disability-specific facilities	Better location	Less maintenance required	Better access to help / services	Better temperature control	Better bathroom	n ^c
MS (n=100)	3	20	1	57	22	13	15	2	4	14	100
MND (n=13)	0	4	0	7	3	3	5	0	0	1	13
PD (n=66)	4	26	0	28	8	13	24	7	1	6	66
HD (n=7)	2	1	0	6	0	1	1	1	0	0	7
Total ^b (n=186)	9	51	1	98	33	30	45	10	5	21	186

Note: ^a The cell totals are not additive across the rows as some respondents gave more than one reason for moving. ^b 24 respondents who moved did not give any reasons for their moves. ^c Cell contents in this column are numbers of unique individuals.

The final table of information on respondents' housing is Table 20. Here, home ownership is summarised. At the time of the survey, over half of all respondents owned their own home without a mortgage but this ranged from 42 per cent for people with MS to 76 per cent for people with PD. This result is not surprising because people with MS tend to be younger (average age is 53.1 years, see Table 4) and therefore may still be paying off a mortgage. People with PD are older on average (72.3 years, see Table 4), often being diagnosed after they have retired. Generally, people aim to pay off their mortgages before retirement (see, for example, ANOP Research Services, 2001). In total, people with MS, MND and PD are more likely to be homeowners with 76.4 per cent, 78.5 per cent and 84.2 per cent owning their home with or without a mortgage. Respondents with HD reported a lower level of home ownership, 60 per cent in total.

A number of respondents live in public housing managed by Homeswest. For example, 7.2 per cent of respondents with MS are in Homeswest homes and two thirds of these live in disability housing. People with PD are less likely to be living in Homeswest housing and this is probably linked to their higher than average level of home ownership. Sixteen per cent of respondents with HD (n = 4), with an average age of 45 years, live in homes owned by other family members including parents.

Table 20: Home Ownership by Disorder

Disorder	Who Owns Home								All (n)
	Self with mortgage	Self without mortgage	Private landlord	Other family members	Homeswest disability housing	Other Homeswest	Other	Self/partner mortgage unspecified	
MS (%)	33.4	41.8	9.9	6.1	4.6	2.6	0.3	1.2	605
MND (%)	19.6	57.1	10.7	5.4	3.6	1.8	0.0	1.8	56
PD (%)	6.9	75.7	5.6	7.9	0.8	1.6	0.0	1.6	378
HD (%)	0.0	60.0	12.0	16.0	4.0	4.0	4.0	0.0	25
All^a (n)	239	586	90	74	34	24	3	14	1,064
Chi square = 164.2744 p = 0.000									

Note: ^a 16 respondents did not report their home ownership.

3.3 Home Care Services and Service Gaps for Care Recipients

A key issue in this project is whether or not people with neurodegenerative disorders are receiving the home care support they need to continue living at home as their conditions worsen. Table 21 summarises, by level of dependency, whether respondents reported receiving any services¹⁸ from a home care service provider, a support agency or a local council.

Table 21: Whether Respondents Receive Services by Level of Dependency

Level Of Dependency	Receiving Services		All (n)
	No	Yes	
Independent (%)	93.6	6.4	248
Low Level of Dependency (%)	60.5	39.5	352
Medium Level of Dependency (%)	51.0	49.0	210
High Level of Dependency (%)	20.6	79.4	247
All^a (n)	603	454	1,057
Chi square = 273.3107; p = 0.000			

Note: ^a Five respondents did not specify whether or not they were receiving services and 18 respondents could not be classified by level of dependency.

¹⁸ See NDP No 5 for more detailed information on the types of assistance people with NDD may access in the community from various sources.

Three in five respondents to the survey (n = 603) reported that they did not receive any services from a home care service provider, support agency or local council. Of these, 38 per cent (n = 231) did not need any help with activities of daily living. Of those with a high level of dependency but who are not receiving any home care support services (n = 51), 47 live with their carers and four live with others but have no carer.

Most respondents who have a medium level of dependency but receive no services (n = 107) live with others who may or may not be their carers. Four of these respondents live alone and have no carer. All four have MS with mild to extreme difficulties but all either have no trouble walking or have some trouble but do not use any walking aids. The dependency rating for these three respondents is related to their need for occasional help with eating (help from independent children) or managing their bladder (helper(s) unspecified) or managing their bladder and bowels (help from others, unspecified).

There are 213 respondents who receive no services and whose level of dependency is low. That is, they need help occasionally or always with at least one of the nine IADL categories and no help with any of the ADL categories (see Attachment D for a breakdown of IADL and ADL categories). Some of these respondents live with their carer (n = 63) and one has a carer who doesn't live with him. A further 106 live with others. Forty-three respondents with low dependency needs live alone and have no carer. These respondents need help at most with six of the nine IADL categories. Most (n=29) need help with only one or two of these categories. For most of the respondents who did not receive any services, it appears that they had sufficient access to care from family or friends if they needed it.

The services referred to in Table 21 include the four main categories of assistance in the home - personal care including meal preparation, housework, social support including companionship and accompanying to the shops or appointments, and gardening or home maintenance. Other categories of services include nursing care, specialist care advice from, for example, a Parkinson's nurse specialist, a Multiple Sclerosis Society care worker or an MND care advisor, delivered meals, social worker assistance, physiotherapy, podiatry, occupational therapy, dietetics, or speech pathology.

For the purposes of the analyses to follow, a clarification of various subsets of respondents receiving services is constructive. As shown in Table 21, 43 per cent (n = 454) of respondents reported that they received services provided by home care service providers, support agencies and/or local councils. Of these, four in five (n = 349) reported receiving assistance with at least one of the four main categories of services. These types of services are delivered in either of two ways as shown in Table 22. One of these is via packages of care. These can include combinations of personal care, housework, gardening or home maintenance, social support and transport services. About one third (n = 117) of respondents receiving assistance with at least one of the four main categories of services were receiving a care package. Two thirds of respondents (n = 227) who were receiving at least one of the four main categories of services, received their home care support via unpackaged care. The two different types of home care support – packaged and unpackaged care – are explained in the following.

Generally, packages of care include a total number of hours of service which can be divided between the different service type categories depending on an individual's needs. For example, one respondent receiving twenty-two hours of packaged care per week, may be getting two hours per day of personal care including meal preparation, 1.5 hours of housework per fortnight and 7.5 hours per week of social support.

Another respondent, also with 22 hours of packaged care per week, may be receiving 1.5 hours of personal care in the mornings, 1 hour of personal care in the evenings, 1 hour of housework per fortnight, 3 hours of social support per week and 4 hours of gardening or home maintenance per month. See Attachment E for a more comprehensive discussion of packaged care.

Table 22 shows respondents receiving, in terms of the four main categories of home care support services, packaged care (Column 1) and those receiving services that are not packaged (Column 2), disaggregated by level of dependency. Of those people who reported receiving services (n = 349¹⁹), 34 per cent (n = 117) reported that these services came in the form of a care package, averaging 8.5 hours per week of services. Those receiving unpackaged care services (n = 227) received 3.6 hours per week of services on average. This difference is not unexpected as care packages allow for more hours of service than can be funded through combinations of unpackaged care.

Table 22: Respondents Receiving Home Care Support Services (Four Main Categories) by Type of Support and Level of Dependency

Level Of Dependency	Receiving a Care Package (%)	Receiving Unpackaged Care Services (%)	All ^a (n)
Independent	0.00	1.76	4
Low Level Of Dependency	17.95	33.48	97
Medium Level Of Dependency	17.95	21.59	70
High Level Of Dependency	64.10	43.17	173
All^a (n)	117	227	344
Chi square = 15.8941; p = 0.001			
Average Hours Of Service^b	8.5 (n=114)	3.6 (n = 217)	n.a.

Note: ^a Five respondents indicated that they received services in the four main categories but did not specify whether these represented packaged or unpackaged care. ^b Hours of service were not provided by thirteen respondents.

In the top part of Table 22, the cell contents are percentages of the column totals. Of interest in Table 22 is that the distributions of packaged and unpackaged care services in terms of levels of dependency are similar. It can be seen that the proportion of respondents receiving a care package (that is, a higher level of service) increases as respondents become increasingly dependent. That is, whilst no respondents who are independent receive packaged care, 64 per cent of those receiving packaged care are at the highest level of dependency. The proportion of respondents with unpackaged care also increases from under 2 per cent of respondents who are independent to 43 per cent of those at the highest level of dependency. In summary, as functioning decreases, more people with neurodegenerative disorders are receiving home care support services.

¹⁹ Five respondents who reported receiving home care support services did not specify whether these were provided in a care package or as unpackaged care.

Also derived from Table 22 is that 50 per cent of respondents (n = 173) receiving packaged or unpackaged care are in the late stage of their disorder, needing help with most activities of daily living. A further 28 per cent of respondents (n = 97) receiving home care support are at the early stage of their disorder and most of these are receiving unpackaged care services. Twenty per cent of respondents (n = 70) receiving home care support are at a medium level of dependency.

Disaggregating type of home care support by both level of dependence and level of mobility is shown in Table 23.

For both respondents receiving packaged care and respondents receiving unpackaged care, level of mobility and level of dependency are inversely related. That is, as mobility decreases, level of dependency increases. These results are statistically significant at the 1 per cent level. Table 23 shows that the number of respondents in the highly dependent/highly immobile category is proportionately higher for respondents receiving packaged care (n = 27, N = 115, p = 23.5 per cent) than for respondents receiving unpackaged care (n = 21, N = 220, p = 9.5 per cent). As discussed earlier, this result is not surprising as packaged care is generally more available to people with high needs.

Table 23: Respondents Receiving Home Care Support Services (Four Main Categories) by Level of Mobility, Level of Dependency and Type of Home Care Support

Level of Dependency	Level Of Mobility						All
	No trouble walking	Trouble walking but use no aids	No aid inside the home but aid outside	Aid inside the home	Use wheelchair inside with use of arms	Use wheelchair inside but little or no use of arms or bedridden	
Respondents Receiving Packaged Care							
Low Level of Dependency	4	3	6	2	5	0	20
Medium Level of Dependency	0	6	6	4	4	1	21
High Level of Dependency	2	9	5	16	15	27	74
All^a	6	18	17	22	24	28	115
Chi square = 36.2263; p = 0.000							
Respondents Receiving Unpackaged Care							
Independent	0	1	1	2	0	0	4
Low Level of Dependency	8	21	24	13	8	1	75
Medium Level of Dependency	4	11	11	14	6	2	48
High Level of Dependency	0	9	14	31	18	21	93
All^b	12	42	50	60	32	24	220
Chi square = 51.0068; p = 0.000							

Notes: ^a Two respondents did not specify their mobility level. ^b Seven respondents did not specify their mobility level.

At the other end of the dependency/mobility continuum, there is a similar proportion of respondents receiving packaged care that have a low level of dependency and are reasonably mobile (n = 4, N = 115, p = 3.5 per cent) and respondents receiving unpackaged care who are similarly dependent or mobile (n = 8, N = 220, p = 3.6 per cent). People whose levels of difficulties are minimal are more likely to receive unpackaged care initially and move to packaged care as their need for assistance crosses a threshold level of need.

Table 24 disaggregates respondents receiving packaged care by their levels of dependency and living arrangements. The category of lives alone includes respondents who live alone and have no carer as well as those who live alone and have a carer who lives elsewhere. Respondents living with others may be living with partners and/or children. Some respondents are living with parents.

One quarter of respondents receiving packaged care live alone (n = 30) and just over half of these have medium to high levels of dependency (n = 18). Two thirds of respondents receiving packaged care are living with their carers (n = 80). Seventy-one per cent of respondents with a low level of dependency (n = 21) either live alone (n = 12) or live with others but have no carer (n = 3). This proportion falls to 24 per cent for respondents with a medium level of dependency and to 21 per cent for respondents at the highest level of dependency. These differences are statistically significant at the 1 per cent level.

Table 24: Respondents Receiving Packaged Care (Four Main Categories of Service) by Levels of Dependency And Living Arrangements

Level Of Dependency	Living Arrangements				All
	Lives Alone	Lives With Others			
		Has No Carer	Including Carer	Has Carer Who Lives Elsewhere	
Independent	0	0	0	0	0
Low Level of Dependency	12	3	6	0	21
Medium Level of Dependency	5	0	16	0	21
High Level of Dependency	13	3	58	1	75
All	30	6	80	1	117

Chi square = 24.2766; p = 0.002

As already discussed, about seventy per cent of people receiving home care services in the four main categories of service (n = 344) obtain services that are not packaged (n = 227). In Table 25, it can be seen that about half of these respondents live with their carer (n = 124) and a further 12 per cent live with others but have no carer (n = 28).

Table 25: Respondents Receiving Unpackaged Care Services by Level of Dependency and Living Arrangement

Level Of Dependency	Living Arrangements				All
	Lives Alone	Lives With Others			
		Has No Carer	Including Carer	Has Carer Who Lives Elsewhere	
Independent	2	1	0	1	4
Low Level of Dependency	46	14	15	1	76
Medium Level of Dependency	9	6	34	0	49
High Level of Dependency	15	7	75	1	98
All	72	28	124	3	227

Chi square = 83.6952; p = 0.000

As discussed earlier, there is considerable variation in the total number of hours of service delivered via a care package as well as differences in the combinations of the four main categories of services. For example, of the 117 respondents who reported that their home care support was via a care package, some were receiving as few as two hours and several as much as 18 hours per week in their package²⁰. The average weekly care package was 8.5 hours. This package may have included only one type of service or all four types of service. As mentioned earlier, even when the numbers of service hours are the same, individuals may be receiving completely different combinations of the four main categories of services.

The effect of this heterogeneity in the hours and types of services for people receiving care packages is that the calculations of average hours of service and average hours of unmet need are not meaningful for this group. Determining average service hours in terms of various combinations of, for example, disorder, level of dependency or mobility, and living arrangement is also not useful as cell sizes are too small. The impact of excluding this group from calculations of average current and needed home care support services is that projections of needed services for people with NDD (outlined in NDP Report No 6 – Projections of unmet need) may be underestimated.

Whilst the precise extent of this underestimation is unknown, it is possible that it is minimal. The reasoning is thus. Given that care packages are more generous in terms of total hours, it is possible that individuals receiving a package of care are closer to receiving the number and flexibility of hours that they require compared with people receiving unpackaged care in which total hours are capped at a much lower level and there is no flexibility to move hours of service between the different service types.

Given the aforementioned difficulties with analysing the home care support needs of individuals receiving care packages, the analyses to follow are based on the responses of people receiving unpackaged care for the four main categories of home care support services.

²⁰ Note that some individuals were recently assigned a care package based on changes in their needs, hence, at the time of the survey, they were yet to use the total weekly hours allocated.

For respondents who indicated that their services from a home care service provider, support agency or local council were not packaged, the survey asked questions about hours of service currently received and hours of services needed for personal care, housework, social support and gardening or home maintenance. Some respondents currently receive no hours for a particular service type but would like some hours, some respondents are happy with the current amount of services and some respondents indicated that they needed more hours of services²¹.

It can be seen from Table 26 that the most prevalent home care service is housework with an average of 1.4 hours per week currently received. Respondents have asked for an extra half an hour per week on average for housework. The average amount of personal care services, such as a daily shower or bath, is 5.2 hours per week. On average respondents need 6.5 hours of personal care per week. The average need for social support, such as in-home respite or shopping, is 4.8 hours per week. This is about forty per cent higher than average current hours of social support of 3.5 hours per week. The average amount of gardening or home maintenance received is 0.5 hours per week and respondents, on average, need 1.3 hours per week.

Table 26: Home Care Service Hours by Type of Service

Type of Home Care Service	Number of Respondents Reporting Current Services	Average Hours of Current Services (s.d.)	Average Hours of Services Needed (s.d.)
Packaged Care	114	8.5 (10.03)	n.a.
Personal Care	60	5.2 (7.23)	6.5 (7.95)
Housework	186	1.4 (1.13)	1.9 (1.49)
Social Support	50	3.5 (3.09)	4.8 (4.29)
Gardening or Home Maintenance	82	0.5 (0.75)	1.3 (1.18)
All^a	217	3.6 (5.40)	5.02 (7.11)

Note: ^a Some respondents receive more than one type of home care support service so the totals by type of home care service do not sum to the total figure.

The difference between current service provision (met need) and required services (total need) represents a gap in current home care support. This gap can be loosely referred to as unmet need or unmet demand. However, this service gap is quite a narrow definition for unmet demand for two reasons. First, it is measured quantitatively in hours of service rather than in terms of the 'quality' of services provided. That 'quality' is difficult to define is defensible but outside the scope of this study with its emphasis on hours and timing of home care support.

²¹ The survey specifically asked about hours of service. Subsequent interviews with a subset of respondents highlighted that quality of service might also be an issue.

The second reason for service gap being a narrow definition of unmet demand is that it tends to rely on information from people already within the system of home care support services and ignores the needs of people who, through self-selection or ineligibility, remain outside this system. In this study, respondents include those who are currently clients of home care support providers as well as those who are not current clients. If the latter have expressed their home care support service needs, then the service gap is unlikely to be biased, that is under- or over-stated.

It should be noted that the service gap discussed in this report is based on the self-reported unmet need of survey respondents. It does not necessarily reflect requests for more services. Nor does it reflect professional assessment of service requirements. However, during subsequent interviews (see NDP Report No 2 – Client and carer interviews) it was clear that many respondents were familiar with the cut-offs for service provision and generally felt that these were too low.

In Table 27, the gaps in home care service provision for people receiving unpackaged care in terms of the four main categories of service, are shown. These gaps are measured in hours.

Table 27: Home Care Service Gaps By Type Of Service

Type Of Home Care Service	Respondents Needing More Services		Average Gap In Service Hours Per Week (s.d.)	Gap Range In Hours Per Week	Respondents Happy With Current Level Of Service	
	n	%			n	%
Personal Care	18	30.0	4.5 (6.22)	1 - 27	42	70.0
Housework	66	35.5	1.4 (1.13)	.25 – 6.25	120	64.5
Social Support	20	40.0	3.3 (3.01)	.25 – 11	30	60.0
Gardening Or Home Maintenance	54	65.8	1.3 (0.95)	.08 – 4.5	28	34.1
All^a	109	50.2	2.8 (4.29)	.08 – 34	108	49.8

Note: ^a See Note to Table 26.

The following comments refer to Table 27 which refers only to unpackaged care assistance in the four main categories of services. Just over a half of respondents have a current unmet total need averaging 2.8 hours per week. One third of respondents receiving and/or needing personal care services have a current unmet need averaging 4.5 hours per week. These unmet needs increase with an increase in the respondent's level of dependency, a result supported by both Krivickas, *et al* (1997) in their US study of people with MND and Solari, *et al* (2005) in their study of MS patients in Italy.

Of the 186 respondents receiving and/or needing housework, 36 per cent (n = 66) reported a gap of 1.4 hours per week on average. There appeared to be little difference in the size of the gap as a respondent's level of dependency increased. This is a reasonable result as, compared with personal care, cleaning is less related to the capabilities of the client. O'Hara, *et al* (2004) reported, in their UK study, that three quarters of MS respondents required housework. However, unlike the present study, their survey population was biased towards people recruited by voluntary community-based organisations, hence they were more likely to be receiving services.

Twenty people needed more hours of social support. The mean gap in social support is 3.3 hours per week. As with personal care, unmet needs for social support appear to increase as level of dependency increases. Kristjanson (2004), in her Australian study, concluded that people with neurodegenerative disorders were most in need of assistance with transport and social support but did not quantify unmet need for either of these services. Nonetheless, she found that 76 per cent of these people were either satisfied or very satisfied with the services they received, including home care support as well as respite, financial assistance, access to palliative care and equipment.

The number of respondents currently receiving services related to gardening and home maintenance (GHM) is 82. All but one of these, have homes they need to maintain themselves – house, unit, unit in retirement village or mobile home in caravan park. One respondent boarded with family members so probably felt obliged to contribute to the maintenance of this home and garden. Table 27 shows that one third of these respondents did not need extra GHM services. A further third needed between one extra hour every three months to one extra hour a week. The remaining respondents needed from 1.5 to 4.5 extra hours per week. This category of home care support had the highest frequency, 66 per cent, of reported gaps in service. As with housework, there was no apparent relationship between unmet need for gardening and/or home maintenance and level of dependency.

There is recognition by health professionals and home care service providers that the needs for support in the home for people with neurodegenerative disorders are not represented by current care models for the frail aged or for people with other neurological disorders that are not degenerative. In particular, there are two aspects of the service needs of people with neurodegenerative disorders which are essential. These are that services are both timely and appropriate. Neither of these aspects of home care support can be precisely determined for any given individual. This argument lends support to a case management approach to organising home care support for this group. See NDP Report No 5 for further discussion of this issue.

Table 28: Home Care Service Needs by Type of Other Home Care Support Service

Other Home Care Support Services	More Often (%)	Same as Current (%)	Number of Respondents (n) ^A
Nursing Care	12.2	85.4	41
Specialist Care Advice	20.7	79.3	29
Meals Delivered	11.1	88.9	18
Services from a Social Worker	0.0	100.0	3
Physiotherapy	34.9	60.5	86
Podiatry	12.1	86.2	58
Occupational Therapy	13.3	80.0	15
Services from a Dietitian	9.1	90.9	11
Speech Pathology	16.7	83.3	18

Note: ^a Some respondents reported wanting some of these services less often hence percentages in Columns 2 and 3 may not add to 100.0 per cent.

Other home care support services are listed in Table 28. These results show that most respondents receiving regular support are happy with the frequency of the current arrangement. Services from physiotherapists and specialist care advisors are two services which some respondents would like more often. For example, one third of respondents currently having regular physiotherapy visits would like to see the physiotherapist more often, and one quarter of people receiving specialist care advice would prefer to receive it more often.

Another home care support need that was identified in the survey related to respite. Table 29 gives a breakdown of respite by current use of, and preference for, respite.

Table 29: Respite Services: Use and Needs

Current And Future Use Of Respite	Number Of Respondents
Currently use respite and happy with this amount	54
Currently use respite and would like to increase this amount	61
Not using respite but would like to	85
Not using respite and do not want to use it	500
Total	700

Note: ^a 380 respondents did not provide answers regarding their current use of respite and/or their future use of respite.

Table 29 shows that, whilst 16.4 per cent of respondents are currently using respite (n = 115), 14.5 per cent of people not currently receiving respite would like to access it (n = 85). Also, just over half of those respondents currently receiving respite would like to access more (n = 61). It is not clear from the survey responses whether these needs for respite or more respite are related to current choices by carers and care recipients not to avail themselves of respite services at the moment.

Some of the literature suggests that this is not necessarily the case. For example, De San Miguel, *et al* (2004) refer to carers' up-take and continued use of respite services being dependent on the type and quality of respite being offered. See NDP Report No 5 – Key issues and unmet needs: health, allied health and service provider perspectives for a discussion of the suitability of current respite beds and facilities for people with neurodegenerative disorders.

3.4 Characteristics and Home Care Assistance Needs of Carers

A number of socio-demographic characteristics of carers²² were collected in the survey. The following tables look at the average age of carers and care recipients and the gender split for carers and the people they care for.

Table 30: Average Age of Carers and Care Recipients by Disorder

Disorder of Care Recipient	Care Recipients		Carers	
	Number	Mean Age (yrs) (s.d) Range (yrs)	Number	Mean Age (yrs) (s.d) Range (yrs)
MS	194	56.6 (13.01) 18 – 90	198	56.4 (14.63) 14 – 87
MND	46	64.7 (10.01) 40 – 85	46	59.5 (11.98) 35 – 82
PD	227	73.7 (8.40) 49 – 93	227	70.2 (9.11) 40 – 87
HD	21	58.0 (11.73) 34 – 71	21	61.5 (7.68) 42 – 70
All	488	65.4 (13.44) 18 - 93	492	63.3 (13.50) 14 - 87

It can be seen from Table 30 that the average ages of carers is 63.3 years and of the people they care for, 65.4 years. These averages differ by disorder. For example, the average age of people with PD who have carers is 73.7 years and their carers are aged, on average, 70.2 years. A similar pattern is seen with care recipients who have MND. The average age of care recipients with MND is 64.7 years and the average age of their carers is 59.5 years. Care recipients with MS are about the same average age, 56 years, as their carers. For people with HD, their average age is 58 years and their carers are 61.5 years, on average.

In the 1998 profile of carers in Western Australia, Carers WA found that 54.2 per cent of carers) were women (Vitali, 1999). Table 31 shows that for the sample of people with neurodegenerative disorders in the survey, the proportion of female carers is about 56 per cent. There are differences by disorder with 39.8 per cent of carers of people with MS being female (n = 78). This is not unexpected as over 70 per cent of care recipients with MS are women.

²² See Appendix 1 for the Extract from the Carers' Recognition Act which defines who a 'carer' is and who would not be considered a 'carer'.

Of care recipients with MND, PD and HD, the proportions of carers who are female are 69.6 per cent (n = 32), 66.7 per cent (n = 152) and 52.4 per cent (n = 11), respectively. The table also shows that very few male carers are looking after male family or friends. In the case of male care recipients with MND, all are being cared for by female carers. The differences shown in the table are statistically significant at the 1 per cent level overall as well as by disorder.

Table 31: Care Recipients and Carers by Gender and Disorder

Disorder	Gender Of Care Recipient	Gender Of Carer		All
		Female	Male	
MS	Female	25	115	140
	Male	53	3	56
MND	Female	6	14	20
	Male	26	0	26
PD	Female	9	71	80
	Male	143	5	148
HD	Female	2	9	11
	Male	9	1	10
All	Female	42	209	251
	Male	231	9	240

The survey asked carers if the person they cared for would be able to manage to live in their own home if they (the carer) were unable to provide caring assistance. Table 32 shows that four in five carers responded that their care recipient would not be able to manage at home. Of the remainder, forty per cent said that their relative/friend could be looked after by someone else. This could be another family member or friend in most cases, or care worker(s) or subsidised service provider(s) in a few cases.

Table 32: Alternative Care Arrangements

Alternative Care Arrangements	Number Of Carers
Care recipient could not manage without a carer	358
Care recipient could manage with assistance from other family or friends	34
Care recipient could manage with care from care worker(s)	2
Care recipient could manage with care from subsidised service provider(s)	4
Care recipient could manage without a carer and any assistance from anyone	61
Total^a	459

Note: ^a Some carers did not respond to the question about alternative care arrangements.

One of the issues raised in two earlier studies (Finlayson, *et al.*, 2003; McGarva, 2001) is whether or not carers and care recipients are in agreement when asked questions related to health and services. Finlayson, *et al* (2003) reported that perceptions of health status for and by people with MS differed. McGarva (2001) found that perceptions of difficulties by people with HD and their carers were different with care recipients painting a bleaker picture than carers for some issues as well as carers perceiving more problems than care recipients on other issues.

The survey for the current project asked similar questions, related to home care support, of both the carer and the care recipient. This has enabled some assessment of the concordance between these viewpoints. In Table 33, it can be seen that there are cases where both the carer and the care recipient want more services or both are happy with the current provision of services. However there are occasions when the care recipient wants more services or the carer wants more services. For example, about thirty per cent of care recipients and their carers want more personal care services. Just under a half of care recipients and their carers agree that the current amount is enough. That is, both are happy with the level of personal care services they currently receive.

Table 33: Care Recipient and Carer Satisfaction with Current Amount of Home Care Support

Service Type	Number of Observations				Total
	Both Want More Services	Care Recipient Happy/Carer Wants More Services	Carer Happy/Care Recipient Wants More Services	Both Are Happy With Current Services	
Personal Care	11	5	4 ^a	18 ^a	38
Housework	32	23	5	38 ^a	98
Social Support	3	3	3 ^b	11 ^c	20
Gardening/Home Maintenance	21	3	10 ^{c,d}	9 ^{a,b}	43
Nursing Care	12	11	14 ^d	41 ^{c,d}	78 ^e

^a One carer wants more services but has not specified who from. ^b One carer wants more services but not from homecare providers. ^c Two carers want more services but not from homecare providers. ^d Two carers want more services but haven't specified who from. ^e Less than 10 per cent of surveys had sufficient information to make this comparison.

In Table 33, nine survey responses revealed that carers and care recipients disagree about whether or not the current amount of personal care services is sufficient. In half of these cases the carer wants more services but the care recipient is happy with the current amount; in the other cases, the reverse is apparent. In the four cases where the care recipient wants more personal care services but the carer is happy with the current amount, three are male carers caring for female partners and one is a female carer assisting her male partner. Two couples are aged less than 55 years and the others are aged 70 years or older. In five cases where the care recipient is happy with the current amount of personal care services and the carer wants more services, four carers are male and one carer is female. All are caring for females and the couples are not necessarily partners. For example, a female carer is a friend of the person with MS and lives elsewhere.

Twenty-nine per cent of care recipients and their carers reporting their current amount of housework services disagree over whether or not they are happy with the current level of service. In the main, the care recipients are satisfied with the current hours of housework assistance and the carers want more. Similarly, 30 per cent of care recipients and carers disagree over whether they want more social support and gardening and home maintenance services, and 32 per cent disagree over whether they need more nursing care.

3.5 Selection of Respondents for Interview

Survey respondents were asked to indicate whether or not they would be available for interview. For three in every four completed surveys (n = 804), respondents made this known by providing their name and contact phone number. For the interview component of this project, 48 people were to be selected for interview.

Table 34: 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
MD				
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 selection of people for interview depended on their disorder, their living arrangements and their level of dependency. Table 34 provides frequencies of willing respondents in each sub-category. It was not intended to interview any respondents who were independent (n = 228). For most sub-categories, there was considerable choice of respondents to interview. Other characteristics, such as where they live (metropolitan Perth, regional centres), their carer status and whether they had dependent children, were also used in the selection process. In four sub-categories, there were no potential interviewees.

During the interviews, the research team found that some survey respondents had changed needs resulting in them belonging in a different category (more or less dependent) in the matrix. Five interviewees had lower levels of dependency than reported in the survey and three had higher levels of dependency. See NDP Report No 2 – Client and carer interviews for a discussion of the number of interviews conducted and the subsequent matrix of interviewee characteristics.

4 CONCLUSIONS AND FURTHER RESEARCH

One of the key issues by which the postal survey of individuals with neurodegenerative disorders and their carers might be judged is the generality of results. This may be compromised in the presence of two types of biases. Non-response bias may arise if the profile of survey respondents is different, in a statistically significant way, to the profile of the sample being surveyed. Selection bias occurs if the sample being surveyed is, in some non-random way, different to the population it is purported to represent. Both non-response and selection bias can effect the broader interpretation of the results.

In relation to non-response bias, are people who didn't return a completed survey in some way different to those people who did complete and return a survey? For example, did survey length and difficulty - 'respondent burden' (Saleh, *et al.*, 2002) – discourage participation? The survey was quite long - sixteen A4 pages and 37 main questions many of which had sub-questions. Some questions required respondents to give considerable detail, such as how many hours per week of various types of home care support they received and how many hours per week they thought they needed. People with neurodegenerative disorders may have physical and cognitive disabilities to varying degrees so that, whilst they may be helped with the survey by, for example, their main carer, the process of responding could have been tiring and/or onerous.

A comparison of the age and gender profile of survey respondents and agency members suggested sufficient similarities to assume that the survey results can be generalised to characteristics of agency memberships. That is, non-response bias is unlikely. Moreover, the response rate of 54 per cent²³ was sufficiently high that this assumption is not spurious.

Determining the survey response rate without a merged mailing list was difficult initially as it was unclear how many unique individuals were being surveyed. When the data linkage component of the project was completed (see NDP Report No 4 – Data Linkage 2006), the process identified 2,550 unique individuals (69 per cent) in the linked dataset of 3,695 observations. If this percentage is applied to the 2,939 posted surveys, then the number of unique individuals across all mailing lists is 2,028. Thus, the adjusted response rate becomes 54 per cent (1,095 returned surveys from an adjusted number of posted surveys of 2,028). Note that the linked dataset of 3,695 observations contains individuals who at any time during 2006 were receiving services from any one of the participating organisations. It is to be expected that this number is larger than the combined mailing lists (unadjusted survey population) of 2,939 individuals who were receiving services at the time of the survey.

This report shows that the proportions of respondents decrease as mobility worsens. That is, whilst 30 per cent of respondents have no trouble walking, at the other end of the mobility scale, about 6 per cent are bedridden. In some respects this skewed distribution reflects non-response bias in the respondent sample. That is, people with greater mobility probably have fewer difficulties overall and would find responding to the survey less onerous whilst people whose mobility is severely compromised are less likely to respond to the survey.

²³ In social science research, response rates of at least 30 per cent are considered acceptable. There is even some scepticism about the reliability of really high response rates. Martikainen, *et al* (2007) reported that non-response rates of 20 to 40 per cent are typical in epidemiological studies. In their study of social class and health, their response rate was 67 per cent. They were also able to conclude that “survey non-response does not seriously bias analyses of social class inequalities in sickness absence and possibly health inequalities more generally” (pg 215).

However, the alternative explanation for this skewed distribution is attrition. That is, as the neurodegenerative disorder progresses, the survival rate (staying alive and at home) at consecutive stages of the disorder diminishes. People may die or be placed in assisted living environments for reasons other than restricted mobility. In these cases they would not be in the catchment for this study. The extent to which non-response bias and/or attrition are influencing the profile of survey respondents is unclear.

Generalising the survey results beyond agency memberships to the populations of people with these disorders is another issue. It is likely that, due to biases related to age, education, income and gender, agency members may be non-random subsets of these populations. This is the case of selection bias.

It is not possible, given the data, for the survey results to be corrected for either non-response or selection bias.

The postal survey produced a number of interesting results related to home care support needs. Firstly, the three part survey attempted to collect information from both individuals and carers with a view to comparing how each viewed their home care support needs. There was some expectation that these views may conflict as supported in the literature. In fact, the survey responses revealed cases in which both the carer and the care recipient wanted more services or both were happy with the current provision of services. However there were also cases in which either the care recipient wanted more services or the carer wanted more services.

Second, the survey data enabled estimation of the gaps (unmet need) in home care support across various categories of home care support and across the three levels of dependency (low, medium and high). Just over a half of respondents have a current unmet total need averaging 2.8 hours per week. One third of respondents receiving and/or needing personal care services have a current unmet need averaging 4.5 hours per week. These unmet needs increase with an increase in the respondent's level of dependency. The mean gap in social support is 3.3 hours. As with personal care, unmet needs for social support appear to increase as level of dependency increases.

Of those respondents receiving and/or needing domestic assistance, the gap is about 1.4 hours per week on average. The size of this gap is not related to level of dependency. This is a reasonable result as, compared with personal care, cleaning is not necessarily related to the capabilities of the client. Two thirds of respondents receiving and/or needing gardening and/or home maintenance reported unmet need. As with domestic assistance, there was no apparent relationship between unmet need for gardening and/or home maintenance and level of dependency.

The survey shows that about 16 per cent of respondents are currently using respite and a further 12 per cent of people would like to access it. Also, just over half of those respondents currently receiving respite would like to access more. It is not clear from the survey responses whether these needs for respite or more respite are related to current choices by carers and care recipients not to avail themselves of respite services at the moment. Previous studies have suggested that individuals and carers are happy to know that respite is available if needed even if they are reluctant to use it.

The survey asked carers if the person they cared for would be able to manage to live in their own home if they (the carer) were unable to provide caring assistance. Four in five carers responded that their care recipient would not be able to manage at home. Of the remainder, forty per cent said that the care recipient could be looked after by someone else. This could be another family member or friend in most cases or care worker(s) or subsidised service provider(s) in a few cases.

In summary, the survey provides some useful quantitative data on the characteristics and needs of people with neurodegenerative disorders. Interviews of a subset of survey respondents (see NDP Report No 2 – Client and carer interviews) were able to expand some of the survey responses as well as explore the lifestyle changes made by individuals and their carers. Diaries used in the development of four case studies (see NDP Report No 3 – Case studies) provided yet another view of the lived experience of individuals with similar and high needs but different circumstances. Whilst not intended to undertake longitudinal data analysis, the timing of the survey, the interviews and the case studies allowed the project to make some comment on the progression of each of the disorders over time.

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ATTACHMENT A: SURVEY COVERING LETTER

March 2007

Dear

An Investigation Into The Home Support Needs Of Adults Living With Multiple Sclerosis, Huntington's, Parkinson's And Motor Neurone Diseases

You are invited to participate in a study of the home support needs of people living with neurodegenerative diseases. The study is being conducted by a research group which includes home care agencies and support groups.

This is an important study because it will examine the current provision of home care services to these individuals. This will help health care planners, policy makers and providers better understand the needs of individuals and families living with these diseases, and how they may be assisted to live well at home. The information from this study will also assist us in understanding how, and how quickly, these needs change as the diseases progress. We are also looking at how these needs are currently met and the extent to which these needs are unmet. This information will result in better planning and funding of home care services, and their funding.

To gather this information, I would greatly appreciate your completion of the attached survey. Your responses in this survey will provide valuable insights into understanding these issues. Whether you choose to complete the survey or not will in no way affect the services you receive currently or in the future. **Please complete and return the survey by Friday, 30 March 2007.**

If you would like to respond to this survey over the telephone, or you would like a researcher to come to your home to help you complete it, or if you need an interpreter, please feel free to call Margaret Giles on 9242 0185 or Dawn Woods on 9201 6758.

This study has a second part, an interview, which is designed to explore some of the issues raised in the survey to obtain a more complete picture of your lived experience, including how your needs have changed over time. We would really appreciate it if we could interview you. **If you agree to being interviewed, please fill in your details in the survey.**

This survey has been sent to you by one of the support groups for people living with neurodegenerative diseases or by a home care agency that is providing you with services. It is therefore possible that you may be sent more than one survey. We apologise if this happens to you and ask that you only complete one survey.

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 other agencies and providers who are involved in this study.

Any concerns or complaints about the conduct of the study should be directed to Chairperson of the Ethics Committee at Silver Chain on 9242 0242. Further information about the study can be obtained from **Margaret Giles on 9242 0185** or Dawn Woods on 9201 6758. Follow up interviews can also be arranged by contacting Margaret or Dawn.

Yours truly

ATTACHMENT B: SURVEY

Neurodegenerative Disorders Project:

Office Use Only

Home support needs

An investigation into the home support needs of adults living with Multiple Sclerosis, Huntington's Disease, Parkinson's Disease and Motor Neurone Disease.

About this survey: Many people living with neurodegenerative disorders 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 better understand the needs of individuals and families living with these diseases, and how they may be assisted to live well at home. The project is supported by a number of organisations: 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 Health Department (Neurosciences Unit) and Disability Services Commission.

Completing this survey: This survey has three sections.

- Section A is for you to complete. You can ask your carer (if you have one) to help with this.
- Section B can be completed by you, or you and your carer together.
- Section C is for your carer to complete (If you have one)

Please tick the most appropriate responses or write in the space provided.

Returning this survey: Please return your completed survey to Silver Chain in the envelope provided by 30 March 2007.

Section A: Questions for the person with the neurodegenerative disorder

1 Which disorder do you have? Multiple Sclerosis _1 Motor Neurone Disease _3 Parkinson's Disease or Parkinson's Plus condition _3 Huntington's Disease _4

2 In which year did you first have symptoms? Don't know or unsure _3

3 In which year was your disorder first diagnosed? Don't know or unsure _3

4 Do you have any other medical conditions or disabilities? No _0 Yes _1 Please specify below

Section A: Questions for the person with the neurodegenerative disorder

5 Are you currently a member of any of these organisations or groups?

Multiple Sclerosis Society of WA	No <input type="checkbox"/>	Yes <input type="checkbox"/>
Motor Neurone Disease Association of WA	No <input type="checkbox"/>	Yes <input type="checkbox"/>
Parkinson's Western Australia Inc	No <input type="checkbox"/>	Yes <input type="checkbox"/>
Australian Huntington's Disease Association	No <input type="checkbox"/>	Yes <input type="checkbox"/>
Any other support organisations	No <input type="checkbox"/>	Yes <input type="checkbox"/> Please specify below

6 Please indicate which best describes your current mobility?

You have no trouble walking	<input type="checkbox"/>
You have trouble walking, but don't use any type of aid to help you walk inside or outside the home	<input type="checkbox"/>
You can walk inside your home without any type of aid, but you need a walking stick or frame to walk outside your home	<input type="checkbox"/>
You use a walking stick or walking frame inside your home	<input type="checkbox"/>
You use a wheelchair inside your home and have use of your arms	<input type="checkbox"/>
You use a wheelchair inside your home and have limited or no use of your arms	<input type="checkbox"/>
Other <input type="checkbox"/>	<input style="width: 150px;" type="text"/>

7 Do you currently have difficulties with the following?
 You may currently be taking medication (eg to reduce pain) and/or using equipment (eg a wheelchair) or aids (eg reading glasses). However, you may still be having some difficulties.

balance	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
bladder incontinence	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
boredom	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
bowel problems	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
breathing	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
clumsiness	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
communicating	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
constipation	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
depression	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
dizziness	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
expressing feelings	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
falling	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
fatigue/tiredness	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
hallucinations	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>

Section A: Questions for the person with the neurodegenerative disorder

7 Do you currently have difficulties with the following? *(continued)*

hearing	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
heat intolerance	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
hunger	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
irritability	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
itching	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
lapses of concentration	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
loneliness	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
muscle spasms/tremors/ involuntary movements	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
nausea	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
pain	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
remembering	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
responding appropriately to others	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
sensitivity to cold	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
sleep disturbance	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
speaking	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
swallowing	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
swollen feet/hands	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
tearfulness	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
uncontrollable anger or aggression	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
uncontrollable laughter	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
understanding or comprehending	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
weak arms and/or legs	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
weight gain	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
weight loss	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
your eyesight	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
your teeth and/or mouth	No <input type="checkbox"/>	Unsure <input type="checkbox"/>	Yes <input checked="" type="checkbox"/>	Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
other ▶				Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>
				Is this difficulty	Mild <input type="checkbox"/>	Medium <input type="checkbox"/>	Extreme <input type="checkbox"/>

Section A: Questions for the person with the neurodegenerative disorder

You may be getting help with every day activities from home care service providers. These include Silver Chain, Perth Home Care Services, Brightwater Care Group and Mercy Aged Care. Home care services are also provided by Neurological Council of WA, Multiple Sclerosis Society of WA, Australian Huntington's Disease Association of WA, Parkinson's Western Australia Inc, Motor Neurone Disease Association of WA, Neurosciences Unit, Red Cross and local councils.

You might also be getting help from a partner or family, friends or volunteers.

8 Please tick any activities that you get help with

using the telephone	Occasionally <input type="checkbox"/> 1 Always <input type="checkbox"/> 2	Who gives this help? (please tick as many as apply) Home care service providers <input type="checkbox"/> 1 Partner/family/friends <input type="checkbox"/> 1 Volunteers <input type="checkbox"/> 1 Others <input type="checkbox"/> 1
shopping	Occasionally <input type="checkbox"/> 1 Always <input type="checkbox"/> 2	Who gives this help? (please tick as many as apply) Home care service providers <input type="checkbox"/> 1 Partner/family/friends <input type="checkbox"/> 1 Volunteers <input type="checkbox"/> 1 Others <input type="checkbox"/> 1
preparing food	Occasionally <input type="checkbox"/> 1 Always <input type="checkbox"/> 2	Who gives this help? (please tick as many as apply) Home care service providers <input type="checkbox"/> 1 Partner/family/friends <input type="checkbox"/> 1 Volunteers <input type="checkbox"/> 1 Others <input type="checkbox"/> 1
managing finances	Occasionally <input type="checkbox"/> 1 Always <input type="checkbox"/> 2	Who gives this help? (please tick as many as apply) Home care service providers <input type="checkbox"/> 1 Partner/family/friends <input type="checkbox"/> 1 Volunteers <input type="checkbox"/> 1 Others <input type="checkbox"/> 1
managing medications	Occasionally <input type="checkbox"/> 1 Always <input type="checkbox"/> 2	Who gives this help? (please tick as many as apply) Home care service providers <input type="checkbox"/> 1 Partner/family/friends <input type="checkbox"/> 1 Volunteers <input type="checkbox"/> 1 Others <input type="checkbox"/> 1
managing medical equipment	Occasionally <input type="checkbox"/> 1 Always <input type="checkbox"/> 2	Who gives this help? (please tick as many as apply) Home care service providers <input type="checkbox"/> 1 Partner/family/friends <input type="checkbox"/> 1 Volunteers <input type="checkbox"/> 1 Others <input type="checkbox"/> 1
laundry (washing and/or ironing)	Occasionally <input type="checkbox"/> 1 Always <input type="checkbox"/> 2	Who gives this help? (please tick as many as apply) Home care service providers <input type="checkbox"/> 1 Partner/family/friends <input type="checkbox"/> 1 Volunteers <input type="checkbox"/> 1 Others <input type="checkbox"/> 1
housework	Occasionally <input type="checkbox"/> 1 Always <input type="checkbox"/> 2	Who gives this help? (please tick as many as apply) Home care service providers <input type="checkbox"/> 1 Partner/family/friends <input type="checkbox"/> 1 Volunteers <input type="checkbox"/> 1 Others <input type="checkbox"/> 1
going out/ attending appointments, social activities, etc.	Occasionally <input type="checkbox"/> 1 Always <input type="checkbox"/> 2	Who gives this help? (please tick as many as apply) Home care service providers <input type="checkbox"/> 1 Partner/family/friends <input type="checkbox"/> 1 Volunteers <input type="checkbox"/> 1 Others <input type="checkbox"/> 1
eating and drinking	Occasionally <input type="checkbox"/> 1 Always <input type="checkbox"/> 2	Who gives this help? (please tick as many as apply) Home care service providers <input type="checkbox"/> 1 Partner/family/friends <input type="checkbox"/> 1 Volunteers <input type="checkbox"/> 1 Others <input type="checkbox"/> 1
caring for children	Occasionally <input type="checkbox"/> 1 Always <input type="checkbox"/> 2	Who gives this help? (please tick as many as apply) Home care service providers <input type="checkbox"/> 1 Partner/family/friends <input type="checkbox"/> 1 Volunteers <input type="checkbox"/> 1 Others <input type="checkbox"/> 1

Section A: Questions for the person with the neurodegenerative disorder

8 Please tick any activities that you get help with (continued)

showering or bathing Occasionally _1 Always _2 **Who gives this help? (please tick as many as apply)**
 Home care service providers _1 Partner/family/friends _1 Volunteers _1 Others _1

dressing and grooming Occasionally _1 Always _2 **Who gives this help? (please tick as many as apply)**
 Home care service providers _1 Partner/family/friends _1 Volunteers _1 Others _1

getting on and off the toilet Occasionally _1 Always _2 **Who gives this help? (please tick as many as apply)**
 Home care service providers _1 Partner/family/friends _1 Volunteers _1 Others _1

managing your bladder Occasionally _1 Always _2 **Who gives this help? (please tick as many as apply)**
 Home care service providers _1 Partner/family/friends _1 Volunteers _1 Others _1

managing your bowels Occasionally _1 Always _2 **Who gives this help? (please tick as many as apply)**
 Home care service providers _1 Partner/family/friends _1 Volunteers _1 Others _1

moving about the house Occasionally _1 Always _2 **Who gives this help? (please tick as many as apply)**
 Home care service providers _1 Partner/family/friends _1 Volunteers _1 Others _1

getting from the bed to a chair or wheelchair and back again Occasionally _1 Always _2 **Who gives this help? (please tick as many as apply)**
 Home care service providers _1 Partner/family/friends _1 Volunteers _1 Others _1

other (specify)
 Occasionally _1 Always _2 **Who gives this help? (please tick as many as apply)**
 Home care service providers _1 Partner/family/friends _1 Volunteers _1 Others _1

other (specify)
 Occasionally _1 Always _2 **Who gives this help? (please tick as many as apply)**
 Home care service providers _1 Partner/family/friends _1 Volunteers _1 Others _1

other (specify)
 Occasionally _1 Always _2 **Who gives this help? (please tick as many as apply)**
 Home care service providers _1 Partner/family/friends _1 Volunteers _1 Others _1

Section A: Questions for the person with the neurodegenerative disorder

9 Do you receive any services from a home care service provider, support agency or local council? No Please go to **Question 13** on page 8
Yes
 Including any you may have identified in Question 8.

10 Are these services provided as a package of care? Yes How many hours per week do you receive? hours per week

Home care services may be provided as a package (such as EACH, CACP or DSC individual-funded package) or as separate services. No or unsure

What services are included in the package? (please tick as many many as apply)

Personal care Housework Gardening or home maintenance
 Social support Transport Other

Do you receive any of these separate services?

a Personal care (showering, night preparation, and/or meal preparation, etc) No Yes How many hours do you currently receive? hours per week
How many hours do you think you need? hours per week

b Housework (vacuuming, dusting, washing floors, cleaning bathrooms and kitchens, etc) No Yes How many hours do you currently receive? hours per week
How many hours do you think you need? hours per week

c Social support (including: being assisted in your home or accompanying you on a trip; helping you to manage your affairs (such as paper work, paying bills, banking and shopping) or to attend an appointment or participate in the community.) No Yes How many hours do you currently receive? hours per week
How many hours do you think you need? hours per week

d Gardening or home maintenance No Yes How many hours do you currently receive? hours per week
How many hours do you think you need? hours per week

Section A: Questions for the person with the neurodegenerative disorder

11 Do you currently receive any of these other services from a home care service provider, support agency or local council?

Nursing care	Never <input type="checkbox"/>	As needed <input type="checkbox"/>	Regularly <input checked="" type="checkbox"/>	How often? <input type="text"/>
Specialist care advice (eg Parkinson's nurse specialist, MS nurse, MND care coordinator)	Never <input type="checkbox"/>	As needed <input type="checkbox"/>	Regularly <input checked="" type="checkbox"/>	How often? <input type="text"/>
Meals delivered	Never <input type="checkbox"/>	As needed <input type="checkbox"/>	Regularly <input checked="" type="checkbox"/>	How often? <input type="text"/>
Services from a social worker (eg information, advocacy, referrals to other agencies)	Never <input type="checkbox"/>	As needed <input type="checkbox"/>	Regularly <input checked="" type="checkbox"/>	How often? <input type="text"/>
Physiotherapy	Never <input type="checkbox"/>	As needed <input type="checkbox"/>	Regularly <input checked="" type="checkbox"/>	How often? <input type="text"/>
Podiatry	Never <input type="checkbox"/>	As needed <input type="checkbox"/>	Regularly <input checked="" type="checkbox"/>	How often? <input type="text"/>
Occupational therapy	Never <input type="checkbox"/>	As needed <input type="checkbox"/>	Regularly <input checked="" type="checkbox"/>	How often? <input type="text"/>
Services from a dietitian	Never <input type="checkbox"/>	As needed <input type="checkbox"/>	Regularly <input checked="" type="checkbox"/>	How often? <input type="text"/>
Speech pathology	Never <input type="checkbox"/>	As needed <input type="checkbox"/>	Regularly <input checked="" type="checkbox"/>	How often? <input type="text"/>
Other <input type="text"/>	Never <input type="checkbox"/>	As needed <input type="checkbox"/>	Regularly <input checked="" type="checkbox"/>	How often? <input type="text"/>

12 How often would you prefer to receive these other services from a home care service provider, support agency or local council?

Nursing care	Never <input type="checkbox"/>	More often <input type="checkbox"/>	Less often <input type="checkbox"/>	About the same as you currently do <input type="checkbox"/>
Specialist care advice (eg Parkinson's nurse specialist, MS nurse, MND care coordinator)	Never <input type="checkbox"/>	More often <input type="checkbox"/>	Less often <input type="checkbox"/>	About the same as you currently do <input type="checkbox"/>
Meals delivered	Never <input type="checkbox"/>	More often <input type="checkbox"/>	Less often <input type="checkbox"/>	About the same as you currently do <input type="checkbox"/>
Services from a social worker (eg information, advocacy, referrals to other agencies)	Never <input type="checkbox"/>	More often <input type="checkbox"/>	Less often <input type="checkbox"/>	About the same as you currently do <input type="checkbox"/>
Physiotherapy	Never <input type="checkbox"/>	More often <input type="checkbox"/>	Less often <input type="checkbox"/>	About the same as you currently do <input type="checkbox"/>
Podiatry	Never <input type="checkbox"/>	More often <input type="checkbox"/>	Less often <input type="checkbox"/>	About the same as you currently do <input type="checkbox"/>
Occupational therapy	Never <input type="checkbox"/>	More often <input type="checkbox"/>	Less often <input type="checkbox"/>	About the same as you currently do <input type="checkbox"/>
Services from a dietitian	Never <input type="checkbox"/>	More often <input type="checkbox"/>	Less often <input type="checkbox"/>	About the same as you currently do <input type="checkbox"/>
Speech pathology	Never <input type="checkbox"/>	More often <input type="checkbox"/>	Less often <input type="checkbox"/>	About the same as you currently do <input type="checkbox"/>
Other <input type="text"/>	Never <input type="checkbox"/>	More often <input type="checkbox"/>	Less often <input type="checkbox"/>	About the same as you currently do <input type="checkbox"/>

Section A: Questions for the person with the neurodegenerative disorder

13

What transport do you use to get around?

For example to go to work, or to doctors' appointments, to go shopping etc. (please tick as many as apply).

Private vehicle and drive yourself	<input type="checkbox"/>	HACC taxi (Community West Transport)	<input type="checkbox"/>
Private vehicle, family/friend drives	<input type="checkbox"/>	Taxi subsidised by Taxi Users Subsidy Scheme (DPI)	<input type="checkbox"/>
Private vehicle, volunteer drives	<input type="checkbox"/>	Taxi subsidised by other provider (please specify)	<input type="checkbox"/>
HACC bus	<input type="checkbox"/>	<input type="text"/>	
Local council bus	<input type="checkbox"/>	Unsubsidised multi purpose (maxi) taxi	<input type="checkbox"/>
Public transport	<input type="checkbox"/>	Unsubsidised ordinary taxi	<input type="checkbox"/>
You don't go out	<input type="checkbox"/>	Other <input type="checkbox"/>	<input type="text"/>

14

Do these transport arrangements meet your needs?

Yes

No Please give details

15

Do you have all the equipment you need at home to assist you with daily activities?

N/A—don't need any equipment currently

Yes—you have all the equipment you currently need

No—you do not have all the equipment you currently need

16

Do you receive help at home from any of the following people?

Spouse or partner	No <input type="checkbox"/>	Yes <input type="checkbox"/>	Does this person live with you?	No <input type="checkbox"/>	Yes <input type="checkbox"/>
Parent(s)	No <input type="checkbox"/>	Yes <input type="checkbox"/>	Does this person live with you?	No <input type="checkbox"/>	Yes <input type="checkbox"/>
Child(ren)	No <input type="checkbox"/>	Yes <input type="checkbox"/>	Does this person live with you?	No <input type="checkbox"/>	Yes <input type="checkbox"/>
Other relative(s)	No <input type="checkbox"/>	Yes <input type="checkbox"/>	Does this person live with you?	No <input type="checkbox"/>	Yes <input type="checkbox"/>
Neighbour(s)	No <input type="checkbox"/>	Yes <input type="checkbox"/>			
Friend(s)	No <input type="checkbox"/>	Yes <input type="checkbox"/>	Does this person live with you?	No <input type="checkbox"/>	Yes <input type="checkbox"/>
Volunteer(s)	No <input type="checkbox"/>	Yes <input type="checkbox"/>			
Other(s)	No <input type="checkbox"/>	Yes <input type="checkbox"/>	Does this person live with you?	No <input type="checkbox"/>	Yes <input type="checkbox"/>

Section A: Questions for the person with the neurodegenerative disorder

17 What sort of home do you live in?

House (including detached house, semi-detached house, townhouse, duplex, triplex, etc.)	<input type="checkbox"/>	Unit/flat	<input type="checkbox"/>
Room in a boarding house or hostel	<input type="checkbox"/>	Nursing home/aged care residential facility	<input type="checkbox"/>
Self-contained home in a retirement village	<input type="checkbox"/>	Hostel in a retirement village	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="text"/>	

18 Who owns this home?

Self (with a mortgage)	<input type="checkbox"/>	Other members of your family	<input type="checkbox"/>
Self (with no mortgage)	<input type="checkbox"/>	Homeswest Community Disability Housing Program	<input type="checkbox"/>
Private landlord	<input type="checkbox"/>	Other Homeswest	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="text"/>	

19 Have you had to make changes to this home because of your condition?

No Yes

What modifications have you made?

Added a purpose-built bedroom and ensuite	<input type="checkbox"/>
Installed internal/and/or external rails	<input type="checkbox"/>
Built ramp to access home	<input type="checkbox"/>
Replaced bath with hobless shower	<input type="checkbox"/>
Changed lighting	<input type="checkbox"/>
Placed non-slip strips on steps	<input type="checkbox"/>
Other	<input type="checkbox"/>

Did you get financial help or a subsidy to do this? No Yes

20 Have you moved into a different home because of your condition?

No Yes

Are you living with the same people? No Yes

Did you get financial help to move? No Yes

How is this home different from your previous home?

Section A: Questions for the person with the neurodegenerative disorder

21 In which year were you born?

22 Are you Female Male

23 What (main) language do you speak at home? English Other

24 What is your home postcode?

25 Do you have children living with you at home? No Yes How old is the youngest child living with you?

26 Please tell us about any other needs you have now or might have in the future. Do you think these needs will impact on your ability to stay living at home?

27 Please tell us who completed this survey

You (the person with the neurodegenerative disorder)

You and your carer

Your carer

Someone else

Your responses in this survey provide valuable insights into understanding any difficulties you may be experiencing and their impact on living at home and participating in your community.

This study has a second part, an interview, which is designed to explore some of the issues raised in the survey so that a more comprehensive picture of your lived experience can be developed. For example, the interview will derive how your needs for support are changing over time and how quickly home care providers are able to respond to these changes. We would really appreciate it if we could interview you. If you agree to being interviewed, please provide your name and a contact phone number.

Name **Contact phone number**

The researcher will contact you and arrange a convenient day and time to interview you.

▶ If you have a carer, please complete Section B on page 12 with them. If you do not have a carer, please complete Section B yourself.

Section B: Questions for the person with the neurodegenerative disorder and their carer (if they have one)

Respite services provide family and friends who care for a relative/friend with short breaks from the physical and emotional demands of caring. They can use these breaks to catch up on sleep, go to a movie, play sport or visit a friend. For the person needing support, respite services can enable them to socialise, go sightseeing, help them learn how to use new equipment or enjoy a variety of activities such as craft and exercise.

28 Do you use respite services? Yes No Would you like to? Yes No Please go to Section C

29 What type(s) of respite services do you use?

Nursing home or aged care residential facility Camp Day care centre
 Holiday home Hospice facility Hospital Host family home
 Own home Relative's home Respite house Carer's retreat
 Other

30 How much do you use respite services?

Service type	Frequency (eg daily/weekly)	How many hours or days at a time	When do you use it (eg daytime/overnight/weekend/evening)	Who pays for it?
eg hospice facility	monthly	two days	24 hours a day	family
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

31 Would you like more respite services? No Yes

What type of respite? How much would you like (eg three hours per week)

eg respite house	once a week
<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>

Section C: Questions for your carer (If you have one)

This section should be completed by your main carer, if you have one (a person such as a family member, friend or neighbour who provides regular and sustained care and assistance). If you do not have a carer, there is no need to complete this section. We thank you for your contribution, please return the survey in the envelope provided.

32 How long has your relative or friend needed help from you for their disorder? years

33 Has the amount of help you give changed over this time? Increased _1_ Decreased _2_ Stayed about the same _3_

34 Please tick any tasks that you help with

Personal care _1_ Do you receive any assistance to provide this help currently? No _0_ Yes _1_ Would you like any or more assistance to provide this help? No _0_ Yes _1_ From Home care service providers _1_ Relative/friends _2_ Volunteers _3_ Other _4_

Housework _1_ Do you receive any assistance to provide this help currently? No _0_ Yes _1_ Would you like any or more assistance to provide this help? No _0_ Yes _1_ From Home care service providers _1_ Relative/friends _2_ Volunteers _3_ Other _4_

Gardening/home maintenance _1_ Do you receive any assistance to provide this help currently? No _0_ Yes _1_ Would you like any or more assistance to provide this help? No _0_ Yes _1_ From Home care service providers _1_ Relative/friends _2_ Volunteers _3_ Other _4_

Nursing care/procedures _1_ Do you receive any assistance to provide this help currently? No _0_ Yes _1_ Would you like any or more assistance to provide this help? No _0_ Yes _1_ From Home care service providers _1_ Relative/friends _2_ Volunteers _3_ Other _4_

Meals prepared _1_ Do you receive any assistance to provide this help currently? No _0_ Yes _1_ Would you like any or more assistance to provide this help? No _0_ Yes _1_ From Home care service providers _1_ Relative/friends _2_ Volunteers _3_ Other _4_

Minding _1_ Do you receive any assistance to provide this help currently? No _0_ Yes _1_ Would you like any or more assistance to provide this help? No _0_ Yes _1_ From Home care service providers _1_ Relative/friends _2_ Volunteers _3_ Other _4_

Section C: Questions for your carer (if you have one)

34 Please tick any tasks that you help with (continued)

Social support Do you receive any assistance to provide this help currently? No Yes Would you like any or more assistance to provide this help? No Yes From Home care service providers Relative/friends Volunteers Other

Transport Do you receive any assistance to provide this help currently? No Yes Would you like any or more assistance to provide this help? No Yes From Home care service providers Relative/friends Volunteers Other

Child care Do you receive any assistance to provide this help currently? No Yes Would you like any or more assistance to provide this help? No Yes From Home care service providers Relative/friends Volunteers Other

Other (please specify) Do you receive any assistance to provide this help currently? No Yes Would you like any or more assistance to provide this help? No Yes From Home care service providers Relative/friends Volunteers Other

35 If you did not provide this assistance, would your relative or friend be able to manage to live in their own home? No Yes Is this because there is someone else who could provide this help or assistance? No Yes Who?

36 A little about you In which year were you born?
 Are you Female Male
 Do you live with the relative/friend that you care for? Yes No
 What is your home postcode?

ATTACHMENT C: CODES FOR OPEN-ENDED QUESTIONS

Q4 – Other Medical Conditions

ICD-10 CODE	Name
K46	Abdominal hernia
R12	Acid stomach
D33	Acoustic neuroma
Z89	Acquired absence of limb
J42	Airways disease
L27	Allergy to some antibiotics
G30	Alzheimer's disease
Z89	Amputation
D64	Anaemia unspecified
I20	Angina
F41	Anxiety
I71	Aortic aneurysm Aortic dissection
Z95	Aortic and mitral valve replacement
D61	Aplastic anaemia
I49	Arrhythmia
M17	Arthritis of knee
M19	Arthritis unspecified
J45	Asthma
H52	Astigmatism
I48	Atrial fibrillation
I37	Atrial stenosis
Z99	Autoimmune muscle problem
S39	Back injury (unspecified)
M54	Back pain (lower)
Z99	Back operation
K22	Barrett's disease
G51	Bell's palsy
D24	Benign breast cancer
D29	Benign prostate cancer
D30	Benign bladder cancer
F31	Bipolar affective disorder
D41	Bladder cancer
N32	Bladder disorder unspecified
K27	Bleeding ulcer
H54	Blind eye
I70	Blocked arteries
D37	Bowel cancer of unknown behaviour
Z99	Bowel operation (lower)
D48	Breast cancer of unknown behaviour
J47	Bronchiectasis
J40	Bronchitis
W34	Bullet wound in femur
L12	Bullous pemphigoid
M70	Bursitis of hip
M75	Bursitis of shoulder
M48	Canal stenosis of spine
D48	Cancer unspecified
I78	Capillaritis
I49	Cardiac fibrillation
I51	Cardiovascular disease

	Cardiomegaly
H26	Cataract
D18	Cavernous haemangioma
K90	Celiac disease
G80	Cerebral palsy
I20	Chest pain
R06	Cheyne stokes
J44	Chronic obstructive pulmonary disease
M47	Chronic spinal degeneration
I70	Clogged neck arteries
K51	Colitis
Z46	Colostomy bag
I50	Congestive heart failure
I25	Coronary artery dissection
C78	Colon cancer (secondary)
K50	Crohn's disease
Z99	Cyanotic episodes
N81	Cystocele
Q82	Darier disease
I80	Deep vein thrombosis
F03	Dementia
F32	Depression
L30	Dermatitis
E14	Diabetes unspecified
E10	Diabetes type 1 (insulin dependent)
E11	Diabetes type 2
G63	Diabetic polyneuropathy
H53	Diplopia
M51	Disc degeneration
K57	Diverticulitis
K26	Duodenal ulcer
G24	Dystonia
J43	Emphysema
N80	Endometriosis
N40	Enlarged prostate
G40	Epilepsy
D12	Familial polyposis
M47	Facet joint disease
K90	Fat malabsorption
M79	Fibromyalgia
L27	Food allergy
S42	Fractured arm
S62	Fractured hand
S82	Fractured leg
S12	Fractured neck, spine
K82	Gallbladder problem unspecified
K80	Gallstones
Z99	Gastric parietal antibody positive
H40	Glaucoma
K21	GORD
M10	Gout
E05	Graves' disease
I84	Haemorrhoids
E06	Hashimoto's disease
J30	Hay fever
Z99	Heart unspecified

Z95	Heart bypass
I34	Heart valve problem
Z99	Heart surgery
M77	Heel spur
E83	Hemochromatosis
K44	Hiatus hernia
E78	High cholesterol
Z96	Hip replacement
B24	HIV
E34	Hormonal
I15	Hypertension (high blood pressure)
I11	Hypertensive heart disease
E05	Hyperthyroidism
I95	Hypotension (low blood pressure)
E03	Hypothyroidism
D84	Immune system (low function)
R73	Insulin resistance
F79	Intellectual disability
H20	Iritis
K58	Irritable bowel disease
I25	Ischaemic heart disease (assumed to be chronic)
N28	Kidney problem
N20	Kidney stones
Z96	Knee replacement
E73	Lactose intolerance
Z99	Laminectomy
I34	Leaking heart valve
I34	Leaking left ventricle
I44	Left bundle branch block
C95	Leukaemia
M47	Lumbar spine disease
Z85	Lumpectomy
I50	Lung problem (gets fluid)
M32	Lupus
I89	Lymphoedema
Z85	Lymphoma past
H35	Macular degeneration
C50	Malignant breast cancer
Z85	Mastectomy
Q61	Medullary sponge kidney
D03	Melanoma behind eye
D42	Meningioma
I34	Mitral regurgitation
Z85	Meningioma removed
I34	Mitral valve prolapse
C90	Multiple myeloma
M24	Musculoskeletal injuries
D46	Myelodysplasia
D47	Myeloproliferative disease
D41	Neobladder
Z99	Neurofibroma
Z90	No gallbladder
E66	Obesity
F42	Obsessive compulsive disorder
K20	Oesophagitis
Z85	Operation of bowel cancer

H46	Optic neuritis
F06	Organic delusional disorder
M19	Osteoarthritis
M81	Osteoporosis
D39	Ovarian tumour of unknown behaviour
Z95	Pacemaker
M88	Paget's disease
I73	Peripheral vascular disease
D51	Pernicious anaemia
Z85	Personal history of cancer
E70	Phenylketonuria
B07	Plantar warts
Z99	Pinched nerve
D45	Polycythemia
M35	Polymyalgia rheumatica
G62	Polyneuropathy
I97	Postmastectomy lymphoedema syndrome
F43	Post-traumatic stress disorder
L89	Pressure ulcer
D40	Prostate cancer of unknown behaviour
Z92	Prostate restruction
L40	Psoriasis
O88	Pulmonary emboli
J68	Pulmonary fibrosis
I73	Raynaud's syndrome
Z85	Rectal cancer
N81	Rectocele
M89	Reflex sympathetic dystrophy
K21	Reflux
N28	Renal disease
M06	Rheumatoid arthritis
Z99	Scar tissue to bladder
F20	Schizophrenia
M54	Sciatica
M41	Scoliosis
G40	Seizure
B02	Shingles
J32	Sinusitis
Z85	Sinus tumour removed
M35	Sjogren's syndrome
M32	SLE
G47	Sleep apnoea
L57	Solar keratosis
G82	Spastic paraparesis
M43	Spinal fusion
Q76	Spinal kyphosis
Z99	Spinal surgery
Z95	Stent in heart
I64	Stroke
P10	Subdural haematoma
I47	Supraventricular tachycardia
G57	Tarsal tunnel syndrome
D43	Thalamus tumour
D56	Thalassemia
D37	Throat cancer
D75	Thrombocytosis

D44	Thyroid cancer
Z90	Thyroidectomy
E07	Thyroid unspecified
B35	Tinea
H93	Tinnitus
Z93	Tracheostomy
S43	Torn ligament - shoulder
G45	Transient global amnesia
G45	Transient ischaemic attack
D37	Tumour near salivary glands
K22	Ulcerated oesophagus
K51	Ulcerative colitis
N39	Urinary tract infection
Z85	Uterine cancer previous
I83	Varicose veins
I51	Ventricle hypertrophy
E56	Vitamin deficiency
D68	Von Willebrand's disease
M17	Worn knee joint
Z99	Other

Q5b – Other Support Organisations

Code	Other Support Organisation
1	Diabetes Australia
2	National Diabetes Service Scheme
3	Alzheimer's Australia
4	WA Carers
5	Headwest WA
6	People With Disabilities WA
7	Health Consumers Council WA
8	Transverse Myelitis Association
9	Parkinson's Disease Society London
10	Blind Association of WA
11	Celiac Society
12	Partners of Veterans
13	MS Society of Victoria
14	Heart Foundation WA
15	Australian Crohn and Colitis Association
16	Cerebral Palsy Association
17	Aphasia Group
99	Unspecified

Q7 – Difficulties

Current Difficulties
Balance
Bladder incontinence
Boredom
Bowel problems
Breathing
Clumsiness
Communicating
Constipation
Depression
Dizziness
Expressing feelings
Falling
Fatigue/tiredness
Hallucinations
Hearing
Heat intolerance
Hunger
Irritability
Itching
Lapses of concentration
Loneliness
Muscle spasms/tremors/involuntary movements
Nausea
Pain
Remembering
Responding appropriately to others
Sensitivity to cold
Sleep disturbance
Speaking
Swallowing
Swollen feet/hands
Tearfulness
Uncontrollable anger or aggression
Uncontrollable laughter
Understanding or comprehending
Weak arms and/or legs
Weight gain
Weight loss
Your eyesight
Your teeth and/or mouth

Q7 – Other Difficulties

Code	Other Difficulties
1	Urinary urgency
2	Muscle rigidity
3	Trigeminal neuralgia
4	Bleeding
5	Stuttering
6	Numbness and tingling
7	No motivation
8	Sensitive to temperature change
9	Headaches/migraine
10	Dribbling
11	Sweaty hands
12	Restless legs
13	Cramps
14	Burning feeling in hand/leg
15	Making decisions
16	Dry mouth
17	Confusion
18	Cold feet
19	Sensory disturbance including decreased sensation, loss of taste and smell and proprioception
20	Frustration
21	Croaky voice
22	Lack of appetite

Q11b – Service Frequency

Code	Service Frequency
1	Daily, including 7 hours per day
2	Twice daily
3	Once a week
4	Twice a week
5	Three or more times a week
6	Once a month
7	Twice a month or once a fortnight
8	6 – 11 times a year, including <ul style="list-style-type: none"> • 6 times a year • every 8 weeks • once every 6 weeks
9	1 – 5 times a year, including <ul style="list-style-type: none"> • every 6 months • 3 weeks a year • once every 3 months • 8 week periods 4 times a year • 5 times a year • every 10 weeks • occasional

Q14 – Types of Transport Problems

Code	Types of Transport Problems
1	Impracticality of private vehicle, including no wheelchair lift in car and van being difficult to get into
2	Impracticality of taxi/HACC bus, including unreliability, safety, unavailability, driver rudeness, inconvenience, no wheelchair-friendly taxi in town
3	Impracticality of public transport, including inconvenience, unavailability, not wheelchair-friendly, safety
4	Financial difficulties, including expensive and on waiting list for HACC support
5	Don't like being dependent on others
6	Need more frequent/appropriate help
7	No one to drive them
8	Difficulty driving
9	Live out of town
10	Can't go out

Q19b – Other Modifications to Home

Code	Other Modifications
1	Modified floors or steps, including changing flooring, extra steps, removed steps, lowered steps, made one level, glow in the dark strips on path
2	Temperature control, including air-conditioning or fans, insulation, heat lamps
3	Made wheelchair-friendly, including wider doorways, chair lift, sliding doors, electric front door, removed doors
4	Bathroom renovation, including changed taps, floors, mats and shower door, hobless shower, bigger shower, therapeutic spa, purpose-built bathroom
5	Kitchen renovation, including adjusted heights, island, drawers, purpose-built kitchen
6	Outside/garden modification, including patio, swimming pool, pool hoist
7	Other, including extra power points, switch timers, bed in lounge room, re-assigned mirrors, special mattress

Q20 – Differences Between Previous and Current Home

Code	Types of differences
1	Bigger
2	Smaller
3	Different size, unspecified
4	Accessibility, including single storey, double storey, one level, no gradient, no steps, less stairs, smooth flooring, sliding doors, garage opens into house, wheelchair-friendly, bigger rooms
5	Facilities for people with disabilities, including exterior medi alert, call buttons
6	Location, including closer to family, in town, convenient, country lifestyle, cooler climate
7	Less maintenance and/or gardening
8	Access to help/services, including community care, health/medical services, nursing home, retirement village, aged care services, nuns live there, services
9	Temperature control, including central heating and air conditioning
10	Better bathroom, including hobless shower, better toilet, accessible bathroom, ensuite, non-slip tiles, easy/low/larger shower entry, non-slip tiles
11	Financial reasons

Q26 – Other Needs

Code	Types of Other Needs
1	Current personal care needs, including more personal care (such as feeding), more affordable personal care
2	Current medical delivery care needs, including specialist care at home, more remedial care, more affordable specialist care, full nursing care, financial support, GP or nurse to visit at home, help for fatigue
3	Current allied and alternative health care needs, including access to allied health professionals, financial support for alternative medicines, counselling
4	Current home help needs, including more home help (including meal preparation), more affordable home help, gardening and/or home maintenance, housework, subsidies
5	Current carer needs, including live-in or full-time carer
6	Current housing needs, including house modifications, more suitable house, retirement home
7	Current social support needs, including more social support, emotional and psychological support, male company, company, social network, agency/provider contact, family
8	Current childcare needs, including more childcare
9	Current transport needs, including vehicle modifications, ACROD sticker, taxi vouchers, allowance for medical appointments
10	Current equipment needs, including oxygen, more suitable bedding, more mobility equipment, hoist/pulley system, finger aids, internal communication system, answering machine, computer assistance, support stockings, incontinence pants
11	Current government assistance needs, including guidance for employment, advice on changing profession, financial support
12	Other current needs, including more information on available services, facilities for younger people needing full care, holidays with non-disabled people, help to care for (sick) partner, respite, overnight accommodation in Perth when going to hospital
13	Future personal care needs, including more personal care (such as feeding), more affordable personal care, continence care
14	Future medical delivery care needs, including specialist care at home, full nursing care, financial support for medication
15	Future allied and alternative health care needs, including access to allied health professionals
16	Future home help needs, including more home help (including meal preparation), more affordable home help, gardening and/or home maintenance, housework, financial support
17	Future carer needs, including live-in or full-time carer, outside carer
18	Future housing needs, including house modifications, more suitable house, high care residence
19	Future social support needs, including more social support, company, social network, close to family
20	Future childcare needs
21	Future transport needs, including vehicle modifications, ACROD sticker
22	Future equipment needs, including adjustable bed, more mobility equipment, hoist/pulley system, computer assistance
23	Future government assistance needs, including financial support
24	Other future needs, including facilities for younger people needing full care, day care centres

Q30a – Type of Respite Services

Code	Type of Respite Services
1	Respite house
2	Holiday home
3	In home respite
4	Residential facility
5	Day care centre
6	Host family
7	Hospice facility
8	Relative's home
9	Hospital
10	Carer's retreat
11	Camp
12	Other, including IFS, disabled unit at local holiday unit, symptomatic group getaway, onsite caravan

Q30b – Frequency of Respite

Code	Service Frequency
1	Daily, including 7 hours per day
2	Twice daily
3	Once a week
4	Twice a week
5	Three or more times a week
6	Once a month
7	Twice a month or once a fortnight
8	6 – 11 times a year, including <ul style="list-style-type: none"> • 6 times a year • every 8 weeks • once every 6 weeks
9	1 – 5 times a year, including <ul style="list-style-type: none"> • every 6 months • 3 weeks a year • once every 3 months • 8 week periods 4 times a year • 5 times a year • every 10 weeks • occasional

Q30d – Timing of Respite

Code	Time of Day
1	Daytime
2	Overnight
3	Weekend
4	Evening
5	24 hours a day
6	Other

Q30e – Respite Funding

Code	Respite Paid By
1	Self
2	Family
3	Support agency wholly
4	Support agency partly
5	Other
6	n.a.

Q31 - Type of Respite Services Desired

Code	Type of Respite Services
1	Respite house
2	Holiday home
3	In home respite
4	Residential facility
5	Day care centre
6	Host family
7	Hospice facility
8	Relative's home
9	Hospital
10	Carer's retreat
11	Camp
12	Other, including IFS, disabled unit at local holiday unit, symptomatic group getaway, onsite caravan

Q31 – How Much Respite Desired

Code	Service Frequency
1	Daily, including 7 hours per day
2	Twice daily
3	Once a week
4	Twice a week
5	Three or more times a week
6	Once a month
7	Twice a month or once a fortnight
8	6 – 11 times a year, including <ul style="list-style-type: none"> • 6 times a year • every 8 weeks • once every 6 weeks
9	1 – 5 times a year, including <ul style="list-style-type: none"> • every 6 months • 3 weeks a year • once every 3 months • 8 week periods 4 times a year • 5 times a year • every 10 weeks • occasional

Q35 – Who Else Could Provide Assistance in the Home

Code	Others
1	Family or friends
2	Paid employee
3	Subsidised services

Q37 – Carer Issues

Code	Carer Issues
1	Carer's health and other needs, for example, the physical demands of caring has affected carer's health
2	Carer's ability to care, for example, the need for a contingency plan if the carer goes into hospital or is suddenly unable to care
3	Financial needs, for example, carer needs more financial assistance to continue caring in the home
4	Respite needs, for example, respite is difficult to organise
5	Problems with government agencies and/or service and support agencies, for example, town does not have enough services for disabled and elderly
6	Other, for example, carer needs place to stay in Perth when care recipient is in a Perth hospital

ATTACHMENT D: LEVEL OF DEPENDENCY

Responses to whether or not respondents need help with any of the activities listed in question 8 are used to develop the categories for the level of dependency variable. Three activities are not included in this categorisation as responses were few – caring for children (less than 10 per cent needing help, gardening (less than 1 per cent) and fine motor skills (less than one per cent).

Instrumental Activities of Daily Living (IADL) and Activities of Daily Living (ADL) categories are based on Lawton and Brody's (Lawton & Brody, 1969) and Barthel Activities of Daily Living (Collin, Wade, Davies, & Horne, 1988), respectively

Instrumental Activities of Daily Living (IADL) categories:

- Using the telephone
- Shopping
- Preparing food
- Managing finances
- Managing medications
- Managing medical equipment
- Laundry
- Housework
- Going out/attending appointments, social activities

Activities of Daily Living (ADL) categories:

- Eating and drinking
- Showering or bathing
- Dressing and grooming
- Getting on and off the toilet
- Managing your bladder
- Managing your bowels
- Moving about the house
- Getting from the bed to a chair or wheelchair and back again

Levels of dependency:

- 1 Independent – if respondent receives no help for any IADL or ADL activities.
- 2 Low level of dependency – if respondent receives help either occasionally or all the time for any IADL activity and no help for any ADL activity.
- 3 Medium level of dependency – if respondent receives occasional help for any ADL activity.
- 4 High level of dependency – if respondent receives help all the time for any ADL activity.

ATTACHMENT E: A SUMMARY OF PACKAGES OF CARE

There are a number of home care support packages available to people who wish to remain living in the community. Some of these are federally funded and some are funded out of State revenue. Eligibility criteria differ for each package. For example, some are only available to people over the age of 64 years.

Transition Care Packages

Transition Care is a collaborative Australian Government and State Government funded program, which is specifically for frail older people at the conclusion of their hospital stay. It provides time-limited, goal-oriented therapeutic care in a non-hospital environment that aims to improve or maintain the older person's level of independence whilst assisting them and their family to make longer term care arrangements.

Transition Care provides a mix of services that includes low intensity therapy (such as physiotherapy, occupational therapy and social work) and either nursing support and/or personal care in either a residential setting or in a community setting, including the person's home. Only those older patients assessed by an Aged Care Assessment Team as requiring Transition Care can receive these services.

The average duration of transition care is expected to be 8 weeks, with a maximum duration of 12 weeks. The transition care episode may be extended by a further 6 weeks, if the care recipient has further transition care needs

Personal Enablement Packages

Personal Enablement Packages is a short term, home-based care program, which operates across the Perth metropolitan area. It is delivered by Silver Chain and funded by the Home and Community Care (HACC) Program.

Enablement Packages provide a rapid response to frail older patients following discharge from hospital. The program aims to assist HACC eligible people boost their confidence and achieve their highest level of independence after a hospital stay. An individual care plan is developed for a package of HACC services to be provided for up to 8 weeks after discharge in the person's home. The package may provide nursing care, personal care, domestic assistance and allied health input.

Home Care Packages (Funded by the WA Department of Health)

Home Care Packages are used as a short-term interim package aimed at improving the health status and independence of the older person being discharged from hospital. The program offers a mix of post-acute care, therapy, domestic and personal care services to support the older person's safe return home. The service also provides a short-term alternative for patients waiting for other services.

These services are brokered through the health services directly. All Metropolitan Public Health Services have access to these services and each site has the ability to provide CAP Home Care Packages.

Home Care packages are fully State funded.

Aged Care Assessment Team approval is not required for the individual to access Home Care Packages.

The average duration of a Home Care Package is expected to be 8 weeks, with a maximum duration of 12 weeks. In some circumstances the care episode may be extended if further care is required.

A review of the packages shows that on average 24 older people are assisted per week (1265 annually) through this program.

Aged Care Packages (Funded by the Commonwealth)

Community Aged Care Packages (CACP) and Extended Aged Care at Home (EACH) are flexible health care and support packages which enable people to remain in their own home when they would otherwise require admission to a residential care facility.

CACP and EACH offer holistic care delivered in the home and are tailored through negotiation to meet people's needs.

To be eligible for CACP or EACH, needs must be assessed by a member of the Aged Care Assessment Team (ACAT).

Examples of services available through CACP and EACH include:

- Personal care such as bathing or dressing.
- Meals, laundry and short term respite.
- Transport, shopping and social activities.
- Housework, gardening and home maintenance.
- 24 hour on call emergency assistance.

The advantages of CACP and EACH are the flexibility. For instance, assistance may include care of a family pet, installing smoke detectors, improving mobility, visiting family and friends and opportunities to learn new skills such as pottery or computing. Importantly, these packages enable people to maintain your independence with the security and support of family and friends.

CACP

These packages will be integrated with our existing home care services and will enable a proportion of these care recipients to access a more appropriate level of care for their increasing care needs to assist them to continue to live independently in the community.

A comprehensive mix of services will include therapy activities, social support, personal care, domestic assistance, respite, personal alarms and/or equipment. Care recipients will be cared for by a team of home support workers, with access to care specialists and services. Individual assessed needs will determine the range and level of service, delivered according to care plans developed with care recipients and their carers and co-ordinated by a dedicated case manager.

Our case management model is designed to improve care recipient independence, reduce demand for service and delay/prevent residential admission. Through service co-ordination service gaps will be addressed. Collaboration with other providers such as GPs and Alzheimer's Association will ensure continuity of care.

EACH and EACH D

EACH and EACHD packages can be integrated with our existing home care services thus enabling a proportion of care recipients to access a more appropriate level of care for their increasing care needs to assist them to continue to live independently in the community. This is particularly important for people with neurodegenerative disorders.

The mix of services includes therapy activities, social support, personal care, domestic assistance, respite, personal alarms, equipment, nursing, allied health and transport. Care recipients are cared for by a team of home support workers, with access to care specialists and services. Individual assessed needs will determine the range and level of service, delivered according to care plans developed with care recipients and their carers and co-ordinated by a dedicated case manager.

Dependent upon care recipient needs, the equivalent of approximately 20 hours per week per package will be provided. A 24 hour emergency response is available through Silver Chain's Customer Operations Centre.

APPENDIX 1: EXTRACT FROM CARERS RECOGNITION ACT 2004

(see <http://www.carerswa.asn.au/supportus/documents/carersrecact.pdf>)

5. Meaning of “carer”

(1) Except as provided in subsection (2), a person is a carer for the purposes of this Act if he or she is an individual who provides ongoing care or assistance to —

- (a) a person with a disability as defined in the *Disability Services Act 1993* section 3;
- (b) a person who has a chronic illness, including a mental illness as defined in the *Mental Health Act 1996* section 3;
- (c) a person who, because of frailty, requires assistance with carrying out everyday tasks; or
- (d) a person of a prescribed class.

(2) However a person is not a carer if he or she —

- (a) provides the care or assistance under a contract for services (other than an agreement entered into under the *Disability Services Act 1993* section 25) or a contract of service; or
- (b) provides the care or assistance while doing community work as defined in the *Volunteers (Protection from Liability) Act 2002* section 3(1).

(3) A person is not a carer for the purposes of this Act only because —

- (a) the person is a spouse, de facto partner, parent or guardian of the person to whom the care or assistance is being provided; or
- (b) the person provides care to a child under an arrangement with the chief executive officer of the department principally assisting the Minister administering the *Child Welfare Act 1947* in the administration of that Act.