

Characteristics and home support needs of people with MND in Western Australia, 1996 - 2006

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Background

- Cross provider group
 - Concerns regarding home support for people with neurodegenerative diseases, including MND
 - Lotterywest funded project 2006 – 2008
- Project components
 - Postal survey
 - Interviews and vignettes
 - Linking data (from 9 organisations)
 - Summary statistics (by organisation)
- This presentation includes survey results and summary statistics.

Summary statistics

MNDAWA

- 122 members in 2006
- Average age of members in 2006 – 64 years
 - 65 years for men; 63 years for women
- Average age at diagnosis – 61 years (18 to 100 years)
 - 61 years for men; 62 years for women
- Average age at joining – 64 years
 - 63 years for men; 65 years for women
- Average age at death – 66 years
 - 65 years for men; 66 years for women
- Average membership length - 1.6 years
 - 1.6 years for men; 1.4 years for women

MNDAWA Membership 1996 - 2006

Year of joining	New members	Membership ^a at year's end											Actual 2006	Unknown 2006
		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	1
1997	28		25	16	11	7	7	7	7	6	6	6	3	3
1998	25			20	14	10	7	6	5	4	4	4	2	2
1999	45				34	19	15	10	8	7	6	5	4	1
2000	43					38	25	17	11	7	6	6	3	3
2001	36						29	19	13	5	4	4	2	2
2002	26							20	10	7	5	5	4	1
2003	56								45	30	24	18	16	2
2004	45									32	19	13	13	0
2005	40										33	18	16	2
2006	35											29	28	1
	389	10	31	41	61	76	85	81	101	100	109	110	92	18

Postal survey respondents: Characteristics 2007

- socio-demographic characteristics
 - Number with MND = 60 (49 members of MNDAWA)
 - 55% of MND respondents were men (cf 37% of all respondents)
 - Average age of MND respondents is 64 years with a range of 26 to 84 years (cf 61 years with a range of 11 to 93 years for all respondents)
 - Females with MND have an average age of 64.5 years (all female respondents have an average age of 58.4 years)
 - Males with MND have an average age of 63.6 years (All male respondents have an average age of 65.4 years)

Postal survey respondents: Characteristics 2007

- Health
 - 60% of MND respondents have other medical conditions
 - Difficulty with balance affects 80% of respondents with MND (cf 72% of all respondents)
 - Fatigue affects 82% of respondents with MND (cf 84% of all respondents)
 - 43% of respondents with MND have depression (cf 39% of all respondents)
 - Muscle spasms, tremors or involuntary movements are experienced by 70% of respondents with MND (cf 67% of all respondents)
 - 55% of MND respondents were experiencing pain at the time of the survey, one third of these experiencing extreme pain (cf 48% of all respondents with less than one fifth of these in extreme pain)
 - Two thirds of MND respondents were experiencing disturbed sleep (cf just over half of all respondents)

Postal survey respondents: Characteristics 2007

- Symptoms first appeared: 1972 – 2007
- First diagnosed : 1972 - 2007
- Mobility
 - 27% not needing or using walking sticks or frames
 - 35% using sticks or frames outside and/or inside the home
 - 30% using wheelchairs
 - 3% bedridden

Home care support needs

- On average, MND respondents receive 7.5 hours of care per week and would like 1.8 hours more (unmet need of 19 percent)
- On average, MND respondents receive 1.4 hours of housework per week and would like another hour (unmet need or 42 percent)
- On average, MND respondents receive 2 hours of social support per week and are happy with this (no unmet need)
- On average, MND respondents receive 1 hour of gardening or home maintenance every two months and would like 4 more hours every two months (unmet need of 80 percent)
- 55 percent of people with MND who currently use respite want more; 22 percent who do not currently use respite would like to.

Life with MND

- Issues raised by survey respondents with MND
 - Lack of financial support for alternative treatments
 - Need for specialised equipment
 - “Yes I need extra care 24 hrs a day. I’m now having trouble as my daughter wishes to go back to work for financial reasons. I am looking for a nursing home of high care but there are no available positions.”
- Issues raised in the survey by carers of people with MND
 - Support for carers
 - Information for carers
 - A ‘lay’ explanation for the illness I am dealing with
 - Paying a high cost for unsubsidised care (for example, overnight minding)
 - Respite for carers
 - “The whole process of communication between *medical, allied health and home care providers* is hopeless at present...the left hand needs to stop referring people to the right hand until they are fully aware of what they are sending their patients on to...this really should be one person’s job or small team who can have all this information from one place and they can ensure the information is right per disease.”

Other project components

- Interviews and vignettes
 - Starting in July
- Linked data
 - Underway currently
 - A first attempt at data linkage in the disability sector
 - Will enable estimation of home care needs for people with neurodegenerative disorders in the next 50 years
- Project's final outcome = policies related to funding models for care in the home for people with neurodegenerative disorders