

Doing Not Waiting
on Behalf of People with
Neurodegenerative Disorders

Source Document

“An Investigation into the Home Support Needs of Adults Living with Multiple Sclerosis, Huntington’s, Parkinson’s and Motor Neurone Diseases”.

Dr Margaret Giles – Project Coordinator

Dr Gill Lewin – Project Manager

Collaborative Research Partners

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

Collaborative Research Partners

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

Purpose of the Project

- To provide home and community care providers, planners and policymakers with information that would **enable better understanding** of current and future home care needs of people with Neurodegenerative disease living in the community and **facilitate more effective funding and planning decisions**.

Initiating the Research

A Cross Agency group of service providers had a major concern about the well being of people with NDD disorders. Their needs

- Spanned the disability, aged care and health sectors
- Could change rapidly and
- Generally were NOT well met

Initiating the Research

The Cross Agency Group

- Initiated the scope and design of the research
- Applied for funding from Lotterywest
- Worked with Dr Gill Lewin, Research Director, Silver Chain to develop and tailor the research proposal.

Funding Source

- The project was financially supported from 2006 – 2008 by a Social Research grant from Lotterywest, the official state lottery for Western Australia.

Asking the People Involved to Tell Their Story

A comprehensive postal survey of members of disorder specific agencies and clients of home care support organizations was undertaken

2,550 surveys – 54 % Return

Report No 1

Asking the People Involved to tell their story

Interviews with clients and members and their carers

48 Report No 2

Detailed Case Studies

4 Report No 3

Linking and Analysing a range of relevant databases

- Summaries of 1996 to 2006 and linkage for 2006 of member and client data
- This resulted in firm information about the similarities and differences between people with the different disorders in terms of age, gender and living arrangements
- Report No 4

Participating in the Research

Interviews were conducted with a range of health, allied health and staff of home care support organizations to determine the key issues and unmet needs . Three main areas for people to remain at home

- Clinical management of disorder & symptoms
- Home support
- Respite

Key Issues and Unmet Needs

For home support and respite providers were agreed that provision within the existing framework of disability and aged care funding is

inadequate and often also inappropriate.

Report no 5

Need for Flexibility of Provider Role

Providers also agreed that people in the target group have varying competencies in accessing the health and community care system.

- One extreme – people living alone with few financial or social resources.
- Other extreme – people (or their partners) with good problem solving skills, resourceful and strong social supports.

Choreography of Care

Despite the constraints and inflexibility of policy and funding providers and the absence of a formal case management mandate there is a lot of

Coordination, Collaboration & Advocacy

occurring on behalf of clients to navigate the maze and tailor supports to meet needs.

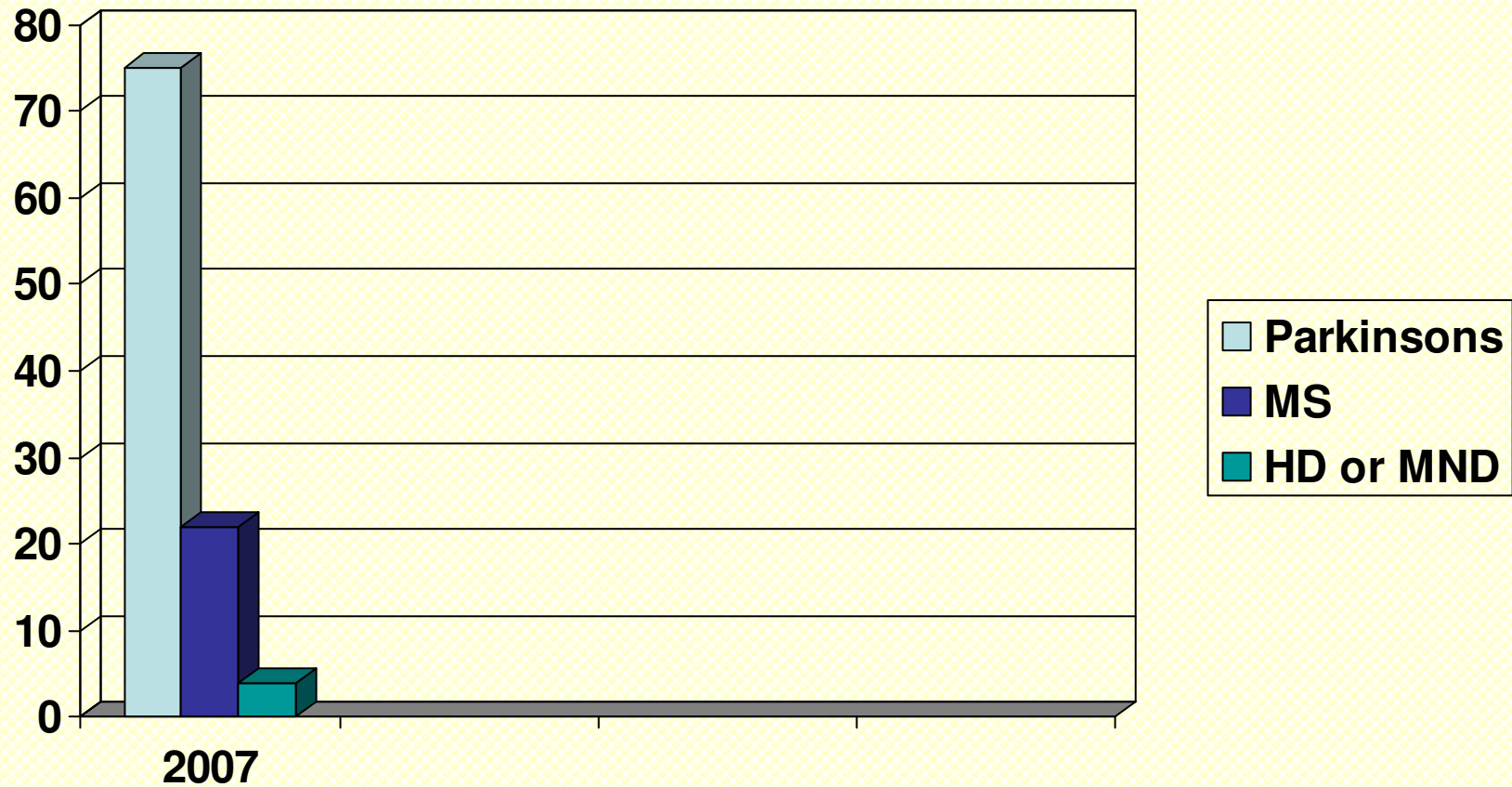
Living & Dying at home with dignity

- There was evidence that with a committed carer and the necessary supports available this outcome was preferred and possible.

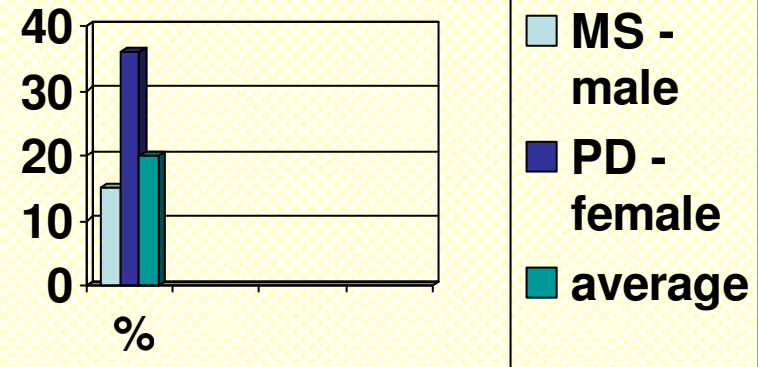
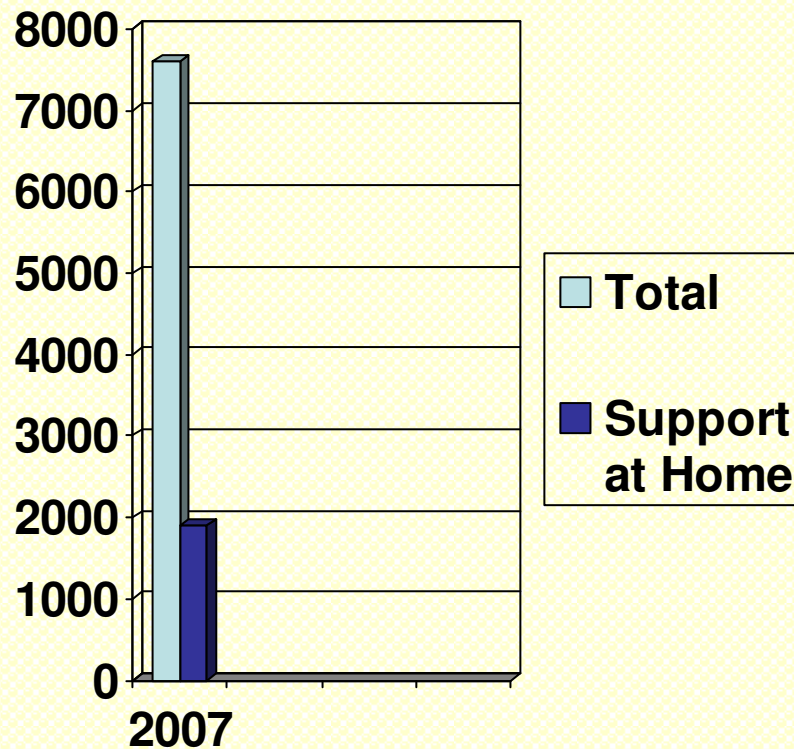
Projecting Home Care support needs

- The major requirement is more coordinated, flexible and responsive service.
- Different types of respite are required that are readily available
- The quantum of service increase required is relatively small (\$1,800 per person in 2007 or a 2% increase in the HACC budget).

Adults in 2007 – 7,600



Proportion of Target Group Accessing Home Care Support



A new service begins

Service providers welcomed the decision by the Disability Services Commission to fund a new service

Neurodegenerative Conditions
Coordinated Care.

\$4m for four years commencing in 2008 to provide additional support for individuals with rapidly escalating support needs to live in their own home.

NCCCP - Eligibility

- Eligible for Disability Service Commission services (ASF /IFS parameters)
- Clients must be under the age of 65 years at the time of diagnosis with a rapidly degenerative neurological condition.
- Referred to NCCCP within 4 years of diagnosis; with some exceptions made on an individual basis.
- Confirmation of diagnosis is required from a Neurologist in Western Australia.

NCCC Service Statistics

Since January 2008

- Total Referrals 151 92 (M) 59 (F)
- 116 – Metro 35 – Rural
- Determined as not eligible – 22
- Transferred to residential care – 6
- Deceased – 31
- Diagnosis – Motor Neurone Diseases 107

Service Statistics – Aged Distribution

< 10	10-20	20-30	30-40	40-50	50-60	>60
15	5	15	22	53	21	20

Main Service Types

Personal Care

In home respite

Domestic Assistance

Nursing Assessment

OT Assessment

Home Modifications

Counselling (recent)

Equipment – loan

- Hospital Beds
- Hoists
- Wheelchairs
- Electronic Bidet
- VPAP Machines
- Vehicle – Wheelchair
– able to be booked

Positives of the NCCCP

- Wide range of responses possible
- Flexibility to meet individual needs in terms of services, equipment and support
- Capacity for a rapid response
- Block funding allows range of responses for individuals that can be increased or decreased as required
- Diverse referral sources

Issues for NCCCP

- Narrow eligibility criteria means many people with significant degeneration and increased needs are not able to access
- Appropriate out of home respite still a difficulty
- Lack of recognition and
- funding for clinical assessment and collaborative case management

Other Developments

- HACCC Guidelines for Services to People with Disability – negotiated with DSC and published
- ACAT Assessment Guidelines in place that improve eligibility for respite in high care residential facilities
- Young People in Nursing Home program targeting community support for people who might otherwise enter residential aged care
- Increased inter government departmental communication

Conclusion

- The collaborative effort by service providers resulted in a significant research project that provided high quality evidence.
- Some positive changes have occurred (we can't be sure how much credit can be claimed)
- We will continue to Get Up and Stand Up for the people involved