

Ageing with dignity

Older persons should be able to live in dignity and security and be free of exploitation and physical or mental abuse.

Older persons should be treated fairly regardless of age, gender, racial or ethnic background, disability or other status, and be valued independently of their economic contribution.¹

- 3.1 Evidence to the Committee raised issues around people's fears of losing control of their lives – of no longer being able to maintain their sense of personal dignity. The Committee also heard about the ways in which families, communities and governments may contribute to such fears, or respond to them.
- 3.2 The issues put before the Committee are complex and sensitive. They range from the practice and impacts of discrimination on the basis of age, to the personal, ethical, moral and legal aspects of end of life issues. Facing these issues can increase older people's fears of losing their dignity and result in distress for families, carers and professionals providing aged care and health services. It also provokes community and legal debate about who has the right to make decisions on behalf of those older people who can no longer make their own decisions.
- 3.3 This chapter first looks at the community and professional attitudes held about ageing and older people and the discrimination directed at older people which, in their more extreme forms, constitute elder abuse. Issues raised about age discrimination, safety in the

1 United Nations Principles for Older Persons 1999, viewed 24/05/2004, <<http://www.un.org/esa/socdev/iyop/iyoppop>>. Also cited in Older Women's Network (Australia) Inc, sub 58, p 21; Australian Medical Association Ltd, sub 86, p 11.

community and elder abuse are then discussed. Finally, evidence regarding the practical steps people can take to protect their assets, their person, and respect of their wishes is presented.

Are attitudes to ageing changing?

I teach speech pathology students, and every semester I have about 100 speech pathology students sitting in front of me. I start off by putting the word 'ageing' on the board and I ask them to freely associate with the word ageing. Every word is negative: wrinkles, grey, senile, forgetful – there are no positive words that come through their mouths.

... These are speech pathology graduates who are going to be in management positions and who will be employing people...²

- 3.4 Some positive indications of changes in attitudes to ageing and older people were included in the previous chapter on 'Age friendly communities' among others, the joy of children listening to living history stories from a district pioneer; and the realisation that seniors are actually part of society.
- 3.5 But the Committee also heard that the attitudes of speech pathology graduates referred to above are typical of those still held by many Australians and many health aged care professionals. Negative attitudes to older people and reluctance to address the ageing of the population persist among individuals of all ages, within organisations and within governments.
- 3.6 The issue of attitudes is broad, encompassing attitudes to the ageing process, attitudes to the older population, attitudes to older individuals as well as individuals' attitudes to their own ageing.
- 3.7 Only some small progress appears to have been made since research on community attitudes to ageing and older people was undertaken as part of the development of the *National Strategy for an Ageing Australia*. That research showed:
- the public perception of older people is fairly negative;
 - older people by and large are felt to lack value and potential;
 - media portrayal is often unfair and unkind to older people; and

2 Worrall L, transcript 20/05/2003, p 507.

- the expectations of the future for older people (and for younger people when they become older) are relatively bleak and pessimistic.³

3.8 These impressions of older people by all ages of Australians have been diagrammatically represented as follows:

Figure 3.1: Impressions of older people, by all ages of Australians



Source: <http://www.seniors.gov.au/nacoa/attitudes.htm>

- 3.9 The research for the development of the *National Strategy* also emphasised that images of ageing are presented as a matter of extremes, with older people being portrayed as extremely active or as dementia sufferers (frail and mentally fading). In reality, neither is a true picture of most older Australians.⁴
- 3.10 Evidence to the Committee made clear that there is continuing concern about the impacts of negative attitudes on the Australian community and on older people's desire to maintain their sense of personal control and dignity.
- 3.11 Dr Silcox, of the City of Nedlands WA, was concerned that in the face of strident expressions of inter-generational envy, older people found it difficult to put forward their views:

...it was not an environment that seniors felt comfortable in to stand up and say: this is what I want and these are the reasons I want it, when they have an aggressive young person standing there demanding: 'They have had the luxury of

3 Di Marzio W, *A research report on community attitudes towards ageing and older people*, 1999, viewed 27/05/2004, <<http://www.seniors.gov.au/nacoa/attitudes.htm>>.

4 Di Marzio W, *A research report on community attitudes towards ageing and older people*, 1999, viewed 27/05/2004, <<http://www.seniors.gov.au/nacoa/attitudes.htm>>.

bringing their children up on quarter acre blocks. We should have the same luxury.⁵

- 3.12 That negative attitudes can erode older people's sense of worth, replacing it with fear of being a burden was emphasised by the Social Issues Executive of the Anglican Diocese of Sydney:

... Perceptions that aging is an illness or that people reach a 'use by date' are unhelpful. ... the elderly are fearful of becoming a 'burden' on those around them. This is a sad indication of the unhealthy attitudes held about what makes life worthwhile.⁶

- 3.13 Negative attitudes may in part arise from lack of understanding and fear of ageing. Even so, they can further diminish the dignity and worth of older people:

Ageism ... has generated and reinforced fear and denigration of the aging process, and has given rise to negative stereotypes and presumptions regarding the incompetence and dependence of older [people]. ...the dominant stereotypes which imply that ageing equals debility, have largely eroded the images of wisdom, power, benevolence and respect which were once associated with elders.⁷

- 3.14 In contrast, Mrs Kunoth-Monks, told the Committee of the respect in which her community elders are held:

... We have a group of elders who to us are priceless. I am happy to say I am included as one of them. These elders hold together the age-old songs, the land and the ceremonies through their continuing knowledge, which was handed to them verbally and not in written form ...⁸

- 3.15 Despite negative community attitudes to ageing, the research for the development of the *National Strategy for an Ageing Australia* found that most older individuals have a positive attitude to their own ageing. This finding was echoed in evidence to the Committee.⁹

- 3.16 Professor Andrews reminded the Committee that there is a long way until there is a general shift in attitudes:

5 Silcox S, transcript, 29/03/2003, p 426.

6 Social Issues Executive, Anglican Diocese of Sydney, sub 67, pp 3-4; see also Morrison R, sub 189, p 4.

7 The Aged-care Rights Service, sub 87, p 10; see also Lgov, sub 89, p 4.

8 Kunoth-Monks R, transcript 2/02/2004, p 734.

9 Di Marzio W, *A research report on community attitudes towards ageing and older people*, 1999, viewed 27/05/2004, <<http://www.seniors.gov.au/nacoa/attitudes.htm>>; Jones D, transcript 24/02/2004; Holmes B, transcript 4/07/2003, p 650.

...The National Strategy for an Ageing Australia is a step in the right direction – no doubt about that – but it is more about words than action, and we need to explore steps that can be taken in terms of shifting public perceptions and understanding.¹⁰

- 3.17 While negative attitudes continue, there is a danger that older people will be treated like second-class citizens. The worse manifestations of negative attitudes give rise to discrimination and elder abuse.
- 3.18 The Centre for Ageing and Pastoral Studies referred the Committee to research which reported that fear and no longer being in control are major issues for many older people. People want to have control of their life, including their end of life:
- We have now added years of life, but for numbers of older people, these added years may have no meaning. Fear of future vulnerability and no longer being in control were major issues for many of the independent living older people interviewed.¹¹
- 3.19 Concerns about loss of control may be triggered or increased by acts of discrimination just because a person is getting older.
- 3.20 As people age and become more dependent on others, they may have less control over their destiny and are more open to being taken advantage of, or becoming the victim of abuse by others. It should be borne in mind however that Australian and overseas studies, indicate older people are less likely to be a victim of crime (robbery, theft, fraud, rape and homicide), than are younger people.¹² Even so older people's concerns and their fear of losing control over their personal dignity are real.
- 3.21 Families and the community have a responsibility to support older people's desire for dignity. As a society, Australia is only beginning to grapple with these issues. As Dr Mahajani stated to the Committee:
- We have postponed dealing with end of life issues as being too difficult but increasingly healthy elders are coming forth wanting to ask questions and [seek] information.¹³
- 3.22 To date, public debate has often focussed on euthanasia and this was raised with the Committee (see below). However, the issues are much

10 Andrews Prof, transcript, 28/04/2003, p 357.

11 Centre for Ageing and Pastoral Studies, sub 167, p 2.

12 Noble J, transcript 2/02/2004, p 711; Australian Institute of Criminology 1996, James M, 'Crime and older people', paper presented at conference 23-25 February 1993, p 1.

13 Mahajani S, sub 181, p 3.

broader and more complex. These include assisting older people to make known their preferences for the safe handling of their assets and affairs and for their own care as they become frail. They also include supporting and protecting older people against abuse of their wishes and directions, and against physical, sexual, financial, psychological/emotional, social and neglect.¹⁴

Age discrimination

- 3.23 The Committee heard evidence of age discrimination including difficulties that mature aged people experienced in finding employment and the age-restrictions imposed by some insurance companies. The U3A reported a 'relatively new' age restriction by insurance companies on personal accident policies for those 85 and over. This means that over 85s involved in U3A activities – activities which 'cannot be classified as high risk' – are not covered for injury or disability and, if problems do arise, U3A organisations could be exposed to substantial compensation claims.¹⁵
- 3.24 As a nation, action had already been taken to discourage age discrimination through legislation.
- 3.25 Age discrimination laws were introduced by each State and Territory by 1998. In an employment context the federal Workplace Relations Act 1996 also specifies anti-age discrimination objectives and provisions. However the coverage of the state and territory legislation did not extend to Commonwealth laws, employment in the Commonwealth public sector or acts done under Commonwealth laws and programs.¹⁶ To cover these gaps the Australian Government passed the Age Discrimination Act No. 68 of 2004, which was assented to 22 June 2004. This is used to ensure a person is treated fairly in areas such as employment, education, access to goods and services as well as the administration of Commonwealth laws and programs.

14 Aged Rights Advocacy Service, 'Preventing abuse of older people', viewed 23/08/2004, <<http://www.sa.agedrights.asn.au/prevent/forms.html>>.

15 Polich T, sub 43, p 1; Department of Family and Community Services, sub 156, pp 11-14; Venner R, sub 168, pp 1-3; University of the Third Age, City of Melbourne Inc, sub 44, p 7-8.

16 Explanatory memorandum for Age Discrimination ACT 2003, p 10.

The legislation means that, for the first time, there will be an enforceable remedy in federal law for people who suffer discrimination on the basis of their age.¹⁷

- 3.26 The Australian Age Discrimination Act 2004, is not a substitute for State anti-age discrimination laws or a replacement for the federal workplace law.
- 3.27 Recent court cases indicate that there is still room for improvement despite the legislative protections.

Safety in the community

- 3.28 The Committee received evidence about community initiatives addressing older peoples' fears about safety in their homes and communities. Some of these initiatives are equally relevant to making homes more age-friendly (see further, Chapter 4, Housing and transport).
- 3.29 The Institute of Chartered Accountants in Australia (ICAA) advised the Committee of a free home safety inspection service for older people, facilitated through their ElderCare service in collaboration with the Victorian Government and Archicentre. Home inspections by architects have identified hazards that could cause falls or other injuries:
- ...Many homes inspected by Archicentre architects had slip and trip hazards, including slippery steps, poorly lit steps, rugs on slippery floors, moss on outside steps and paths which became like ice when damp.¹⁸
- 3.30 Mrs Noble mentioned a local council in Darwin that makes early morning calls to people who might be at risk. She also expressed concern about initiatives intended to improve safety that prove to have unintended consequences. Older people were encouraged to install deadlocks. However, if something goes wrong the deadlocks mean that nobody can get in to give assistance, so now a spare key arrangement is being put in place.¹⁹
- 3.31 As a result of the Community Liaison and Advisory Safety Project (CLASP), older residents in the ACT have free access to a home Safety

17 Human Rights and Equal Opportunity Commission, 'Human Rights Commission welcomes age discrimination laws', Media release, 17/06/2004, p 1.

18 Institute of Chartered Accountants in Australia, sub 30, p 9.

19 Noble J, transcript 2/02/2004, pp 706, 711.

and Security Review which provides comprehensive personal advice on crime prevention, improved security, fire safety and personal safety. The Safety and Security Review team consists of officers from the Australian Federal Police, the ACT Fire Brigade and the ACT Ambulance Service. The Review is free and people on Centrelink Aged Pensions may access vouchers to help cover the costs of changes needed and for the installation of smoke alarms. The Community Liaison and Advisory Safety Project, instigated by the Council of the Ageing (ACT), also produced a handbook on home safety and security which covers aspects of general safety, medical safety, fire safety, and security.²⁰

- 3.32 Organisations such as Neighbourhood Watch, and the Community Safety Council in Tasmania (in conjunction with governments) also play a role by promoting practical advice designed to enable older people to live confidently and safely. *Confident Living for Older Victorians*, for example, states that:

Confident living is a state of mind. It is an attitude which recognises possible threats but encourages older people to fully participate in their personal life and their community. ...

Responsibilities change with age. By planning and making the most of community resources, [age] can be a time of enjoyment, company and new experiences. ...²¹

- 3.33 One source of information and practical advice which takes into account the needs of people from culturally and linguistically diverse backgrounds is the New South Wales Department of Health website. Information sheets (in 13 or more languages) cover a range of topics including the prevention of elder abuse, strategies to stop fear limiting life, and dementia.²²
- 3.34 The Committee commends initiatives such as these, and is aware that they are just a few of many making a difference in the community.

20 Home Safety and Security Handbook, viewed 12/08/2004, <http://www.cota-act.org.au/safety_handbooks/clasp_handbook/clasp_handbook_toc.htm>. See also, Flint P, Council on the Ageing, 'The CLASP partnership: we can all benefit', paper presented at the conference Partnerships in Crime Prevention, convened jointly by the Australian Institute of Criminology and the National Campaign Against Violence and Crime, Hobart, 25-27 February 1998.

21 'Confident living for older Victorians', 2000, viewed 10/08/2004, <<http://www.neighbourhoodwatch.com.au/>>. See also, eg, 'Safe and secure living: your personal handbook', viewed 10/08/2004, <<http://www.police.tas.gov.au/police/police2001.nsf/W/Resources/CCAS-56TUKG/?Open>>.

22 New South Wales Department of Health, viewed 23/04/2004, <<http://www.mhcs.health.nsw.gov.au/health-public-affairs/mhcs/publications/3435.html>>.

Elder abuse

The other thing which is really a neglected problem in our area is abuse of the elderly. We find it so often. It burns out the people like us who are looking after the elderly; it burns out the other people who are identifying the abuse. But there is nothing mandatory we can do about abuse of the elderly. We just have to sit on it and do nothing a lot of the time.²³

3.35 Elder abuse has been defined as:

...wilful or unintentional harm caused to a senior by another person with whom they have a relationship implying trust.²⁴

...any pattern of behaviour by a person or persons that results in physical or psychological harm to an older person.²⁵

3.36 Elder abuse is not confined to particular groups: it may affect all classes, races and cultures, and both men and women. While the frail and dependent may be affected, the physically and mentally fit may also be abused. Elder abuse can take place in the family home or in residential care. Carers can be stressed by the responsibility and difficulty of coping with the physical, emotional and economic costs of caring. Sometimes abuse may be a continuation of domestic violence.²⁶

3.37 Harm may include physical, sexual, and emotional mistreatment, financial exploitation, or neglect of basic needs (see Table 3.1).²⁷ Neglect can include inadequately assisting with personal hygiene, food, clothing, shelter, medical care, health and safety hazards, and failing to prevent malnutrition.²⁸

23 Mahajani S, transcript 3/02/2004, p 790.

24 The Aged-care Rights Service, sub 87, p 15 (adapted from Hailstones, 1992); COTA (NT) and National Seniors, sub 178, National Policy Document 2003, p 26.

25 Australian Institute of Criminology 1996, Roberts J, 'An analysis of situations of elder abuse and neglect in Brisbane, and other Australian studies', p 3.

26 Australian Institute of Criminology 1996, Kingsley B and Johnson S, 'Elder abuse: the ethical dilemma', paper presented at Conference 23-25 February 1993, pp 7-8.

27 The Aged-care Rights Service, sub 87, p 15; COTA (NT) and National Seniors, sub 178, National Policy Document 2003, p 26. See also Australian Medical Association (AMA), sub 86, p 11.

28 Combined Pensioners and Superannuants Association of NSW Inc, Policy Discussion Paper, No 8, May 2002, p 2.

Table 3.1: Forms of elder abuse

Abuse Forms	Behaviour	
Financial	<ul style="list-style-type: none"> • Forgery • Reluctance to pay for accounts/debts • Unwillingness to bring items in for the older person • Forced will changes 	<ul style="list-style-type: none"> • Embezzlement • Withholding funds from the older person • Enduring Power of Attorney's refusal to provide info about financial affairs
Neglect	<ul style="list-style-type: none"> • Not providing adequate clothing and personal items • Unwillingness to allow adequate medical or dental care or personal care 	<ul style="list-style-type: none"> • Over, under or inappropriate use of medication • Refusal to permit other people to provide adequate care, eg food or drinks
Social	<ul style="list-style-type: none"> • Includes being discouraged or stopped from seeing other people eg family or friends 	<ul style="list-style-type: none"> • Prevented from joining in any activities in or outside the residential care facility
Physical	<ul style="list-style-type: none"> • Hitting • Burning • Pushing • Punching • Slapping • Forced confinement in room, bed or chair 	<ul style="list-style-type: none"> • Biting • Arm twisting • Cutting • Hair pulling • Pinching
Sexual	<ul style="list-style-type: none"> • Rape • Indecent assault 	<ul style="list-style-type: none"> • Sexual harassment • Sexual interference
Psychological/ Emotional	<ul style="list-style-type: none"> • Humiliation • Blaming • Intimidation • Insults • Treating the older person like a child • Threats of punishment or abandonment 	<ul style="list-style-type: none"> • Name calling • Silence • Shouting • Emotional blackmail • Threats of restricting access to others • Witnessing family arguments

Source: www.Agedrights.sa.asn.au/prevent/forms.htm

3.38 Enforced isolation is a less obvious example of abuse of older people. Over the next 40 years, increasing numbers of older people are likely to live alone, or to be isolated and lonely because of inability to drive, being fearful of going out at night, or because their families are 'too busy' to help them maintain social activities. Such social isolation often leads to declining health.²⁹

3.39 Recent research identified practices which 'at best place the older person at risk of financial abuse and at worst constitute financial abuse':

²⁹ Centre for Ageing and Pastoral Studies, sub 167, p 6; Country Women's Association of Australia, sub 121, p 3; Wellbeing of Older Men, Hunter Retirement Living/UnitingCare, sub 189, p 4.

- inadequate or no accountability procedures particularly for cash payments;
- appointing attorneys who may lack the required personal or financial skills to take on the responsibility, or who may be subject to influence by a spouse or other significant person whom the donor feels hesitant about;
- asset managers taking over full control – supposedly to make it easier for the older person – but effectively denying the level of control over money sought by the older person;
- asset managers being overly generous with an older person’s money – for example, by using a gifting option excessively;
- fraudulent use of authority such as falsifying a signature or continuing to use an Enduring Power of Attorney after the donor has died or revoked the document in order to get important paperwork done while in a transition period.³⁰

Community action against elder abuse

- 3.40 The Committee heard of preventive, community support and legal initiatives to assist older people to maintain control over their life and affairs.
- 3.41 Dr Mahajani (quoted above) expressed frustration at the absence of clear protocols in the Northern Territory for handling elder abuse. Dr Richardson suggested that if mandatory reporting of elder abuse was introduced, this could be a way of collecting research data.³¹ There are no mandatory reporting laws for elder abuse in Australia.³² The Legislative Assembly inquiry into Elder Abuse in the ACT concluded that mandatory reporting may deprive older people of control over their destinies and making their own decisions about their futures, and represents an invasion of privacy.³³
- 3.42 Prevention, rather than reporting, was suggested to the Committee as a more powerful tool. Prevention should focus on the concerns of

30 Setterlund D et al, 'Financial abuse within families: views from family members and professionals', p 2. Paper presented to the 8th Australian Institute of Family Studies Conference, Melbourne, 12-14 February 2003.

31 Richardson S, transcript 7/03/2003, p 222.

32 Aged Rights Advocacy Service, Preventing Abuse of Older People, viewed 23/08/2004, <http://www.sa.agedrights.asn.au/prevent/law_mandatory.html>

33 Legislative Assembly for the Australian Capital Territory, Standing Committee on Health and Community Care, Report No 11, *Elder Abuse in the ACT*, August 2001, p 40; Kurrle and Sadler cited in Weeks, Elizabeth and Sadler, Paul (1997 'Elder Abuse and Dementia' a discussion paper for the NSW Advisory Committee on Abuse of Older Persons, p 15.

older people and their caregivers, and what can be done to support and educate carers in their role. The ACT Government favours a broad based community education campaign to increase general public awareness, establishing education and training standards for workers in aged care institutions, and implementing a campaign to educate professionals working in the field of elder abuse or those likely to have contact with victims. As part of this approach, an Elder Abuse Prevention Information Line has recently been launched. The ACT Government is also committed to consulting with the ACT Division of General Practice to develop strategies to address elder abuse issues.³⁴

- 3.43 A training kit has already been produced by the NSW Ageing and Disability Department, *Dealing with Elder Abuse of Clients and their Carers*, which the ACT Legislative Assembly could be easily adaptable to another jurisdiction. Such initiatives are encouraging to the Committee and should be shared across the States.³⁵
- 3.44 The Committee notes that consideration of addressing elder abuse is a responsibility of the Positive Ageing Taskforce (a subcommittee of the Community Services Ministers Advisory Council), and a part of the implementation of the Commonwealth, State and Territory Strategy on Health Ageing. The Positive Ageing Taskforce is yet to provide guidance on how this issue might be tackled.

Guardianship

- 3.45 One way of assisting and protecting older people who are being abused, exploited or losing control of their mental capacities, is to seek the appointment of a guardian.
- 3.46 Each State and Territory has a Guardianship Board or Tribunal which can appoint a guardian or administrator. Major advocacy groups such as Carers Australia and Alzheimer's Australia provide information about the roles of these bodies.³⁶

34 Legislative Assembly for the ACT, Standing Committee on Health and Community Care, Report No 11, *Elder Abuse in the ACT*, August 2001, p 37.

35 Legislative Assembly for the ACT, Standing Committee on Health and Community Care, Report No 11, *Elder Abuse in the ACT*, August 2001, pp 37-38; ACT Government Response to the Standing Committee on Health and Community Care, Report No 11, *Elder Abuse in the ACT*, 26/09/2002, pp 15-16; *Canberra Times*, 21/06/2004, p 3. City of Joondalup Elder Protection Network website, launched 24/10/2001 by Western Australia Minister for Seniors Interests, Media Release, 13/09/2001.

36 The Aged-care Rights Service, sub 87, p 14.

- 3.47 However, evidence from Broken Hill and the Northern Territory indicated that arrangements on the ground may not always enable timely protection:
- ...They are very keen that the patients' rights are very carefully managed. We think the average wait for a guardianship hearing is about one to two years. An urgent guardianship application gets done in about two weeks. I think there is a very small office with just a few people and they have something like 300 guardianship orders at any one time³⁷
- 3.48 Ms Jones advised the Committee that the processes involved can put aged care workers in remote areas at risk:
- ... we have remote workers in remote communities having to put their name on application forms to the Guardianship Tribunal and then the tribunal or the person who is reporting it having to hand these documents over to the alleged abuser with their name and contact details on them. We are putting our staff at risk.³⁸
- 3.49 Dr Lowe emphasised the need for improvement of the Northern Territory arrangements and standardisation and coordination of the various arrangements across the States: '...I would like to plead that we get some Commonwealth standardisation of these, as they are better done in other places'.³⁹
- 3.50 In this respect, the Committee notes the role of the Australian Guardianship and Administration Committee (AGAC) which provides a national forum for all relevant state and territory agencies associated with protection through guardianship and administration. Major functions of AGAC include developing consistency and uniformity, a collaborative focus and consistency of nomenclature in relation to guardianship and administration.⁴⁰
- 3.51 Recent work has focused on interstate recognition of orders of tribunals, interstate recognition of enduring powers of attorney (financial) and interstate recognition of enduring powers of guardianship. The Committee notes that, on the basis of the status

37 Lowe M, transcript 3/02/2004, p 793. See also, Lowe M, transcript 3/02/2004, pp 788, 795; Sneesby K and Burfoot C, transcript 19/05/2003, p 475.

38 Jones D, transcript 24/02/2004, p 869.

39 Lowe M, transcript 3/02/2004, pp 788, 793.

40 Australian Guardianship and Administration Committee, sub 194, pp 1-2 and attached status reports at April 2004, re interstate recognition of Enduring Powers of Attorney (Financial) and Enduring Powers of Guardianship.

reports provided by AGAC (see Box/ Appendix), while encouraging progress is being made there is still much work to be done to achieve cross-jurisdictional consistency and uniformity in relation these matters.⁴¹

Planning for end of life issues

There is a wish volunteered by almost all patients whom I meet in the course of my medical practice, regardless of their intellectual or social background, that they want to have control of their life, and implicitly, their end of life. Most have not thought through the practicalities of how this can be achieved for themselves or their family. On the contrary, there seems to be a view that unnecessary suffering or prolongation of life is due to some medicolegal requirement that if there is something which can be done to maintain life, then it has to be done.⁴²

3.52 This statement by Dr Glover raised for the Committee a complex set of medical, ethical and legal issues around the concepts of 'dying with dignity', 'voluntary euthanasia' and/or 'right to die'. Other evidence also stressed the need for older people to plan for end of life and to make known in advance their preferences for the safe handling of their assets, affairs and their own care as should their capacity to make their own decisions be diminished by dementia or other causes.

3.53 As stated by Dr Mahajani (above) thinking about, and planning for, end of life issues it too often postponed as being 'too difficult'. In part this is because there is a lack of understanding about the family, medical and legal matters that should be planned for, and about the ways in which older people can plan to protect their wishes.

3.54 Mrs Teltscher stated that:

The issue of the rights of aged patients to refuse treatment will become more important as an ageing population considers [its] future 'style of dying'. Many may not wish to spend years in a nursing home, doubly incontinent, totally dependent on others for their feeding and toileting, with no physical or mental capacity.⁴³

41 Australian Guardianship and Administration Committee, sub 194, pp 2-3.

42 Glover A, sub 5, p 2.

43 Teltscher B, sub 27, p 1. See also, Rey P, sub 62, p 1; Voluntary Euthanasia Society of Victoria Inc, sub 22, p 5; Kearney J, sub 34, p 1.

- 3.55 Both Dr Glover and Mrs Teltscher drew the Committee's attention to the *Medical Treatment Act 1988* (Vic), and the fact that many health professionals do not understand patient's rights under its provisions, or disregard them. The Act allows a patient (or legally appointed agent) to refuse treatment or interventions which the patient considers no longer appropriate or beneficial. A guardian can refuse medical treatment on behalf of a patient, but cannot refuse palliative care. Where a refusal of treatment certificate is in place, medical practitioners and persons acting under the direction of a medical practitioner must comply. The Act protects medical practitioners and people working under their direction who comply with refusal of treatment certificates.⁴⁴
- 3.56 In addition to Victoria, medical treatment legislation is in place in South Australia and the Northern Territory. Legislation is being considered by the Western Australian Government. Some states have both medical treatment legislation and enduring powers of guardianship provisions which potentially both cover end of life decision making around personal care.⁴⁵
- 3.57 The Committee was urged to recommend that patients and health workers in all jurisdictions be given protection by:
- [changing] the Federal and State laws so that medical and nursing professionals who assist a mentally competent person to implement a well-documented decision to end their life, are not legally or professionally compromised.⁴⁶
- 3.58 In contrast, the Social Issues Executive of the Anglican Diocese of Sydney argued that euthanasia 'should continue to be outlawed in Australia'; instead, there should be increased resources for palliative care.⁴⁷ Although legislation differs across jurisdictions, euthanasia is a criminal offence throughout Australia.
- 3.59 The contrasting evidence put to the Committee indicated strong beliefs about who should have the right to decide whether older people should have the right to make their own end of life decisions.
- 3.60 The Committee is concerned that there appears to be wide-spread confusion about end of life care options, leading to inadequate and inappropriate treatment and diminished trust in arrangements to

44 Glover A, sub 8, p 2; Teltscher B, sub 27, p 1; AMA (Vic), *The Medical Treatment Act 1988*, viewed 12/08/2004, <<http://www.amavic.com.au/downloads/dec03MTA.rtf>>.

45 Australian Guardianship and Administration Committee, sub 194, p 3.

46 Glover A, sub 5, p 3.

47 Anglican Diocese of Sydney, Social Issues Executive, sub 67, p 4. See also, Kearney J, sub 34, p 1; Right to Life Australia Inc, sub 36, p 1; Mirabella C, sub 41, p 1.

protect patients' rights to make end of life decisions. This confusion extends to palliative care. Further, where medical treatment legislation is in place there is ignorance among medical practitioners of what the legislation entails.⁴⁸

- 3.61 In May 2003, the Victorian Supreme Court was asked to determine whether artificial feeding and hydration (percutaneous endoscopic gastronomy or PEG) via a tube is medical treatment or palliative care.
- 3.62 The Court decided that PEG feeding is 'medical treatment' within the meaning of the *Medical Treatment Act 1988* (Vic), not 'palliative care'. The decision 'carefully balanced the competing moral and ethical values of the sanctity of life and the right to self-determination and dignity'. It helps to clarify the intent of the legislation and give doctors and other health professionals legal certainty with regard to the protection it provides.⁴⁹
- 3.63 As the population ages, more individuals and families will face the practical and moral dilemmas considered by the Victorian Supreme Court. Dr Glover, among others, stressed the need for widespread, objective public education and debate by all age levels, about end of life issues and decision making:
- ...education and information should be encouraged and actively promoted by government as occurs with other major public health issues. It should not be left to editorial decisions by media where the emphasis is inevitably on dramatic crisis situations.⁵⁰
- 3.64 In this respect, the Institute of Chartered Accountants in Australia drew the Committee's attention to developments in Elder Law at the University of Western Sydney.⁵¹ The Centre for Elder Law contributes to the advancement and awareness of the legal rights and responsibilities of older people in Australia through undertaking sponsored research, contributing to discussion, debate and

48 Cartwright C, 'End-of-life decision-making: practical and ethical issues for health professionals', *Australasian Journal on Ageing*, vol. 19-2, May 2000, p ??;

49 AMA (Vic), 'The Medical Treatment Act 1988', viewed 12/08/2004, <<http://www.amavic.com.au/downloads/dec03MTA.rtf>>; Phillip Fox, Health e-Update 29 May 2003, 'Does artificial feeding constitute medical treatment or palliative care - the Victorian Supreme Court makes a declaration'; Victorian Government Health Information, 'Supreme Court decision on the Medical Treatment Act', viewed 12/08/2004, <<http://www.health.vic.gov.au/mta/decision.htm>>.

50 Glover A, sub 5, p 3. See also, Mahajani S, transcript 3/03/2004, p 790; Voluntary Euthanasia Society of Victoria Inc, sub 22, p 5; Trustee Corporations Association of Australia, sub 106, p 5; AMA, sub 86, p 18.

51 Institute of Chartered Accountants in Australia, sub 30, p 8. See also, ??????

- publications, and developing and delivering programs for community and professional education and training, including for aged care workers. The Centre publishes a new journal, the *Elder Law Review*.⁵²
- 3.65 The Committee considers that community education is essential to enable better understanding of the issues and the avenues available for safeguarding end of life decisions regarding both care and financial matters. Developments such as the Centre for Elder Law and the *Elder Law Review* will help focus much-needed attention on defining and protecting the rights of older people.
- 3.66 Practical advice on planning for end of life issues was offered to the Committee by, for example, the Trustee Corporations Association of Australia, including:
- making a will clearly setting out intentions with respect to one's estate; and
 - creating an enduring power of attorney to enable a third party to make financial (and possibly other) decisions on behalf of a person who is no longer able to manage their own affairs.⁵³
- 3.67 The Committee notes the complex range of the legal instruments that may be used to plan end of life affairs including: will, living will, power of attorney, enduring power of attorney, anticipatory direction, and advance directive. Further, for example, there are several types of powers of attorney and in Victoria only the enduring power of attorney (medical treatment) allows an agent to make decisions about medical treatment.⁵⁴ Alzheimer's Australia points out that while an advance directive allows specification of future treatment, requirements (the right form; the witnesses specified etc) are substantially different across the states and territories. In addition they may also be referred to as 'advanced health directives', 'advanced health care directives', 'anticipatory grants' or 'anticipatory directions'.⁵⁵
- 3.68 The Trustee Corporations Association of Australia suggested to the Committee ways in which wills and enduring powers of attorney

52 University of Western Sydney, Elder Law at USW, viewed 14/08/2004, <<http://www.uws.edu.au/about/acadorg/clb/sl/research/elderlaw>>. The *Elder Law Review*, may be accessed online at this address.

53 Trustee Corporations Association of Australia, sub 106, p 2.

54 AMA (Vic), 'The Medical Treatment Act 1988', viewed 12/08/2004, <<http://www.amavic.com.au/downloads/dec03MTA.rtf>>.

55 Alzheimer's Australia, Legal planning and dementia, glossary, viewed 14/08/2004, <<http://www.alzheimers.org.au/content.cfm?topicid=263>>.

could be improved and safeguards strengthened. Overall, the Association proposed that:

- relevant legislation should be unified across Australia, to overcome the difficulties that frequently arise with wills and powers of attorney outside the region in which they are drawn, ... and
- in situations where elderly people are unable to look after themselves and a Court appoints a financial manager and/or a personal carer, the body charged with reviewing their performance should be independent of those parties.⁵⁶

Summing up

- 3.69 The Committee considers that there is still much to be done before negative attitudes and age discrimination are replaced by attitudes that accept the universality of the ageing process and value and are supportive of older people. Old stereotypes may be being shaken but many are yet to tumble. Too frequently references to older people being a 'burden', the 'problem', or 'bed blockers' are still heard.
- 3.70 Successfully addressing the ageing of Australia's population is an ongoing task. In large part success will depend on changing the mindsets of the nation and of individuals. Even so there are some actions that should be taken immediately.
- 3.71 The Australian Government, State and Territory Governments, and a growing number of local governments have developed ageing strategies. The Committee concludes that these strategies should be evolving documents, reflecting community engagement with the issues and responding to debate on the values the community considers should underpin them.
- 3.72 A vision of the sort of society Australians want in the future is lacking in the *National Strategy for an Ageing Australia* and should be included in further development of the Strategy.
- 3.73 The Committee concludes that much greater effort must be put into developing key messages and information in such ways as to engage people of all ages, of different backgrounds, and relevant to the contexts in which people are living and working. The work being undertaken by Treasury is a vital component of the Government's
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56 Trustee Corporations Association of Australia, sub 106, p 2. See also, ACT Government Response to Standing Committee on Health and Community Care, Report No 11, *Elder Abuse in the ACT*, 26/09/2002, p 11, which identifies similar problems and responses.

overall strategic approach. However, it is perceived by many people as focussing solely on the Budget bottom line, disconnected from work being undertaken in other government departments, and perpetuating the notion that older people are a burden.

- 3.74 New approaches are needed, together with a diversity of leadership to help make these messages 'click' with more people.
- 3.75 The Committee concludes that in further developing and implementing the *National Strategy for an Ageing Australia*, the Australian Government should ensure better integration of the relationships between the social, human, fiscal and economic components and a more constant focus on the 'human faces' of ageing Australia.

Conclusion 2

- 3.76 **The Committee concludes that in further developing the *National Strategy for an Ageing Australia*, the Australian Government should include a statement of the underpinning the Strategy. In the first instance, the values would promote a basis for debate. Subsequently as a goal/vision against which further development should be tested and measured.**

The Committee concludes that in further implementing the *National Strategy for an Ageing Australia*, key messages and information must be developed in such ways as to engage people of all ages, of different backgrounds and relevant to the contexts in which people are living and working.

- 3.77 The Committee commends the initiatives being taken to make older people feel more safe in their communities and to take action against elder abuse.
- 3.78 The Committee concludes that the development of national guidance on tackling elder abuse can no longer be delayed. The Community Services Ministers' Advisory Council should direct the Positive Ageing Taskforce to give this matter high priority. In view of the fact that elder abuse is often symptomatic of wider problems, the Committee concludes and that the scope of their work should focus more broadly on ways in which older people can be assisted to maintain control over their lives and affairs.

Conclusion 3

- 3.79 **The Committee concludes that the Community Services Ministers' Advisory Council should direct the Positive Ageing Taskforce to broaden the scope of their work on elder abuse to identify and develop guidance on ways in which older people can be assisted to maintain control over their lives and affairs.**

The Committee further concludes that guidance be implemented by all State and Territory Governments to provide a consistent approach across Australia to protecting the dignity of all older Australians.

- 3.80 The Committee considers that wide-spread objective education around understanding and planning end of life decisions is essential. These are complex and sensitive issues. While many organisations are already engaged in this, their efforts are made more difficult by the plethora of legal concepts and variations across jurisdictions.
- 3.81 A concerted effort must be made to bring greater uniformity to the types of legal instruments used to plan for the full range of end of life decisions, and the administration of these. In this context the work of the Australian Guardianship and Administration Committee is noted. However, the Committee concludes that more comprehensive and urgent action is needed.

Conclusion 4

- 3.82 **The Committee concludes that the Attorney General should work with the State and Territory Attorneys General to review, streamline and unify the legal instruments used for planning end of life decisions relating to management of affairs and assets, protection from abuse and care preferences.**