SENATE COMMUNITY AFFAIRS REFERENCE COMMITTEE

INQUIRY INTO AGED CARE

SUBMISSION REGARDING SECTION C OF TERMS OF REFERENCE
"Appropriateness of Young People in Nursing Homes"

The Inquiry into Aged Care provides for a broad range of issues to be highlighted and discussed primarily relating to the needs of older people with a multi-optional support system. This inquiry has already highlighted a major concern for the MS Society of Tasmania, by including the issues relating to young people within nursing homes, within its terms of reference. The position of this Society is that in terms of the needs of our clients, falling within the category of a young person (under age 65), in most instances current residential aged care facilities are not appropriate. In addition to this, that current funding arrangements are not in place to support the high care needs of young people living with MS within these facilities.

There are a range of issues and considerations that support our position and highlight the inadequacy of the current arrangements for young people. We have broken these into three categories, Medical Considerations, Psycho-social Considerations and Systemic Obstacles. Throughout this submission we make reference to a series of case studies of actual young people living with MS in Tasmania. These case studies demonstrate in vivid reality the failure of our community to recognise and provide adequate care and accommodation. Many more stories could be told but we are sure that these will provide a graphic picture of what young people are going through.

Medical Considerations

MS is a complex medical condition

MS is a chronic progressive neurological disease, which can impact on the individual in a variety of ways both physically and psychologically. People with MS will experience their own journey with this disease. For people with MS entering the nursing home system, it is normally after a long and arduous struggle, then a realisation that appropriate care options are not available or sustainable within the community or family. 'One size fits all' is not an appropriate rationale to adopt in these instances as the disease effects each person in different ways and the care must be responsive and flexible. (see Annexure A - CS 2, 2003 point 7,10, 11, 2004 point 1, CS3 point 9)

Not an accommodation issue its care issue

For young people with MS to reach the point of requiring nursing home accommodation, it is largely based on their inability to access adequate services within the community. The provision of funded care hours is neither adequate nor flexible to meet the demands of some young people. Young people with MS will often have tried several forms of assisted care but

resources are limited and in high demand. The inability of our systems to be flexible and timely is a major factor in forcing young people into nursing homes. (see Annexure A - CS 1)

Demands qualified and skilled nursing

By the time a young person with MS enters a nursing home they will more than likely suffered significant deterioration in cognitive performance, communication skills, motor performance and bladder/bowel incontinence. Mobility is not possible without assistance. Even the act of swallowing, with the risk of aspiration of food and its consequences, can be a life-threatening situation. These people are extremely susceptible to infections, which can result in death if not properly treated. Every day conditions can severely impact on these people and normal nursing home care responses may not be enough. Specialist nursing skills and the ability to provide timely interventions with regards to health conditions are essential in providing the care MS patients need. (see Annexure A - CS 2, 2003 point 7,10, 11, 13, 2004 point 1-19, CS3 point 9)

Access to specialised medical and allied health support

Once a young person enters a nursing home, access to a range of funded services existing within the community, is either reduced or withdrawn. Access to specialised equipment from community equipment schemes is not available and either the nursing home or individual must fund this. Access to physiotherapists and allied health is normally on a self-funded basis. Largely access to these services is dependent on the nursing home administration and service commitment. (see Annexure A - CS 2, 2003 point 2-5)

Confusion as to what nursing homes can access from the community regarding equipment, services and consumables

Because nursing homes largely cater for frail elderly there is not a significant understanding of the range of services and resources for young people that can be accessed through the community. Knowing how the systems work can be of great benefit to these young people and requires good communication skills and monitoring of these areas. This again is a high demand area where the systems are difficult to negotiate and for nursing homes not necessarily funded for these activities.

Psycho-social Considerations

Physical & Cognitive Change

By the time a young person with MS enters a nursing home, they may have undergone a significant physical and cognitive change. This disease normally strikes a person between the ages of 20 and 40, which most consider to be the prime of our lives. The psychological effects are significant with many viewing this as the final step in their lives. It is common for people with MS to experience relationship breakdown. Most common is the development of depression. Nursing homes are not necessarily geared to handle the range of conditions and emotions that younger people with MS are likely to experience.

Inability to communicate needs

One of the most significant factors that young people may experience is the deterioration and sometimes total loss of their ability to communicate. It is part of the progressive nature of the disease and often leads to great trauma. Imagine you have an insect crawling across you face. Firstly, you're not able to raise your hand or arm to remove it. Secondly, you're not able to communicate to anyone that you need help. Cognitively, these people are quite aware, yet physically they are unable to communicate and therefore largely go ignored. (See Annexure A – CS2 & CS3)

Inappropriate social situation

Nursing home environments are largely geared towards the needs of the elderly. Activities and stimulation for younger people are limited or non-existent. Young people have social needs, and in most instances, they want to be around people of their own age with similar interests. These young people often have young families or friends that want to see them but the environment within nursing homes is not geared for this. This is often a deterrent for visitors and frustrating for these young people. (See Annexure A – CS2 – Q – point 4-7 & CS3 point 10)

Exposed to situations beyond their control – cognitively aware but physically unable to respond.

For many young people with MS in nursing homes it is normally a situation where they have lost the ability to move any of their extremities. This exposes them to situations where they have no physical response to protect themselves. Often within nursing homes, residents can have dementia or the other psychological conditions, which may be a potential danger to anyone that cannot respond. Unfortunately, these young people with MS can be fully aware of what is happening but unable to protect themselves. (See CS2 – Qu – point 4)

System is geared towards the elderly – social and specialist services geared towards that demographic.

Nursing homes are normally set up for the needs of elderly. This includes social activities and specialist services. For the nursing home it's about meeting the needs of the majority of their clients. This is a rational business approach but unfortunately does not help young people.

Labelled as being more difficult and demanding in terms of care needs – cognitive characteristics related to MS and long term illness.

Many young people with MS may need ongoing high care for a substantial period of time. There stay can be for much long than elderly residents – averaging approximately 7.5 years as against 2.5 years. This can place a significant strain on the nursing home and therefore they are deemed as being not desirable in terms of nursing home residents.

More challenging for carers emotionally and psychologically because of their age and relating to them

Carers can also be affected psychologically by their interaction with young people with MS. As it is a progressive neurological condition, carers see the gradual deterioration of these young people in similar life stages to themselves. Often these young people with MS have young families and carers picture themselves and their families if placed in this situation. It is vastly different from dealing with an elderly person. Carers need to be specially trained to deal with these situations.

Danger that staff treat all young people the same – lumped in together with other young people with different conditions (intellectual disabilities, ABI)

Young people tend to be lumped together based on age not necessarily condition. The needs of brain impaired young people are not the same as those of young people with MS. Mental stimulation and interests can vary greatly yet it is easier to put them into a group because they are young.

Philosophy of care prior to nursing home

Part of the current care approaches for people with MS is empowering them to deal with their own situation and make decision concerning their care, treatment and life. It includes flexibility and opportunity in life activities. This is underpinned by legislation in the Disability Services Act within Tasmania. Unfortunately, the nursing home situation is one of conformity and routine. This is necessary due to the demands of others, but takes young people from a self-empowered environment and places them in a controlled one. This can have significant psychological repercussions. Even the simple act of closing a door to have time to one's self or family may not be an option as it does not fit within the schedule or policy.

Sexuality prospective

As MS is a disease of the younger adult it is often the case that sexual needs and relationships exist prior to going into the nursing home. Often there is a desire on the behalf of the young person to continue these in some manner and there is a need for opportunity and privacy. These are cognitively lucid consenting adults wanting to express their desires in an intimate manner. Often, however, consideration of these needs is not part of the normal operations of nursing homes.

Palliative care - young person dying

The reality of a young person with MS entering a nursing home is that they are likely to spend the rest of their life there. As the disease progresses there may be a shift from nursing care to palliative care. For a younger person these needs may be different to the more elderly. For carers the impact may be more significant as they relate and compare with their own situations. Most nursing home facilities are not set up to deal with these types of situation involving young people. (See Annexure A – CS3 point 9)

Systemic Obstacles

Discrimination because of residential status
Current systems have been structured so that once a young person enters a nursing home it is presumed that their care needs are the responsibility of the institution. Nursing homes were neither designed for or compelled to provide the specialist care needs of a young person with MS. The resources are there within the community but because they are in a nursing home, not easily accessed. There needs to be a review of policy regarding access for those in nursing homes to the broader range of community services. (See Annexure A – CS2 point 13)

Discrimination because of age in accessing nursing home spaces
Nursing homes are funded for a number beds and the level of funding they received is based on the Classification Index. Traditionally, young people do not fare well on this index and even the maximum index funding is inadequate to cover the care needs of these young people.

Financial capacity to privately access to nursing home spaces
Gaining access to high care nursing homes or facilities is extremely difficult and expensive. Often young people with MS are in a situation where they have not had employment for some time and are often the recipient of a pension. Coming up with amounts, normally for several hundreds of thousands of dollars, is not always an option.

Changing nature of patient's condition and level of disability – system not geared towards this.
The current system of assessing disability is largely geared to the identification of a specific disability at a point in time, with review options on a 12 monthly basis. The Classification index is not sensitive enough to cope with the progressive nature of the MS disease and the resulting deterioration rates. The adequacy of funding is brought into question, which can impact on the ability of the young person to acquire assistance.

There are no other choices
Young people with progressive MS are going into a nursing home because physically they are unable to care for themselves and support networks are exhausted. In reality there are no other choices. Other models of care within the community are not adequate or available to support their high care needs. It is their only option not necessarily one that meets their needs.

The case studies attached provide a grim reminder that we are failing as a community to adequately address the needs of young people requiring high levels of care.

It is the position of the Society that the problem is not one for governments alone but is part of a broader community commitment to addressing these needs. For too long we have been turning a blind eye or saying this is too

difficult. The issues are not going away they are getting bigger. As a community we must explore options for the future and take steps to address these issues.

Ross Duncan
General Manager
31 January 2005.

ANNEXURE A

Case Study 1

- 48yr old male
- Diagnosed MS 2002
- Single
- North West Tasmania
- Living on rural property (farm) by himself.
- Privately funding a cleaner and domestic assistance – including preparation of meals

2004

1. Experience several significant relapses - Increasing disability
2. Unable to access appropriate services in his area.
3. Decides to sell farm and purchases home in rural town with the expectation of being able to readily access services.
4. Again, difficulty-accessing services. He was not receiving a pension and the information was not clear as to what services he could or could not access. Lack of cohesion and communication between services trying to assist.
5. Local bank teller who 'delivers' cash to patient from his bank account finds patient in an incapacitated state following a fall and he was hospitalised.
6. Discharged home after 90 days because the due to the hospital funding systems he was no longer eligible for support.
7. Community nursing provide personal care in the mornings, showering, dressing and HACC funded service provides assistance with meal preparation and assistance to be put to bed. Remained at home for one day as the services were assessed as not being adequate by community nurses. Care needs deemed to be too high. Hospitalised again for further 90 days
8. During the first period of hospitalisation an application had been placed for Individual Support Package from Disability Services. Placed on a waiting list for package.
9. Discharged from hospital to a self-funding nursing home bed because individual support package not available.

Case Study 2

- 44yr old male
- Married
- Wife works to support the family
- Four teenage daughters
- Previously owned and ran a small business
- Diagnosed 1996 with MS

2001

1. Unable to continue to run business
2. Increasing disability but remaining mobile with walking aid.
3. Significant intentional tremor, unable to feed himself or attend to personal care.
4. Has minimal assistance from outside agencies, wife attends to all aspects of care in between working and raising four daughters.

2002

1. Bathroom modifications performed at patients' expense.
2. Marked progression, now unable to weight bear without assistance.
3. Hospitalised twice following severe relapse and resulting progression.
4. Requiring wheelchair for mobility and assistance for all aspects of personal care.
5. Socially isolated and clients increasing disability having profound impact on family.
6. Support from Disability Services obtained and Carer Respite.
7. Deteriorating situation at home.

2003

1. Insufficient support provided to family to enable client to remain at home
2. (Approximately 15hrs per week)
3. Increasing physical care needs including equipment and allied health interventions.
4. Client placed in a nursing home as family believed he would receive improved personal care.
5. Now unable to access community rehabilitation services as in a nursing home. The nursing home has to pay for any occupational therapists, physiotherapists etc... who attend to residents in the home.
6. Patient severely disadvantaged.
7. MS Society Nurses facilitate MS clinic appointments so that client can be seen by allied health team in this clinical setting i.e. no cost.
8. Hospitalised twice during this first year with life threatening infection.
9. Nursing home staff provided with in-service education from MS Society nursing staff following both these hospitalisations to inform carers and nurses of MS specific cares considerations and infection specific risks.
10. Clients' condition deteriorates further.

11. Requires neurosurgery in Melbourne to attempt to relieve severe intentional tremor. Surgery successful for short period of time.
12. Patient requires highly specialised physiotherapy following this surgery to optimise outcome. Unable to be provided in the nursing home and requires a letter from the treating neurologist requesting this from the rehabilitation physiotherapist so that there is no cost incurred by patient.
13. If patient was at home, access to rehabilitative physiotherapy would have been almost immediate. Much easier to facilitate.
14. Difficulty transporting client from nursing home to attend any medical appointments at the Royal Hobart Hospital.
15. Nursing home unable to provide a carer to accompany patient. He either travels alone or his wife has to leave work to travel with him from the nursing home.

2004

1. Appointment made for client to attend MS clinic as alerted by clients' wife that her husband had a lot of broken skin areas on legs.
2. Appointment arranged.
3. Appointment cancelled by nursing home why? Patients' wife had no knowledge of this. Appointment rebooked.
4. Patient attended appointment.
5. Numerous broken skin areas/ pressure sores on calves and feet. One foot had very severe skin breakdown.
6. Consultation with plastic surgeons, wound care specialist, infectious diseases specialist. Bone scans required and care plan put in place.
7. MS Society nurse with wound care specialised knowledge photographed wounds on foot and educated nurses in the nursing home on the specific dressing technique. Photographs provided to them to be placed in patient file to monitor improvement.
8. Specific cream for the foot wounds prescribed by the wound specialist and specialised dressings were not provided by the nursing home. Patient
9. $70.00 out of pocket each week for this.
10. MS Society nurse also liased with an agency Registered Nurse at the home to work together on optimising patients wound management.
11. Agency nurse had implemented wound care management plan in patients file,
12. Provided clear instructions on patients care when she was not working at the home.
13. MS Society nurse received urgent phone call from the agency nurse on a public holiday after Xmas.
14. Nurse described gross deterioration in condition of patients' foot.
15. Wounds on feet now down to the bone and new broken areas developing on legs.
16. No one at the nursing home had sought medical advice or noticed the change in the patients wound.

17. Dressings not undertaken as advised and instructions re bandaging of foot ignored.
18. MS Society nurse arranged urgent admission to hospital.
19. Patient has required amputation of forefoot and a lengthy hospital stay.

QU. Nursing Home Placement for this young man - what has it meant?

1. There is no doubt that this patient has high personal care but personal care needs have been poorly met.
2. In this case, poor care has resulted in this man loosing his foot, and placed him at risk of succumbing to a potentially life threatening infection.
3. It begs the question, “What would have happened if the agency nurse had not alerted the MS Society Nurse?”
4. Additionally, this patient is forced to socialise with elderly often demented patients who at times behave inappropriately. 0n one occasion MS Society staff witnessed another, demented, patient groping clients groin. He is helpless to remove himself from this situation. Unable to use wheelchair or use his arms.
5. Patients’ wife reports that one of her husbands oldest friends no longer visits him at the home as they are always interrupted by an aged resident who takes up ‘lodgings’ in patients room.
6. Nursing home had been advised of this and had done nothing to provide a distraction to the aged resident and allow client to enjoy his friends company alone.
7. Patients’ family extremely distressed at their husbands and fathers situation.
8. They are anxious that he is to return to the same nursing home and that the home does not seem to be concerned about the care he has received whilst a resident there.

Case Study 3

1. 54 yr old female
2. professional person with progressive MS
3. Married with one teenage son
4. Care provided by privately accessed carers and family
5. Diagnosed with MS then 2 years after required to leave the workforce.

6. Condition deteriorated – began to experience cognitive behavioural problems.
7. Family were then unable to care for her and she entered a nursing home.
8. The person knew what was in store because her mother had contracted MS in a primary progressive manner. She organised with a legal representative for a living will to express her wish for her treatment.
9. Her condition continued to deteriorate and became immobile. The most significant conditions related to speech and swallowing. The nursing homes response was to have her PEG fed. Her living will explicitly stated that she did not wish to be PEG fed. Two issues arose. The nursing home was adamant that PEG feeding was necessary. This raised the issue of conforming to the wish of the client or the beliefs and policies of the nursing home management. Secondly, the nursing staffs understanding of palliative care was not appropriate for the nature of this neurological condition. Meetings were organised by the MS Society with representatives of the nursing home, her doctor and palliative care specialist where the most like outcomes were explained.
10. The family has suffered great trauma as a result of her entering the nursing home. There is ongoing resentment between the father and son (both previously being primary carers) regarding the decision to place her in the home. The husband still spends most of his time outside work at his wife's side. The son moved overseas to escape the situation.