



SILVER CHAIN

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## Mind the gap: the home support needs of people with MND in Western Australia

Dr Margaret Giles  
Edith Cowan University and Silver Chain  
Prof Gill Lewin  
Silver Chain and Curtin University of Technology

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# Australia



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- Four disorders – ALS/MND, MS, PD and HD
- Six components of the project:
  - Client and carer survey (n = 1,080; response rate = 54%)
  - Client and carer interviews (n = 49)
  - Case studies (n = 4)
  - Professionals' interviews (n = 9)
  - Clients and members 1996 to 2006 and data linkage 2006 (n = 2,550, excluding PD)
  - Projections of home care support services to 2021

- Client and carer survey - results for home care support services – gaps
- Data summary and linkage
  - Overlap of service provision (10 organisations)
  - Motor Neurone Disease Association of Western Australia membership data for 1996 to 2006

# MNDAWA membership data



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Year of joining	New members	Members remaining										
		1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
1996	10	10	6	5	2	2	2	2	2	2	2	2 (1)
1997	28		25	16	11	7	7	7	7	6	6	6 (3)
1998	25			20	14	10	7	6	5	4	4	4 (2)
1999	45				34	19	15	10	8	7	6	5 (1)
2000	43					38	25	17	11	7	6	6 (3)
2001	36						29	19	13	5	4	4 (2)
2002	26							20	10	7	5	5 (1)
2003	56								45	30	24	18 (2)
2004	45									32	19	13 (0)
2005	40										33	18 (2)
2006	35											29 (1)
	389	10	31	41	61	76	85	81	101	100	109	110

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- Survey response rate was 54 percent
- Survey dataset had 1,080 respondents
- 56 respondents with MND:
  - Average age was 63.8 years
  - 55.4 percent were males
  - 87.5 percent were members of MNDAWA
  - 17.9 percent were living alone
  - 82.1 percent were living with others



- Respondents with MND have:
  - difficulty with balance (83 percent),
  - reduced strength and stamina (94 percent),
  - fatigue (94 percent)
  - sleep disturbance (70 percent), and
  - muscle spasms, tremors or involuntary movements (80 percent).

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- Four main categories of home care support
  - **Personal care** – showering, dressing, meal preparation, feeding
  - **Domestic assistance** – cleaning, tidying
  - **Social support** – minding, shopping, doctors appointments
  - **Gardening and home maintenance**
- Other types of assistance – nursing, specialist care advice, counselling, meals delivered, physiotherapy, podiatry, occupational therapy, dietitian, speech pathology and respite

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- Personal care
  - Current average = 6.5 hours per week
  - Needed average = 7.2 hours per week
  - Gap = 0.7 hours per week on average  
( range of 0 to 4 extra hours)

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- Domestic assistance
  - Current average = 1.1 hours per week
  - Needed average = 1.6 hours per week
  - Gap = 0.5 hours per week on average  
( range of 0.7 to 2 extra hours)

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- Social support
  - Current average = 3.7 hours per week
  - Needed average = 3.7 hours per week
  - No gap

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- Gardening and home maintenance
  - Current average = 0.2 hours per week
  - Needed average = 0.8 hours per week
  - Gap = 0.7 hours per week on average  
( range of 0 to 2 extra hours)



- Gaps in home care support services are wider for
  - Those without carers
  - Those who are at later stages of MND
- About 4 in 10 people with MND and their carers:
  - use respite and want more or
  - have yet to use respite and want to

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- Organisations, including home care service providers, have coordinated support for people with MND ( n = 181) within the current funding models.
- 7 in 10 adults with MND receive services from one organisation only
  - Average age of 64.7 years
  - 63 percent males
- 2 in 10 adults with MND receive services from two organisations
  - Average age of 63.8 years
  - 47.5 percent males
- 1 in 10 adults with MND receive services from three organisations
  - Average age of 59.6 years
  - 50 percent males

- Older people with MND (> 64 years)
  - Diagnosed for a longer period (9.1 years since diagnosis)
  - Need more help (8.5 hours per week)
- Younger people with MND (< 65 years)
  - More recent diagnoses (4.3 years since diagnosis)
  - Need less help (3.1 hours per week)



## Two recent advances in Western Australia:

- MND Model of care adopted by Western Australian Department of Health in 2008. Many project outcomes informed this Model.
- Western Australian Disability Services Commission funding of \$4 million over 4 years, 2008 to 2011, to people with neurodegenerative disorders, particularly MND, who fall outside current funding models (under 65 years or with rapidly deteriorating health).

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- Project outcomes for people with MND:
  - More targeted funding of home care support that is
    - Flexible
    - Timely
    - Appropriate
  - More suitable respite
    - Emergency,
    - Short term,
    - Longer term,
    - In the home,
    - In residential care that is
      - age-appropriate
      - family-friendly
      - with MND-knowledgeable staff