Briefing note on elder abuse and dementia

[Note: while the term ‘elder abuse’ is used throughout this document, abuse may also impact on the lives of people with younger onset dementia and their families and carers. Elder abuse is the most commonly used term in research and other literature on this issue.]

Background
This note has been prepared for the special Aged Care Advisory Committee meeting on elder abuse on Tuesday 14 March 2006. The note sets out an initial Alzheimer’s Australia position on the issue of elder abuse and how it might be addressed. Further information about aspects of elder abuse is attached.

The purpose of the meeting is to ‘explore solutions to allegations of abuse in Australia’s aged care facilities’. The Minister will ask the Committee to look at a ‘broad range of remedial suggestions, including police checks on staff, the issue of mandatory reporting of suspected or actual abuse, how well the complaints scheme is working and whether improvements can be made, and whistleblower protection’.

Research indicates that victims of elder abuse are commonly people with dementia or other cognitive deficit. They, like all residents in aged care facilities, benefit from having a stable and well trained workforce. This means attracting and retaining sufficient staff members who understand about dementia and are able to provide quality dementia care that acknowledges and respects the rights and dignity of people with dementia while meeting their care needs. In the 2003 Aged Care Workforce Census, facilities reported that about 25% of their personal care assistants and nearly one in five of their nurses have to be replaced each year.
Initial AA position

At the meeting, it is proposed that Alzheimer’s Australia will take the following line. This approach will be amended and refined following consultation with consumers and other stakeholders.

i) Crimes do and will occur in residential care and should be handled appropriately. All reports of mistreatment, neglect or abuse should be investigated. Changes in behaviour of people with dementia such as withdrawal or perceived delusion should not be automatically assumed to be related to progression of their dementia.

ii) The abuse of care facility residents and the prevalence of elder abuse in the wider community result, in part, from community and staff attitudes to older people as well as inadequate recognition of the legal rights of those with cognitive deficits. Ageism needs to be confronted and legal rights protected.

iii) There is a need to review and analyse the legal issues around dementia to ensure individual rights and property are protected in the context of the Dementia as a National Health Priority including inter alia, guardianship, mental health, enduring powers of attorney, advanced directives.

iv) There is no single measure to deal with such a complex issue as elder abuse. Any new measures should be adequately resourced to assist in acceptable outcomes and good process.

v) The future capacity of the residential aged care system to adequately care for those with the most complex needs – dementia, palliative care or complex nursing needs – will be dependent on the Government’s new classification system and the way in which it is resourced.

vi) There are two approaches that the Australian Government might take to reduce the impact of elder abuse:
   • by making direct regulatory and other changes within key areas (for which they have responsibility) such as residential care; or
   • by co-operating with other Governments to improve National responses through, for example, awareness campaigns and targeted funding.

These approaches are complementary and are not exclusive. Abuse will be reduced if the sector moves towards agreed minimum staffing levels and appropriate levels of training. An increased community awareness of elder abuse will also support change in residential care.

vii) Current initiatives to address elder abuse need to be reviewed and consideration given to improving awareness and use of relevant resources by people/facilities that support older people.

Such an approach requires some realism about what might be tackled in the short-term and longer term if the task is to be manageable – particularly as some options may have application to other settings.
**Short-term options**
There is a range of initiatives that the Australian Government might introduce in the residential aged care system that would make a difference in the short-term, which should be able to be accommodated within the existing accreditation/complaints mechanisms:

- Progressively introducing **licensing** for all staff in residential care would protect residents by minimising the opportunity for employees to continue in the industry after being sacked for abusive conduct. This kind of approach would
  - be developed in conjunction with the sector
  - start with new employees
  - include police checks and training/education results
  - need to consider the cost implications eg how costs might be shared;

- Recognising that there is a division of opinion (on privacy and rights grounds) about general **mandatory reporting** of elder abuse, a priori, it needs to be made clearer to staff what their obligations are to report abuse as a protection for those with reduced capacity and who are vulnerable because they live in an institutional setting where they have lost control over much of their lives;

- Some review of **internal reporting** might be merited. Services and staff need to be very clear about
  - their duty of care
  - what should be reported and to whom
  - the need to avoid delay in reporting
  - the need for anonymity and other protection of whistle blower rights
  - the protocol that supports the process within their workplace;

- Facilities should be encouraged to **use the outcomes** of their internal reporting/complaints processes to address (perhaps through a continuous improvement process)
  - gaps in staff education/training
  - problems with recruitment approaches
  - cultural and management problems;

- Facilities should be encouraged to **involve residents and family carers** (as far as they are able) in an advisory capacity to their management/Board on elder abuse and more generally
  - partnering with family carers generally will reduce abuse;

- The Government should work with the sector to identify other approaches to improve **awareness** of elder abuse in the sector or more generally, and encourage responsiveness to resident and carer concerns.

- Identify ways in which to strengthen the **Complaints Resolution Scheme**, in particular to
  - make the Scheme more accessible for those who have ‘concerns’
  - identify preferred practice to address ‘urgent’ or ‘serious’ cases
  - promote good practice within internal reporting/complaints handling;
Longer-term approaches

- Work towards steady improvement in the level of training and education of all who work in residential care
  - this would include training on both dementia and elder abuse

- Support opportunities for cross-disciplinary training to support professionals and other workers who might encounter elder abuse cases or have a role in employment checks
  - such training would include dementia education
  - targeted staff could include Domestic Violence Helpline staff;

- Work with the sector to identify ways to strengthen Accreditation processes to support continual improvement in management and delivery of residential aged care
  - some carers propose more spot checks and less warning of inspections.

- Work with State/Territory Governments to
  - improve community awareness and understanding
  - reduce stigma and isolation particularly for people with dementia
  - harmonise legislative approaches
  - trial common approaches to prevention and remedy;

- Introduce a National approach to improve available information about elder abuse including
  - better statistics including agreement on a common definition(s)
  - targeted research into eg prevalence and incidence
  - improved sharing of research outcomes and evidence-based practice
  - funding support/identification of funding sources;

- Legal and other protection approaches should be identified/developed to protect the victims of reported abuse from real or perceived retribution and those who report alleged abuse in good faith.

- Strengthening the consumer focus of the accreditation system through improved information, greater input by consumers to the accreditation review process and enabling consumers to make better informed judgements about different aged care facilities eg quality dementia care.

Alzheimer’s Australia
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What is elder abuse?
There is no single nationally or internationally accepted definition of elder abuse. In a 2003 presentation, Susan Kurrle described elder abuse as

Any pattern of behaviour that causes physical, psychological, financial or social harm to an older person. The abuse occurs in the context of a relationship between victim and abuser.

The following description of elder abuse is largely based on a draft policy being developed to assist Alzheimer’s Australia Vic staff in identifying and assisting people affected by abuse:

- Elder abuse is a human rights issue.
- Everyone has the right to safety, appropriate information and support, and to participate in decision making, as far as they are able, on matters affecting them.
- Abuse is mistreatment, harm, neglect or exploitation, which may be physical, psychological, verbal, sexual or financial.

Abuse includes

- Exploitation, perhaps resulting from the vulnerability that dementia may bring to all those affected;
- Failure to adequately provide for the basic and other needs of a dependent person
  - everyone has the right to be treated with dignity
  - supporting quality of life should be an aim;
- An inappropriate response to the difficulties of caring for a person with dementia or other illness;
- A behavioural or psychological symptom of dementia or other illness
  - in these cases the person with dementia is the abuser;
- Domestic or family violence that may have been occurring over many years;
- Professional (including care worker) malpractice.

- Abuse may be subtle or obvious and may range from life-threatening to annoying or humiliating.
- Assault and some other forms of abuse such as theft and fraud are criminal offences.
- Less severe forms of abuse can indicate situations requiring further investigation.
• The abuse may be carried out by anyone
  - partners, friends or family members
  - care workers, medical professionals or support workers.

• Abuse may take place while living at home or in settings such as hospitals and residential facilities.

• A number of factors contribute to the occurrence of elder abuse including
  - increased dependency and social isolation of the older person
  - abuser psychopathology
  - family dynamics and family violence
  - carer stress and
  - increased emphasis on caring for older people in the community

  These factors are compounded by inadequate staffing and training.

• Younger people with dementia may be both victims of abuse and abusers
  - more needs to be done to provide appropriate services for this group.

• While it is recognised that mistreatment is also abuse, many older people may identify more readily with being mistreated rather than abused.

**How common is elder abuse?**

In a recent paper given at the Tri-State Conference, Gerry Naughtin suggested that ‘up to 130,000 older Australians a year are victims of sexual, financial and psychological abuse, mistreatment and exploitation.’ Wheelchair users over 75 and people with dementia are most at risk.

Helpline data from the Elder Abuse Prevention Unit Queensland for the two years ended 30 June 2005 suggest that psychological (42% of records) and financial (33%) were the common forms of abuse reported

**What is the relationship between dementia and elder abuse?**

Some people with dementia and their families and carers may be particularly vulnerable to elder abuse because of their individual circumstances including cognitive decline/deficit, behavioural changes and living arrangements.

People with dementia who live alone or in non-private dwellings may need particular support.

Many people with dementia retain the capacity to conduct their own lives including financial affairs, for some years after diagnosis.

People with dementia who are vulnerable merit protection.

Significant changes in the behaviour/demeanour of residents with dementia in residential care should be appropriately investigated

• change may be due to abuse or ill health eg mini stroke;
• not all change is due to progression of their dementia.
What do State Governments do to combat elder abuse?
Action has been taken in all States/Territories to address elder abuse. Approaches vary in each jurisdiction in terms of official policy, lead agencies, practical responses and legislative framework.

Currently, there is considerable activity and interest in elder abuse at the State level. Two examples follow.

The Victorian Government consulted on the current prevention and response arrangements during 2005. Recommendations included:

1. strengthened legislative and service arrangements;
2. whole of government policy framework and ongoing monitoring of implementation, evaluation and research;
3. ongoing community education;
4. statewide information and education service;
5. government/community alliance to promote prevention;
6. training and support for agencies and development of local agency protocols;
7. collaboration with services outside health and community services sectors eg Public Advocate, police, financial and legal services, etc;
8. assistance for new and existing local agency networks;
9. support for age-friendly communities and active participation of older people;
10. work with other State/Territory and Commonwealth Governments to research extent and best practice approaches;
11. consider specialised community legal services for disadvantaged older people.

The ACT Government published a Committee report on elder abuse in 2001 which, inter alia, recommended an information line, and mandatory police checks and education/training standards for aged care workers. In 2004, the ACT Office of Ageing commissioned benchmarking research into the level of awareness and understanding of elder abuse, if it is reported and how it can be addressed.