



**A U S T R A L I A**

YOUNG PEOPLE INAPPROPRIATELY  
HOUSED IN NURSING HOMES  
- SUBMISSION TO SENATE  
COMMUNITY AFFAIRS REFERENCE  
COMMITTEE

July 2004

There are currently 235 people with MS inappropriately housed in nursing homes in New South Wales (see attachment 1).

Their average age is 49 and some are as young as 21. They are forced to live with people whose average age is 81<sup>1</sup>.

They are forced to live in nursing homes because family and community care networks can no longer provide the level of care which they require and deserve to enable them to live at home.

In addition, there are approximately 350 people in NSW identified by the MS Society as being at immediate risk of admission to an institution<sup>2</sup>.

Research has shown that the risk of institutionalisation “is related to functional limitations and especially declining cognition, as well as social factors and the role of the primary care giver”<sup>3</sup>. Ankri is supported by Carton H *et al* who found that:” Eighty per cent of informal home caring is provided by persons living with the patients primarily the partner who provides 60% of home caring time. Severely disturbed bowel function and absence of a partner were associated with permanent institutionalisation”<sup>4</sup>.

The MS Society has broken the state into a number of regions with the following MS populations in nursing homes:

Northern Metropolitan	60
Southern Metropolitan	37
Western Metropolitan	51
Illawarra-South Coast	12
Hunter	18
Country Services North	12
Central Coast Region	15
Country Services South	17
Country Services West	10
Country Services New England	3

A total of 100 of these people with MS (43% are under the age of 60).

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<sup>1</sup> Professor Henry Brodaty <http://www.aihw.gov.au/inet/publications/welfare/racfa98-9/index.html>

<sup>2</sup> MS Society of NSW Clients identified “At Risk” for Nursing Home Placement. December 2001

<sup>3</sup> Ankri J. Prevention of loss of functional independence and institutionalisation. *Presse Med* 2000 June 24,29 (22):1255-62 (English Abstract only) .

<sup>4</sup> Carton H *et al*. Quantitative study of unpaid caregiving in multiple sclerosis. *Multiple Sclerosis clinical and laboratory research* Vol 6 Number 4. p274.

They cannot live alone and family and friends can no longer cope because:

- These people with MS are almost always the most physically disabled, they cannot “transfer” from their wheel chair, and consequently become too heavy for the average person to lift.
- Often the person who used to look after them can no longer physically or mentally cope.
- Parents are sometimes getting old.
- They need assistance with all aspects of personal care and that includes showering, dressing, assistance with meals.

The society's record show that, on average, these people require approximately 5.7 hours of direct hands-on nursing/personal care each per day. (see attachment 2)

This 5.7 hours represents a moderate to severe disability range and while nursing homes do provide a more than adequate professional service for their specific target market they are unable to provide an environment which is appropriate to these younger people

When young people with MS are forced to live in nursing homes designed for the frail aged they often feel isolated from the community particularly people their own age. They have lost contact with family and friends

For many young people admission into a nursing home is their biggest fear. They fear that it may well be their final home. People around them are often very elderly, very sick and suffer from severe dementia.

Behavioural disturbances, clinical depression, delusions and or hallucinations occur in over 90% of residents with dementia.

They also feel stranded in an inappropriate environment. (lack of funding and resources prevents them from taking part in the normal recreational and social activities enjoyed by younger people in the wider community). The nursing homes provide a level of care designed for very elderly people, not for young people.

Young people in nursing homes have to fit in to programs and routines designed to meet the needs of the very elderly or demented as opposed to the needs of the physically disabled. They have no choice. **This leads to depression and it is not unusual for people to “give up and lose hope” and as a result deteriorate very rapidly on admission.**

Because this need could no longer remain un-answered, nine years ago the MS Society of NSW undertook to provide a range of services designed specifically for people with MS in nursing homes.

The Society's Community Nursing Home Support Program, which is funded entirely from the Society's own fund raising activities **at an annual cost of \$250,000** provides:

- **Regular and on-going contact** with every person with MS living in a nursing home in NSW
- **Financial Assistance** for additional and highly specialised equipment for each individual with MS. This equipment is always outside the normal purview of nursing homes
- **Flexible individual assistance care packages.** This program aims to assist people with MS living in nursing homes for the frail aged to access the community for regular recreational and leisure activities by the allocation of a generous amount of funding per year from the MS Society. This enables these younger people to experience diversions beyond their limited and isolated environment. In other words it gives clients access to those things which the general community often take for granted  
Support is in the form of:
  - transport
  - attendant carers for outings
  - physiotherapy
  - massage
  - assistance to go home for the day
  - assistance to attend, art gallery, movies, sports functions, community recreation activities, regional recreation programs
- **Specialist Services** of the MS Society, including continence assessment, advice and referral
- **A link** between clients and volunteer services
- **Education and training** for nursing home personnel - Existing personnel are often good-hearted nursing and personal care assistants who have had minimal or no training

- **Information, support and advice** regarding suitable nursing home accommodation.

This program is staffed by two MS Society registered nurses who cover all areas of the state.

In addition the society spends approximately **\$30,000** per annum providing “top up” crisis services to people living at home, and whose supports (eg Community Services) have broken down to the extent that they are in imminent danger of premature and inappropriate admission to an institution.

The society currently has 30 volunteers who visit people with MS in Nursing Homes at least once a week for a minimum period of three to four hours.

A conservative estimate of the \$ value of this visitor service is **\$65,000**.

**One of the dreams of the MS Society of NSW is that all young people with multiple sclerosis who live in nursing homes be given the chance to rejoin the community if they so desire.**

The predicament of younger people with MS who are currently forced to live inappropriately in aged persons nursing homes continues to be a top priority of the Multiple Sclerosis Society of NSW.

The society is constantly examining a range of options designed to provide flexible accommodation support tailored to meet the individual needs of this group of people.

The MS Society of NSW is currently undertaking research to determine the best model to provide appropriate housing for this group of people in NSW.

We are examining all options, and have excluded none.

Western Australia is widely regarded as the leader in innovative and progressive quality residential accommodation for younger people with high support needs. Their model is one which is under consideration.

However, before the society can even contemplate committing to a significant expenditure of this kind, it must have a commitment from Government that it will accept its responsibility and provide for the ongoing recurrent expenditure.

The society estimates that the cost of maintaining one person in a fully supported unit such as those described above is in the order of \$90,000 per annum.

The society acknowledges that the cost of providing nursing home beds is a federal government responsibility.

Australian Nursing Homes and Extended Care Association (ANHECA) reports that the federal Government subsidises each nursing home bed in Australia to about \$70,000 per annum.

If this subsidy (currently paid to people with MS in aged care nursing homes) were transferred to beds in an MS Society facility the amount needed to meet the recurrent costs would be reduced to \$20,000 per person per annum.

Additionally, if 235 people with MS were able to be moved from aged care facilities to young people specific facilities, the critical shortage of beds in aged care nursing homes in NSW would, at least in part, be relieved.

**Attachment 1**

Age of people with MS living in nursing homes

Northern Metropolitan		Southern Metropolitan			Western Metropolitan			Illawarra/South Coast			Central Coast/Hunter			Country South/South West			Country North/New England		
0-29	29-60	60+	0-29	29-60	60+	0-29	29-60	60+	0-29	29-60	60+	0-29	29-60	60+	0-29	29-60	60+		
1	27	32		15	22		25	26	-	5	7	-	13	20	-	9	18	10	
60		37			51			12			33			27			15		
0-29						29-60						60+							
1						99						135							
Metropolitan 148									Country 87										
<b>Total 235</b>																			

**Attachment 2**

**Average level of care over all age groups (per day)**

<b>Northern Metropolitan</b>	<b>Southern Metropolitan</b>	<b>Western Metropolitan</b>	<b>Illawarra/South Coast</b>	<b>Central Coast/Hunter</b>	<b>Country South/South West</b>	<b>Country North/New England</b>
<b>5.4 hrs</b>	<b>5.3 hrs</b>	<b>5.0 hrs</b>	<b>6.50 hrs</b>	<b>6.6 hrs</b>	<b>5.2 hrs</b>	<b>5.8 hrs</b>