# SUBMISSION TO STANDING COMMITTEE ON AGEING

**This submission by the Voluntary Euthanasia Society of Victoria Inc. addresses the related areas of health and aged care, and in particular, the question of choice for ageing persons in this context.**

## INCREASED NUMBERS OF AGEING PERSONS

There is no argument that there will be a significant increase in the numbers of aged persons in the Australian community over the next 40 years, without a dramatic change in the Australian demographic. This fact is the basis for establishing this committee.

## INCREASED NUMBERS OF AGE RELATED PROBLEMS

Ageing, particularly beyond 80, brings with it a rapidly increasing incidence of age related health problems, most of which create increased dependence and requirements for specialized care. The following list details some of the major problems which can need placement in aged care facilities.

1. Dementia – increases dramatically over the age of 80 and is found in 1 in 4 over 90.
2. Blindness
3. Deafness
4. Immobility, due to arthritis, osteoporosis, pathological fracture, and neurological disease such as stroke.
5. Incontinence
6. Frailty and debility
7. Chronic untreatable degenerative disease of the cardio-respiratory system.
8. Cancer

Any one, or a combination, of these common diseases of ageing can lead to loss of the ability for independent living, and the threat of placement in a nursing home.

In the United States there was a 24% increase in the nursing home population in the decade 1980-1990, more than 50% of these were aged over 85. In the United States, 78% of population currently live longer than 65. Most will die slowly, mostly in old age. 75% of these people will contend with cancer, stroke, heart disease, and obstructive lung disease or dementia in their last year of life.

**These diseases are essentially untreatable and incurable illnesses, that are all capable of causing intolerable suffering in their right, without the added burden of nursing home placement.**

## ATTITUDES OF THE AGED TO NURSING HOMES

There are few extensive studies regarding attitudes of the aged in general terms to the prospect of nursing home placement. There are some limited studies that address this question.

1. Surveys in the USA have consistently found that most people would rather continue living at home than in a nursing home. Half of these people with a serious chronic illness would prefer to die at home.
2. The aversion to such a facility is so strong that a new study of seriously ill people in (US) hospitals found that 30% said they would rather die than live permanently in a nursing home (Hogan, Health Affairs, 2000).
3. An Australian research team investigated 194 Australian women over 75. They found that 80% said they would rather be dead than experience the loss of independence and quality of life that results from a bad hip fracture and subsequent admission to a nursing home. (G.Salkeld et al, British.Medical.Journal, 2000; 320:341)
4. Australian studies of nursing home residents have found high levels of distress at nursing home admission, with an overwhelming sense of loss, a lack of choice, and a sense that their admission was for the benefit of others. (R.Nay, J.Clin.Nursing 1995;4:319 – Barbara Fiveash, Lincoln Gerontology Centre, 1997)
5. A.J.Form et al (Age and Ageing, 1995;24:389) studied the incidence of a persistent wish to die in elderly persons (over 70). It was found to be 2.3% and was associated with disability (75%), pain (57%, deafness (38%), blindness (38%), poor health (39%), and **residential care (48%).**

## CONDITIONS IN NURSING HOMES

The following aspects of nursing home conditions need to be seriously considered, particularly those made from the perspective of a nursing home inmate.

1. 25% of cancer patients with pain did not receive any regular analgesic provision in US nursing homes (R.Bernabei et al, Journal of the American Medical Association, 1998;279:1877 – C.S.Cleeland, Editorial (p.1914) in the same issue.).
2. 60-80% of nursing home patients have some degree of dementia
3. Two thirds are admitted on discharge from an acute hospital, the principal reasons for admission are dependence and immobility. 10% are bedfast and 40% are chairfast.
4. The mortality within twelve months is very high. In 1993, 20% of US deaths occurred in nursing homes, expected to increase to 40% by 2020.
5. L.Gorman (Australian Journal of Advanced Nursing, 1996;13:7-11) interviewed **articulate nursing home residents** and found three main themes of concern
   (a) enervation – the exhausting nature of trying to live with socially inappropriate behaviour
   (b) disenfranchisement – loss of health, privacy, choice and living autonomously
   (c) coping – with socially and cognitively impaired residents.

6. Rhonda Nay (Journal of Clinical Nursing,1995;4:319) studied Australian attitudes to nursing home relocation. She found
   (a) the experience was substantially one of loss – of home, possessions, friends,
   (b) family, affection, pets, freedom, roles and life-style, and control over daily activities
   (c) all residents perceived themselves as a burden
   (d) many felt there would be no future
   (e) they had a sense of devalued self
   (f) they perceived the nursing home as a place where sick, old people go to live out their life in dependency.
7. Barbara Fiveash of the Lincoln Gerontology Centre published "The articulate resident's perspective on nursing home life" in 1997. She discussed four main themes.
   (a) Admission issues. There was a profound sense of being without choice, that their admission was for the benefit of others
   (b) Living in the public domain. Residents live with people they have never met before, do not know, and have not chosen to live with. Residents have limited power or control over the nursing home context. It is the public nature of the nursing home experience that is problematic. Large numbers of people do not ordinarily live indefinitely together (*except in prisons).* 'There's nowhere to go that's private' 'It's like living in a hospital, or worse, like a prison – an inmate' 'it's an awful way to live'
   (c) Cultural implications of living with others. They viewed other residents as a reflection of how far they had fallen, a constant reminder of their own inevitable decline, leaving them with no choice but to picture themselves chairbound, confused, sick or dying.
   (d) Impact of nursing home residency. Expressed as boredom, few people to talk to, sense of hopelessness, inability to change situation and fear of complaining, nothing to live for, no purpose in life.

**Her conclusions were that all people need freedom and choice – it is a basic human need.**

## CHARACTERISTICS OF NURSING HOMES

Even with the best will in the world and with the best possible nursing, nursing homes at an affordable price to government and the community are forbidding institutions, and likely to remain so without massive increased funding (which would probably make little difference to the fundamental problem).

Nursing homes are institutions where most people
(a) enter without choice and with an extreme sense of loss
(b) enter in their view for the benefit of others
(c) they will remain for the rest of their short life
(d) at a vulnerable stage of their life, they are forced into congregational living with no choice of companions

(e) their companions may seem coarse and vulgar, dangerous, create physical and mental abuse
(f) they are heavily if not totally dependent on their carers
(g) they will live with boredom, loneliness, frustration, anger, fear, depression and hopelessness
(h) they will have lack of privacy
(i) they will suffer regimentation with regard to meals, toilet and other private matters
(j) they will live in a culture of no complaint and fear of punishment
(k) they will suffer a sense of loss of place, possessions, relationships, independence, role, and life-style.

**Many of these characteristics are those associated with life imprisonment in a penal institution,** as some residents observed.

**Nursing homes, for many, represent futile endeavour or treatment. "**The main purposes of futile treatment are threefold. It satisfies the family that nothing more can possibly be done, often signifying an inability to let go or to accept the loved one's life is over. It satisfies the social value that it is unacceptable to give up and that yes, we may be able to defeat death. That expectation itself is an exercise in futility. It satisfies that everyone is entitled to the fullest of everything, even if it serves no realistic purpose." These words were written in relation to acute end of life care, but are also applicable to end of life nursing home care, which is certainly futile when it completely fails to meet the needs of people. **Their placement in a nursing home may be to meet the needs of the family and society rather than the person.**

## COST OF NURSING HOME CARE

The very high cost of nursing home care is a significant factor in the acknowledged present inadequate numbers of current places. A number of places have been lost due to inadequate standards, at a time when even current approved standards are inadequate from the residents' perspective.

In 1993, in the United States, 28% of Medicare program expenditures (utilised by the elderly) were accounted for by the 6% of persons who died during that year.
Dr Christopher Chambers of the Thomas Jefferson University (Philadelphia) reviewed the costs of 474 dying patients and found that **those without advance directives were three times greater than those with advance directives.**

M.E.Coe (Health and Age, 2001) found that hospital-based physicians tended to choose more treatment than patients preferred.

**The ability to provide effective aged care is closely linked to its cost. The provision of futile, costly care to elderly persons who do not want it is not sensible. Measures to ensure that patients are not given care that they do not want will be valuable to enable more care to be given to those who do want it.**

**RECOMMENDATIONS**

1. **That all older persons are strongly encouraged to appoint a medical enduring power of attorney (medical agent), and that all health care institutions specifically record the agent status on admission.**
2. **That all older persons be encouraged to complete a general advance directive, and that persons being admitted to aged care complete a nursing home advance directive.**
3. **That all older persons have a choice to avoid what they may see as 'imprisonment' at the end of their life, or to escape from that situation if it becomes intolerable.**

Voluntary Euthanasia Society of Victoria Inc.
70 Greville Street,
(PO Box 2056)
Prahran, Vic. 3181
Ph: 03 9521 3297