

## Submission to the Senate Affairs References Committee Inquiry into Aged Care with particular attention to the issue of Young People in Nursing Homes

Experience as a Consultant Neurologist for 23 years and the experiences reported to me by colleagues as well as my position as Director of the Huntington Disease Service at Westmead Hospital lead me to make this submission.

My particular interest is in the neurodegenerative illnesses which affect young as well as older people. These include Frontotemporal Dementia, Alzheimer's Disease, Parkinson's Disease and Parkinson's Plus syndromes, Huntington Disease and Motor Neurone Disease. All progress invariably to severe disablement requiring full personal care. Other Neurological illnesses result in the need for respite and eventually nursing home care either because of a fixed non-traumatic deficit as in the case of severe stroke or because of progression to severe illness for example Multiple Sclerosis, Muscular Dystrophy or the neurological manifestations of HIV-AIDS.

Over the years I have seen the impact of these illnesses on patients and families and witnessed the severe lack of services available to younger patients (ie people under 65years) living in the community or when respite, hostel and nursing home care is required and the inappropriate placement of patients as young as 25 years with demented frail elderly. Services are particularly limited for those with Neuropsychiatric manifestations of disease causing behavioural disturbance (a feature of Huntington Disease), often with aggression. Of more concern now is that in my experience over-burdened Aged Care assessment teams and Aged Care facilities are turning away younger patients altogether even though the need is obvious. This means that there is not only the problem of placement in appropriate facilities for young severely disabled but limited access to any facility at all. While it is essential to maintain adequate high standard facilities for the Aged we have

currently far less adequate services for younger patients to the point of discrimination on the basis of age alone.

The following points need to be considered in the discussion of young people in Nursing homes:

- 1) Young people can incur severe disability requiring nursing home care because of disease causing non-traumatic severe deficit or because of a progressive process, often affecting the nervous system. Access to facilities is discriminatory unless based on need rather than age.
- 2) Young people may be otherwise very healthy and live longer even though the disease resulting in placement may cause severe deficit eg in the case of Huntington Disease the duration may be 20 years, 10 of which may need to be spent in care in hostel and nursing home. While the numbers of younger patients requiring care are less, duration of life with severe disability can be longer.
- 3) There is a perception that young people should be managed at home no matter how severe the deficit. This is simply not possible and is undertaken with great risk and in my opinion often results in severe isolation not to mention earlier death.
- 4) There may be no carer at home.
- 5) If there is a carer, the carer for a young person will often have the additional responsibilities of raising the family as well as being the breadwinner.
- 6) Some children take on the role of carer for an affected single parent or when the healthy parent is working. The impact of chronic illness and the stress of care on families are considerable.
- 7) Young people may not have the assets, fully owned home or support of adult children.
- 8) In the case of inherited diseases it is not uncommon to see some carers who care for more than one family member or may who be at risk themselves. One person reported caring for family members for 30years; affected spouse and several affected adult children all under age 65years.

- 9) With the ageing population it will be increasingly difficult to place young people and already preference is given to those over 65 years when no comparable system of care is available as an alternative to younger patients in need of care, particularly those with dementia and no family carer.
- 10) Some specialized disease specific units exist but in the case of Huntington disease the specialized unit allows for care for < 20% of those known to reside in nursing homes and hostels and cannot cater for long term care, the demand being too great.

### **Possible solutions**

- 1) Establish nursing home clusters for young people across the States, ACT and NT. These would be units of 10-15 beds within established Aged care facilities but designated for young people. Staffing and programs/ surroundings would need to be appropriate for young people. Some beds within these units should be designated as respite/assessment beds.
- 2) Maintain some disease specific facilities but broaden the scope of these units.
- 3) Establish Neuropsychiatric units where patients with severe behavioral disturbance secondary to neurological illness, often with dementia and impaired personal care can be managed. In NSW these patients were originally cared for in the Psychiatric hospital system but following the Richmond report there is often inadequate management and limited options for care usually within the Aged care sector.
- 4) Establish an Outreach care program to assist in management in the community both at home and in hostel/nursing home care. The Huntington Disease Outreach Team, part of the Huntington Disease Service based at Westmead Hospital, was established for this role of supervision in the community, links to other health providers and education.
- 5) Training program for GP's and nursing staff in the management of disorders encountered in the cluster eg

Behavioural management and easy access to specialist advice in the particular disorders.

Ms Angela Lownie(0298045863) Clinical Nurse Consultant, Huntington Disease Outreach Team Co-ordinator undertook a research project as part of a Masters degree in nursing examining the issues of nursing a “different patient” in a nursing home setting and in particular younger Huntington Disease patients. In addition the social workers attached to the Huntington Disease Service (contact Ms Roslyn Curran 0298456699) have considerable experience in the area especially the frequently encountered major difficulties that are due to lack of services available to this group. I would welcome an opportunity to discuss these matters in more detail.

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