

Project undertaken by Alzheimer's Association Victoria
and La Trobe University School of Nursing
Funded by the Department of Human Services, Victoria

Overcoming Abuse of Older People with Dementia and Their Carers

A Discussion Paper

September 2000

© Department of Human Services, Alzheimer's Association Victoria and
La Trobe University, 2000

This work is copyright. Apart from any use permitted under the *Copyright Act 1968*, no part may be reproduced by any process without prior written permission from the Department of Human Services, State Government of Victoria.

La Trobe University Project Team

Susan Koch (Project manager) Rhonda Nay

Gregory Powell (research assistant) Alison Brookes (research assistant)

Reference group

Ms Marion Champion

Ms Susannah Dax, Victorian Association of Health and Extended Care

Mr Wayne Fielding

Ms Phyl Halpern, Ms Mary Rydberg and Ms Margaret Thomas, Department
of Human Services

Ms Fiona Hearn, General Manager/Director of Nursing, Royal District
Nursing Service

Ms Prue Ingram and Ms Debra Parnell, Alzheimer's Association Victoria

Ms Margaret McLaren, Office of the Public Advocate

Mrs Barbara Potter

Ms Leanne Raven, Chief Executive Officer, Nurses Board Victoria

Ms Joyce Rebeiro, Carers Association Victoria

Ms Mary Lyttle, Chief Executive Officer, Residential Care Rights

Mr Gabriel Maligeorges, Executive Director, ADEC

Mr Bill Newton, Chief Executive Officer, General Practice Divisions of
Victoria

Ms Sally Ryan, Director, Aged Services, Brotherhood of St Laurence

Mr Gerald Segal, Australian Medical Association

Ms Jill Thompson, Policy Officer, Council on the Ageing (Vic)

Contents

Executive summary	1
Aims	1
Methodology	1
Issues covered in interviews and forums	2
Conclusion	3
Utilising the protocol and planning for interventions	4
1. Process	7
Aims	7
Methodology	7
The process of gathering information	8
2. Background	8
2.1 Population ageing	8
2.2 Dementia	10
2.3 Elder abuse	10
2.4 Elder abuse and dementia	12
3. Building on the groundwork	13
3.1 Government responses	13
3.2 Existing resources and protocols	16
3.3 Summary	17
4. Findings	18
4.1 Exploring the definition of abuse	18
4.1.1 Intent	19
4.1.2 Neglect	20
4.1.3 Summary	21
4.2 Contexts and precipitators of abuse	22
4.2.1 Issues for carers	23
4.2.2 Issues for staff	24
4.2.3 Nursing staff	25
4.2.4 Medical staff	26
4.2.5 General (including non-clinical) staff	26

4.3 Abusive relationships	28
4.3.1 Decision making	29
4.3.2 Vulnerability and powerlessness	29
4.3.3 Systemic framework for abuse relationships	30
4.3.4 Summary	31
4.4 Types of abuse	32
4.4.1. Physical abuse	33
4.4.2 Psychological abuse	35
4.4.3 Spiritual issues	35
4.4.4 Financial abuse	36
4.4.5 Systemic issues	37
4.5 Mandatory reporting	38
4.6 Summary	38
5. Summary of findings	39
6. Conclusions	39
7. References	42
8. Appendices	45
8.1 Plain language statement	45
8.2 Consent form	46
8.3 Introduction to forum	47
8.4 Notice of study	48
8.5 Forum and interview participants	51

Executive summary

Dementia is often associated with a great deal of stress and vulnerability for both the person with dementia and their carers. This combination of stress and vulnerability can lead to physical or verbal aggression by either the person with dementia or their carer, which can escalate into an abusive situation. Elder abuse may be physical, psychological or financial. It may be active abuse or simply neglect of a person's basic needs. It may be perpetrated by formal or informal carers against their charges or against the carer by a person with dementia.

This paper is a discussion of the issues and management strategies associated with elder abuse as identified by participants in a series of public forums convened to investigate this significant social issue.

Aims

The aims of this project were to:

- identify and investigate the issue of elder abuse in relation to older people with dementia and their carers;
- identify and investigate the awareness of this issue among service providers and the general public; and
- provide advice on more consistent and effective responses by service providers and individuals to elder abuse, with specific focus on people with dementia.

Methodology

The project involved:

- establishment of an expert reference group;
- a comprehensive literature review;
- discussion forums with interested stakeholders in metropolitan and rural sites in Victoria to ascertain the issues surrounding abuse and to identify any related strategies that were in place, being developed or required;
- in-depth interviews with a range of individuals aimed at clarifying, broadening and deepening understandings gained from the literature and forums; and
- analysis of the data to identify current issues and to develop draft protocols for preventing or responding to abusive situations.

Issues covered in interviews and forums

The interviews and forums addressed the issues of:

- what constitutes abuse;
- how it might be recognised;
- the precipitators of abuse incidents;
- abusive relationships;
- what interventions are most effective; and
- how services may best prevent abuse by meeting the needs of older people with dementia and their carers or staff.

During the forums participants raised concerns regarding the use of the term 'abuse' because of the associated stigma. Such a label could create a particularly emotive environment where intervention could be compromised by the emotions experienced by the carer and the person with dementia. The forums were designed to discuss aspects of abuse. Consequently, issues that may have been raised as examples of stress in other situations were raised in the context of abuse in these forums.

Participants were concerned that abuse was perceived by the public to be integrally related to intent. Some participants believed intent is important but generally it was argued that abuse could occur regardless of intent. Situations involving dementia raised particular concerns about whether the behaviours were conscious and controlled or part of the disease process. The experience of the carer or staff member who is abused is influenced by their expectations of the manifestations of the disease process, previous relationships (with the person with dementia) and their role as a carer.

Data collected focuses on three types of relationships:

- carer abuse of older persons with dementia;
- staff abuse of the older persons with dementia; and
- abuse of carers and staff by older persons with dementia.

Abuse was also discussed in relation to settings in which it occurred: community and residential.

It was expressed throughout the interviews and forums that staff employed to care for people with dementia are faced with working under difficult situations. These include:

- insufficient staff numbers;
- lack of education on dementia;

- lack of professional supports;
- lack of activities for service users;
- deficiencies in current practices;
- inflexible systems; and
- poor environments.

These concerns were expressed in ways that implied that abusive or neglectful relationships were inevitable in such circumstances. Carers in the community identified as major issues:

- their vulnerability as service users;
- service staff acting on their perceptions; and
- assumptions about users' level of needs.

A number of features typified the abuse relationships described by the respondents. These were similar for both older people with dementia and those who care for them. A sense of vulnerability and lack of opportunity to negotiate their circumstances characterised the representations of both victims and perpetrators of abuse where carers were involved. Lack of understanding was central to representations of abuse perpetrated by staff. The vulnerability was recognised as seriously limiting the ability of older persons and their advocates to insist on appropriate care in formal relationships.

A variety of issues were suggested as precipitators for abuse of carers, staff or older persons. These included individual reactions to personal situations and lack of social supports and understanding to adequately support the care relationship. Little attention was given to the causes of older persons abusing carers. The frustration of living with dementia and a history of abuse in the relationship were identified as key causes of abuse towards carers.

Conclusion

Participants identified the need for prevention of abusive situations, and a preventive approach was considered to be integral to the successful reduction of abuse. In response to the issues raised in the literature review, forums and interviews, the consultants developed a draft protocol template that reflects the unique set of circumstances surrounding the abuse of a person with dementia and/or their carers. The draft protocol will be evaluated in Phase 2 of the project. The protocol template recognises that there are a number of documents dealing with the issue of elder abuse generally but these are often not applicable in situations where dementia is a factor. The protocol template seeks to supplement existing protocols by providing information and procedures for the prevention of abuse, and processes

to be followed where the unique situation involving the abuse of an older person with dementia or carers and/or staff is encountered.

Utilising the protocol and planning for interventions

A flowchart and a table (Figure 1 and Table 1 respectively, see pp.5–6) are provided as guides to how an agency or individual would utilise the protocol and plan for intervention. Figure 1 reflects the importance of a preventive approach and the need for staff and carer education about aspects of caring for someone with dementia where abuse may be apparent or potential. Table 1 provides a guide to planning for a range of scenarios and interventions. The intervention guidelines identified include specialists, emergency responses, community services, respite care, counselling, education, alternative accommodation and legislation.

Figure 1 Strategies for preventing abuse or intervening where abuse is a concern and dementia a consideration

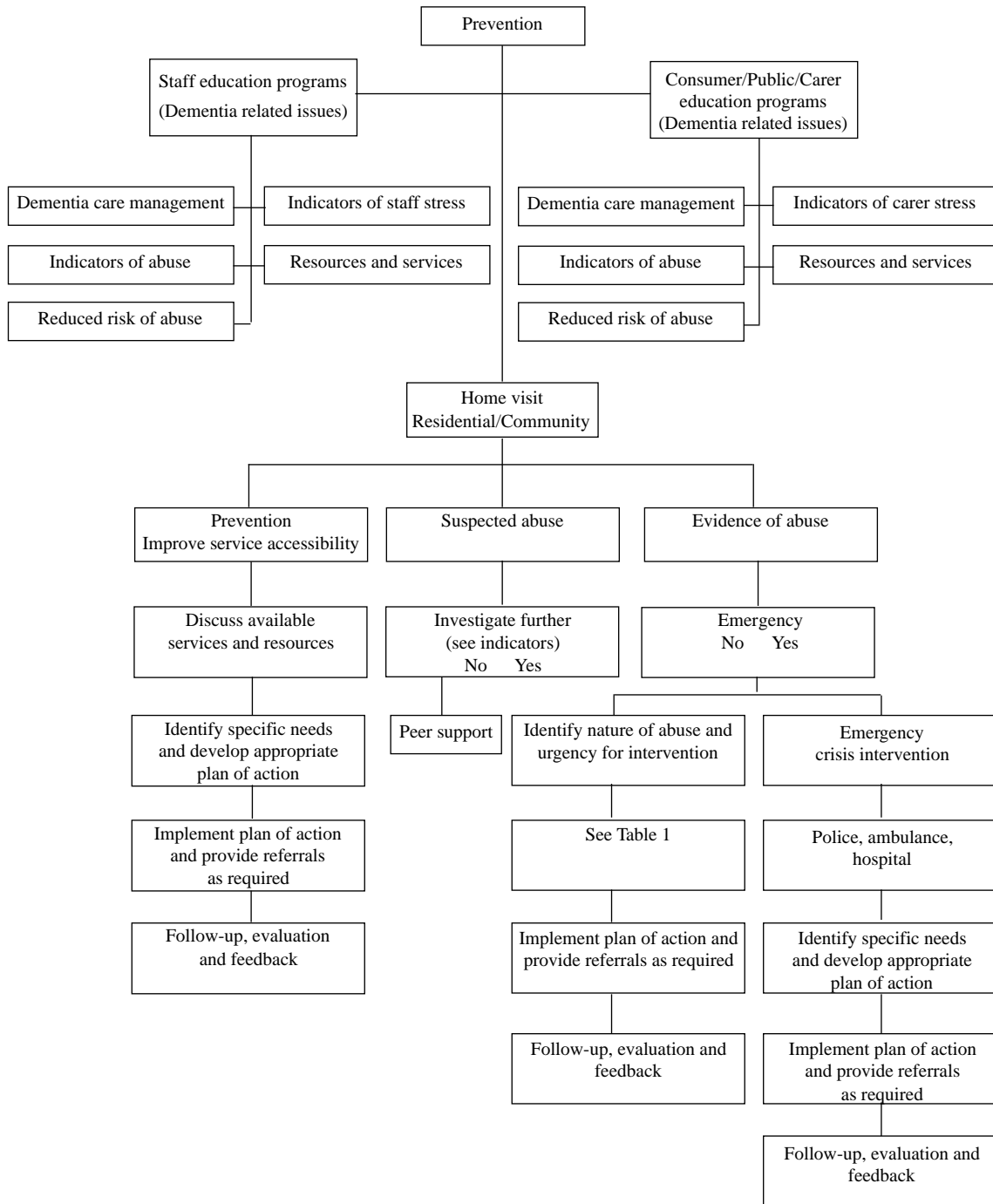


Table 1 Useful interventions

Primary factors contributing to abuse	Specialist	Emergency responses	Community services	Respite care	Counselling	Education	Alternative accommodation	Legislation
Lack of knowledge	Yes	Maybe	Maybe	Maybe	Maybe	Yes	Maybe	Maybe
Carer stress	Maybe	Maybe	Yes	Yes	Yes	Yes	Yes	Maybe
Psychopathology of the person with dementia	Yes	Maybe	Yes	Yes	Maybe	Yes	Maybe	Maybe
Level of dependency of the person with dementia	Yes	Yes	Yes	Yes	Maybe	Yes	Yes	Maybe
History of family violence: Carer retaliation	Yes	Maybe	Maybe	Maybe	Yes	Maybe	Maybe	Maybe

Legend

- **Specialists**—psychiatrists, geriatricians, psychologists, neurologists, psychogeriatricians, neuropsychologists and Cognitive, Dementia and Memory Services (CDAMS)
- **Emergency responses**—police, community policing programs, Aged Care Assessment Teams (ACATs), Aged Psychiatric Assessment and Treatment Teams (APATTs)
- **Community services**—home nursing services, community nursing, Royal District Nursing Service, Home support programs, Carers Association, Alzheimer’s Association Victoria and Carer resource centres
- **Respite**—respite services
- **Counselling**—psychologists, Carers Association, Alzheimer’s Association Victoria
- **Education**—World Wide Web, libraries, Carers Association, Alzheimer’s Association Victoria, Gerontic Nursing Professorial Unit at La Trobe University
- **Alternative accommodation**—supported residential services, hostels, nursing homes
- **Legislation**—accessing mainstream legal services, which may include applications to the Victorian Civil and Administrative Tribunal (VCAT) Guardianship List for revocation of Enduring Powers of Attorney, the Court for

1. Process

The former Victorian Department of Human Services (1999) provided funding through Alzheimer's Association Victoria to auspice a project to address issues related to dementia and elder abuse¹ raised by the Ministerial Task Force on Dementia Services in Victoria (hereafter referred to as the Task Force). These issues were documented in the Task Force (1997) report *Dementia Care in Victoria: Building a Pathway to Excellence*. The investigative phase of the project addressing issues related to dementia and elder abuse is discussed in this document.

Aims

The aims of the project were to:

- identify and investigate the issue of elder abuse in relation to older people with dementia and their carers;
- identify and investigate the awareness of this issue among service providers and the general public; and
- provide advice on more consistent and effective responses by services and individuals to elder abuse, with specific focus on people with dementia.

Methodology

The project involved:

- the establishment of an expert reference group;
- a comprehensive literature review;
- discussion forums with interested stakeholders in metropolitan and rural sites in Victoria to ascertain the issues surrounding abuse and to identify any related strategies that were in place, being developed or required;
- in-depth interviews with a range of individuals aimed at clarifying, broadening and deepening understandings gained from the literature and forums; and
- analysis of the data to identify current issues and possible actions for preventing or responding to abusive situations.

1. It is recognised that younger people have dementia and that abuse may occur at any age, however, the focus of this project is elder abuse (ie abuse of older people) in relation to dementia.

The process of gathering information

Phase one of the project had a three-month timeframe. This timeframe precluded a lengthy advertising campaign. However, Alzheimer's Association Victoria in conjunction with other service providers, members of the reference group and La Trobe University undertook a broad mailout to ensure as many people as possible could have input into the project. A literature review was undertaken to determine the current status of abuse of older people with dementia and their carers to identify issues that would guide the forums and interviews. The Project Team conducted forums in Sale, Warrnambool, Echuca, Wangaratta, Camperdown, the Southern Healthcare Network and the North West Healthcare Network.

Group forums and individual interviews were held at each venue. To meet ethical requirements separate forums were organised: the morning forums were for participants who were staff, and the afternoon for those who identified themselves as family carers and/or people with dementia. Counselling staff were in attendance at all forums for family carers.

Where possible the individual interviews were used to broaden the views presented in the larger groups. Many individuals felt that they had expressed their views in the larger group and therefore did not see any value in also having an in-depth interview. The majority of group participants were nurses and family carers. In addition, interested individuals who had not been able to attend the meetings or who had further contributions to make following the formal group sessions were offered telephone interviews and/or were invited to forward their views in writing. Staff participants were requested to provide copies of their abuse policies. Having two researchers attend each forum allowed one person to ask questions while the other took notes. In all, seven forums were held involving a total of 171 participants (see Table 2, p.9), and telephone and face-to-face interviews were conducted with five participants (see Table 3, p.9).

2. Background

Before exploring elder abuse as it relates to dementia it may be useful to provide some general context by briefly discussing ageing, dementia and elder abuse. The aim of this project was to build on previous work as far as possible. While this project specifically targeted elder abuse, it is recognised that people under the age of 65 years do have dementia and do become carers.

2.1 Population ageing

The Australian population is ageing. In 1998 there were 2.3 million people aged 65 years and over, accounting for 12% of the population.

Table 2 Designation² and number of attendees at public forums

<i>Designation</i>	<i>Number of attendees</i>
Carers	52
Carer support	4
Co-ordinators	8
Counsellors	4
Managers	8
Nurses	
Registered nurses	13
Directors of Nursing	1
Assistant Directors of Nursing	1
Clinical Nurse Consultants	2
Enrolled nurses	3
Occupational therapists	3
Physiotherapists	1
Social workers	7
Person with dementia	1
Other	11

Table 3 Designation and number of participants in telephone and face-to-face interviews

<i>Designation</i>	<i>Number of participants</i>
AMA representative	1
Carers	3
Person with dementia	1

By the year 2051 it is expected that this number will have grown to between 6 million and 6.3 million or 24–26% of the total population of Australia (Australian Bureau of Statistics [ABS], 1999). The number of people aged 85 years and over is expected to increase more than 400% to between 1.1 million and 1.2 million by the year 2051. The proportion of the Australian population represented by this age group is projected to increase from 1% to 5% (ABS, 1999).

It has been suggested by a number of studies that cognitive impairment is a risk factor for elder abuse (Lachs et al, 1997; Weeks & Sadler, 1997). This concern is compounded by our knowledge that the risk of developing cognitive impairment such as dementia increases with age. In 1996 there were thought to be about 35 000 people in Victoria with dementia, a number likely to increase to around 49 500 by the year 2011. In Australia the prevalence of dementia is estimated to increase by 250% between 1989 and 2031 (Task Force, 1997). The growing number of older people in our community and the associated increase in the prevalence of dementia indicates a need for a more comprehensive understanding of the issues surrounding dementia and elder abuse.

2. Participants provided their own designations and these have been replicated here.

2.2 Dementia

Dementia is a global syndrome that can result from many specific disorders. Common symptomatology or behavioural changes of a dementing illness include:

- memory loss;
- disorientation;
- wandering;
- language difficulties;
- impaired comprehension, reasoning and judgement;
- failure to recognise people or objects;
- loss of ability to initiate and learn;
- changes in mood;
- personality changes (such as paranoia);
- night-time wakefulness;
- gradual failure to perform daily living tasks;
- hallucinations or delusions; and
- challenging behaviour such as verbal and physical aggression, resistance to care, suspicion, agitation and repetitive acts, inappropriate sexual behaviour, stealing and hiding things, use of abusive or obscene language (Task Force, 1997: 18).

There are numerous causes of dementia, the most common of which is Alzheimer's disease.

2.3 Elder abuse

There has been much debate regarding what constitutes a functional definition of elder abuse. On an academic level there is discussion over whether different types of abuse should be grouped together or split into discrete categories. At the practical level there is concern that the label of abuse for apparently abusive behaviour is highly emotive (Weeks & Sadler, 1997) and this may hinder attempts to intervene in such situations.

The Victorian Government, Family and Community Development Committee (FCDC, 1997) used MacCallum et al's definition of elder abuse as a 'pattern of behaviour by a person that results in physical or psychological harm to an older person'. The Committee proposes that the main forms of elder abuse include:

- psychological abuse—infliction of mental anguish, including verbal abuse and intimidation, that causes fear of violence, isolation or deprivation;
- physical abuse—non-accidental use of physical force or coercion, including sexual abuse, which inflicts physical pain or injury;
- economic abuse—illegal or improper use of an older person's money, finances, property or assets; and
- neglect—deprivation of basic necessities of food, shelter, clothing, medication or relevant services, both passively and actively (FCDC, 1997, p.528).

The Victorian Department of Health and Community Services (DHCS) document *With Respect to Age* provides a more refined definition of elder abuse: 'neglect or harm to an older person resulting in physical, psychological, sexual or material (financial) injury, caused by the behaviour of a person with whom the older person has a relationship implying trust' (1995, p.7). This definition distinguishes elder abuse from other more general forms of crime or abuse against older people by putting it in the context of a pre-existing relationship between the older person and their abuser. It fails, however, to recognise that the abuse may be perpetrated against the carer or staff member by the person in their charge.

With Respect to Age also provides an alternative approach by defining elder abuse by its context. This definition considers that the perception of abuse and need for or type of intervention may be mitigated by the context in which the abuse may occur. It recognises the historical nature of the relationship between the abuser and their victim and acknowledges that it may be inappropriate to redefine the type of abuse simply on the basis of age. It may not be appropriate to redefine domestic violence that has been ongoing over a period of time, for example, as elder abuse. Examples of elder abuse include maltreatment or neglect by family carers, domestic violence, maltreatment or neglect by a dependent adult, conflict in a shared household, financial exploitation in a non-commercial relationship, maltreatment or neglect by staff in residential care, professional malpractice or maltreatment of an older person by a paid carer and self-neglect (DHCS, 1995).

There is a great deal of literature relating to the issues surrounding the various forms of abuse perpetrated against the older members of the community. Much of the literature is editorial in nature or based on anecdotal evidence and small case studies.

The literature is primarily concerned with the identification and assessment of elder abuse and education and strategies for dealing with elder abuse. The roles of the various health, allied health, social services and legal practitioners in minimising its impact on individuals and society are also prime concerns.

A few attempts have been made by researchers in Australia to quantify the prevalence of elder abuse. These estimates range from 1.2% to 5% (Kurrle et al, 1997; FCDC, 1997). Overseas studies have reported prevalence at 6.5% (Lachs et al, 1997) and 5.6% (Comijs et al, 1998). It is generally accepted that the incidence of elder abuse is under-reported due to a number of social factors. In one study, however, where the incidence was reported to be 6.5% only 1.6% of these cases were corroborated by further investigation (Lachs et al, 1997). Conversely Kurrle et al (1997) found that the incidence of abuse reported retrospectively was double that reported prospectively.

In US studies cited by Wolf (1988), older people living in the community were three times more likely to be directly abused if they were living with someone, and the abuser was most likely to be the spouse. Older people living alone were more likely to be neglected. The current trend toward home and community based care presents a greater degree of environmental vulnerability. This form of care requires a more intimate client–worker relationship in unsupervised environments (Lowell, 1996).

Elder abuse can occur in a variety of settings with both staff and carers. And as discussed, it is not always the person requiring care who is the victim of abuse. Carers and staff may be the victims of abuse. Elder abuse constitutes a diverse phenomenon requiring more detailed attention and a comprehensive response involving a variety of services (Hall, 1989).

2.4 Elder abuse and dementia

There is little literature available on elder abuse concerning individuals suffering from dementia and their carers. What information is available suggests that this group is particularly susceptible to abuse either as perpetrators or victims. Paveza et al (1992) suggested that the person with dementia was at 225% greater risk of a physically abusive episode than other community dwelling older people.

A number of factors have been identified which place the person with dementia at greater risk of abuse: increased strain on the carer because of stressors specifically related to caring and dementia; carer stress related to other life factors; psychopathology or substance abuse by the carer; and a history of domestic violence (Weeks & Sadler, 1997). Dementia is most likely to be associated with abuse if conditions such as family conflict, substance abuse or mental illness exist (Sadler et al, 1995). More often it is the carer who is the victim of abuse in the domestic environment (Hamel et al, 1990; Paveza et al, 1992). In such cases most abuse is verbal (Cahill & Shapiro, 1993; Hamel et al, 1990).

Hamel et al (1990) found that 57.2% of carers report some form of aggression towards them by persons with dementia for whom they provide care. In an Australian study 89% of carers for persons with

dementia had experienced some form of aggression (Cahill & Shapiro, 1993). The care burden is greater for a person caring for someone with dementia (Sadler et al, 1995) and aggression can have a major negative impact on the caregiving relationship and may even lead to premature institutionalisation. This in turn carries a significant economic burden for society.

Aggression in a carer relationship where dementia is a factor has been associated with a premorbid aggressiveness (Hamel et al, 1990). This suggests that difficulties encountered after the onset of dementia are indicative of difficulties in the personal relationship prior to illness and these may even be exacerbated by the condition. However according to the findings of Coyne et al (1993) the incidence of violence prior to onset of dementia is only reported in 8.6% of cases. Cahill and Shapiro (1993) found that onset of aggression has two major elements: care giver–older person with dementia disagreement; and older person with dementia frustration and restraint. Violence in a care relationship has been found to be more likely between spouses than other relatives and violence by the older person has been related to caregiver violence (Pillemer & Suitor, 1992).

3. Building on the groundwork

A major purpose of this project was to build on previous work and to maintain a sharp focus on elder abuse related to dementia. Many of the issues raised are general and could be raised in relation to numerous situations involving caring, however failure to report these issues would remove important contextual understanding and leave the conclusions without supporting evidence.

3.1 Government responses

A number of governments across Australia have recognised issues related to elder abuse and articulated policy responses. As already noted the previous Victorian Government's response is outlined in the document *With Respect to Age*. The document focuses on 'the policies and procedures of local health and community services, and proposes strategies to optimise their ability to deal effectively with problems of elder abuse and neglect' (DHCS, 1995: v). This report proposes a working definition for elder abuse, suggests questions that may be asked and provides a checklist to assist Health and Community Services' workers. It indicates when to refer and to whom, provides an operational framework and case studies, and lists referral agencies with brief descriptions of their functions. Respite is noted to be the most requested service by carers: flexibility and choice are key components of this service provision. Co-ordination of services to deal with challenging behaviours has been recommended (Task Force, 1997).

The New South Wales (NSW) Advisory Committee on Abuse of Older People released a discussion paper on 'Elder Abuse and Dementia' (Weeks & Sadler, 1996). This paper detailed the results of literature reviews and interviews undertaken by the project team. In this paper the authors' definition of elder abuse included physical, psychological, financial and sexual abuse and passive and active neglect. They found that the person with dementia is at risk because of their higher levels of dependency and vulnerability and the increased strain and stress this places on the carer. They also found that a history of domestic violence or psychopathology or substance abuse by the carer indicated greater risk. Carers were found to be at risk because of the nature of the illness and the person with dementia blaming family members for loss of memory, disorientation and language problems. Also the increased force required to overcome the increased resistance to intervention for personal hygiene, wandering and other behaviours was related to greater risk of abuse.

The NSW Advisory Committee on Abuse of Older People's discussion of human rights issues raised concerns about choice versus safety (Weeks & Sadler, 1996). This quandary is faced by police who are bound by their statutory responsibility to detect and prevent crime. The view of the police interviewed was that the rights of the victim must take precedence. The Guardianship Board representatives at the forums felt that choice was not a useful concept for them as their appointment by definition effectively removed the person's decision-making capacity. The Board is bound to act in the best interests of the person with dementia, regardless of whether they are the abuser or the victim. The Alzheimer's Association of New South Wales agreed that choice was often removed dependent on the person's level of dementia and that this extended beyond issues of safety to day-to-day issues such as routine, financial matters and medical intervention. These considerations are different for the person with dementia living alone in the community who is at risk of self neglect or self abuse and abuse from members of the community and service providers.

The Aged Care Assessment Services (ACAS) represented in the report by the NSW Advisory Committee on Abuse of Older People (Weeks & Sadler, 1996) suggested a number of criteria for individual decision making. These considered the level of care required by the person with dementia, their health and emotional state and also that of their carer, their cultural background and the availability of services. This was consistent with the general view that individual situations will differ and intervention needs to be implemented on a case-by-case basis.

The NSW Advisory Committee on Abuse of Older People indicated that mandatory reporting was generally viewed as a removal of people's rights and an unnecessary stigmatisation. A system of mandatory referral to supportive services was suggested as an alternative. It was stated that the full protection of the law is available to anyone regardless of his or her age or cognitive ability.

In New South Wales some protocols exist for dealing with situations of elder abuse involving people with dementia. All agencies contacted were aware of the Draft Inter-Agency Protocol of 1994 but few had put it to practical use. One agency had used it as a basis for their own protocol and others were in the process of developing their own protocols. There was found to be an existing network for addressing elder abuse with the core agencies being homecare services, ACAS, the local general practitioner and the Alzheimer's Association of New South Wales. The Guardianship Board and police offer specialist services to this network.

The NSW Advisory Committee on Abuse of Older People considered it difficult to evaluate the provision of services because of the hidden nature of abuse. However Weeks and Sadler (1996) suggested that improvements could be made through increasing staff understanding of their professional, legal and ethical responsibilities; better use of case management techniques; improved support of workers by their managers; and the development of a database for monitoring abuse and referrals to expedite service provision.

It was suggested that education should play a central role in strategies that deal with abuse. It was recommended that information about elder abuse should form a core element in health and allied health courses. General practitioners were considered a special group of service providers and the development of protocols to guide their practice was suggested. Improvements were also called for in the dissemination of information to carers and the general community about the nature of dementia and issues surrounding elder abuse.

Although there have been a number of programs implemented in the various States and Territories to deal with issues of elder abuse, these programs are usually generic in nature and do not address the specific needs of people with dementia and their carers. There are agencies with specific responsibilities for cases where dementia is a factor, however specific protocols for consistent identification and intervention in these cases are not available. Specific dementia-related issues are generally addressed as a component of these more generic protocols.

Elder Abuse or Elder Protection programs have received varying levels of attention from State governments. In Western Australia the Council on the Ageing was contracted to provide training for service providers in identification of abuse and interventions. The program is ongoing, with further education workshops being held with special groups during 1999–2000 (Office of Seniors Interests, 2000). This program appears general in nature and does not specifically address the needs of individuals where dementia is a factor.

The Queensland Government through the Office of Ageing has undertaken a study into the abuse of older people from which a project report, resource paper and protocol development kit have been developed. These resources look at elder abuse in a generic context

and are not specifically applicable to the issue of elder abuse in the context of dementia care.

The South Australian Aged Rights Advocacy Service was funded in 1997 to provide assistance to older people experiencing abuse. As in other States, this program is generic in nature and has involved the distribution of pamphlets, educational sessions, media promotion and presentation at conferences.

3.2 Existing resources and protocols

A number of resources exist to help address the issue of elder abuse. These resources are generic in approach and are not designed to address specific issues associated with individuals with dementia and their carers. The following resources are presented to illustrate the types of approaches and do not purport to be the only resources. There is no information available regarding evaluation of their applicability and appropriateness in the field.

Assessing and Managing Abuse of Older People: A Handbook for the Helping Professions (Kurrle & Sadler, 1994) is a general handbook to assist professionals in dealing with issues surrounding elder abuse. It provides a general introduction and background to the problem, information about the assessment and identification of abuse and neglect, strategies for the management of abuse, options for intervention and a section on social policies.

Responding to Elder Abuse: A Guide for Carers (Fielding, undated) was compiled from a UK document by 'Action on Elder Abuse'. This document provides definitions of abuse, considerations when confronted with a possible abuse situation and actions to take.

Dealing with Elder Abuse: A Training Kit (Department of Human Services, Southern Metropolitan Region, 1997) is a comprehensive resource developed for workers in aged care in the Southern Metropolitan Region of Victoria. This document provides a description of the issues surrounding abuse from the existing literature. It discusses the signs of abuse, issues for service providers, existing networks, interventions and resources. The kit also offers guidelines for developing an agency policy and procedures guide.

Elder Abuse Resource Kit (Austin and Repatriation Medical Centre, 1996) is based on the *With Respect to Age* report and provides a step-by-step guide for assessment and intervention in cases of elder abuse. It also provides a resource guide with referral information.

Elder Abuse Protocol (Department of Human Services, Northern Metropolitan Region, 1997) provides information about elder abuse, how it is defined and its indicators. Intervention options and factors to consider when devising an intervention strategy are discussed, and a guide to specialist agencies is included.

Supporting Older People at Risk: Protocols for the Prevention of Elder Abuse (Southern Health Care Network, 1999) were developed to inform network staff about elder abuse and its early detection. The Protocols provide definitions of abuse, behavioural and environmental indicators and principles for assessment and intervention. The intervention guidelines provide procedures for a range of different situations and contingencies.

Abuse of Older People: What is it? What can be done about it? Who can you turn to for help? (Public Trustee, 1999) is a guide to resources for older people who have experienced abuse or are concerned about abuse. It provides general information about abuse and resources for further information.

Harm's Way: Abuse Experienced by Residents in Homes and Steps to take to Reduce it (Bright, 1997) is a publication produced by an Counsel and Care advice line in the UK in response to issues raised with them by concerned individuals. This document provides a detailed description of developments in the UK with regard to elder abuse and a description of a workshop developed for aged care facilities. It provides case studies and scenarios, strategies for addressing abuse situations and recommendations for action at various levels.

3.3 Summary

In summary the literature indicates that much has been done in relation to investigation of generic issues associated with elder abuse and recommendations to assist in overcoming these issues. What is not known to date is the impact of the various studies and their recommendations in reducing elder abuse.

With the ageing of the Australian population, those 85 years and over are in the fastest growth area. As evidenced in the literature we know that with an increase in age comes an associated increase in the incidence of dementia. The literature also suggests that cognitive impairment is a risk factor for elder abuse. Factors that place the person with dementia at greater risk of abuse include carer stress and carer burden. Studies also suggest that the carer is more often the victim of abuse in the domestic environment.

Many of the issues raised in the literature could be related to numerous situations of caring. This study will build on these works and ensure a focus on abuse related to dementia.

4. Findings

4.1 Exploring the definition of abuse

Respondents in the current study found the question of what constitutes elder abuse challenging. One participant noted the difficulty of differentiating abuse from other behaviours, raising questions about who is responsible for identification of abuse situations: 'Who sets where the line is... I mean, who makes that decision?'

Participants questioned whether abuse should be defined broadly enough to include situations where people are treated without appropriate care:

[T]his young fella came in from the Agency, and I was there when he came in with the meal, and he put it down in front of her and was about to walk away and she said 'I don't eat that sort of thing.' He said 'If you don't like it, leave it'. Now, is that abuse?

The question of elder abuse also calls into question moral rules of veracity. Does the intent behind lack of veracity outweigh the act of not telling the truth? One respondent clearly struggled with this issue:

[W]e have got a lady who often will ask where her husband is, and he has died years ago. But, if you tell her he has died she becomes argumentative: 'He has not! I saw him half an hour ago. You are lying to me!' Now, is that a form of abuse to [tell her the truth]? ... Others believe that you have to tell them the truth... so she becomes (and this might last a full day)... where she will be upset about that and she will keep on and on and she is just restless. In and out of her room trying to find him. Now is that a form of abuse... by insisting on telling her [the truth]?

Lack of understanding of individual needs, especially in an institutional environment was key to defining abuse for many of the respondents. One participant described an example of where lack of understanding caused significant distress to a woman:

[E]ven the placing of the residents. In mother's unit there was two Jewish ladies. Now, the thought was 'We'll put two Jewish ladies together, they'll be good company. One of them [had] been a prisoner of war... so when she heard German, it spooked her. So, what did the other lady speak? English and German! And when her daughter visited they spoke and conversed in German... ANZAC day, what did the staff do? On with the television... And then they say 'So and so's out of hand today and so and so's doing such and such.' I mean, it's abuse, and ignorance is abuse, isn't it?

The issue of ignorance is closely tied with the question of intent to abuse, or, as one respondent described, reflective awareness of actions: 'I think whether it is done on a conscious or unconscious level, it still constitutes abuse.' However health care workers have a legal

requirement to provide a duty of care to all recipients of their services to ensure they are not placed in danger or mistreated. Poor practice that results in mistreatment or danger to the individual would constitute neglect of duty of care.

4.1.1 Intent

The question of intent was central to the participants' identification of elder abuse. There was substantial doubt as to whether people with dementia could form an intent to be abusive. One participant asked 'Is it constituted [as] abuse, because they have no insight to understand that?' The suggestion that 'It's still abuse, it's whether you are held responsible or not' was put forward as a way of straddling the issue of intent and abuse for people with dementia. While there was a greater leeway given to people with dementia abusing carers—as having their ability to form intent compromised—participants largely agreed that intent was not necessary for carers to be held responsible for abuse. One participant noted that abuse 'can and does frequently' occur without the intent of the carer.

Comparisons with child abuse were common throughout the data. The acceptance of more clearly identified situations that constitute child abuse was compared with the lack of clarity regarding elder abuse:

I talked about this ... as child abuse compared to elder abuse... If it was child abuse people would say it was abuse no matter what the cause is. But when it comes to elder abuse people start trying to justify it. And, to me, if it's abuse, it's abuse.

Adopting the perspective of the recipient of abuse was central to some respondents' rejection of intent as a necessary prerequisite of an abusive episode: 'If you're on the recipient end of the abuse it sure is!' Again focusing on outcomes, another participant noted that 'It doesn't have to be intentional... the result is still the same.'

The alternative to the focus on consequences and outcomes is the evaluation of acts on the basis of their intent. This was a less popular position for the participants of the forums. Respondents' contributions to this framework for identification of abuse were largely contextual, relying on specific circumstances to identify or define abuse: 'Well, you have to weight each situation... You really have to apply situation ethics here and weight each situation on its merits.' Whether an act was meant for the positive care of a patient was important. Of course, this position would then not recognise as abusive any act that is meant to have good outcomes—and could possibly include quite serious harmful events. Whether intent was present in a harmful situation was seen as relevant to the future management of the relationship, including professional interventions.

One solution to the question of intent and its role in defining abuse was the categorisation and sub-categorisation of abuse: 'Maybe you just define [abuse] as intended and unintended.' Neglect, while often seen as unintentional, was also a topic that prompted substantial discussion.

4.1.2 Neglect

While the participants generally accepted that neglect did constitute a form of abuse, there was difficulty addressing at what point behaviour became neglectful (and thus abusive). Only one participant questioned whether neglect constituted a form of abuse. Health concerns (or, more broadly, wellbeing) were suggested as a way of differentiating acceptable behaviour from neglect/abuse:

I think the line should be drawn where it's for their health. No-one's going to die from not having a shower one day and particularly if it's in winter... Obviously, if they're smeared with faeces or something that's a health issue... If they're reasonably clean and they don't want to shower I don't think they should be forced to have a shower every single day.

Similarly, while neglect was not seen as an 'extreme' form of abuse, there was a point when a person's wellbeing was compromised to such an extent that questions of neglect became central.

[Y]ou can often get lots of ... tests or follow-up stuff that would be done by a GP or whoever if that person wasn't demented. But, because they are it's like, why bother?

While the question of decision making will be taken up later, it needs to be noted that people's choices regarding food, hygiene, and other activities of daily living become an arena for concern when respect for decision making becomes confused with neglect. This is the case for both those providing and receiving care making decisions, as illustrated by the following example:

It's like people saying I'm keeping her home because I really, really love her and we always promised that we would look after each other. And I'm going to do that! But to do that I have to lock her in the house while I go and [do] my jobs. And she is burning her slippers, and burning her hands, and doing this and that. But I know, I will keep her home because I love her.

For some participants lack of care and attention to peoples' needs constituted neglect and thus abuse, as the following excerpts indicate:

I think it's abusive when the domestic staff bring in a meal for a person with dementia and just leave it there. They don't assist the person, they don't take the lid off so that they can actually see that it's food, don't have it within reach. All of those sorts of things. And the family come in three hours later and the meal's still there.

[W]hen my mother was in a home, her hearing aid wasn't put in, it wasn't put in properly, it was put in without batteries, it was put in and not turned on! And she'd be having a hell of a day. And I'd come in, see what was wrong, turn her hearing aid on: 'Oh that's better.' And then smiles, but she'd had a hell of a day up 'til then and the staff didn't bother to find out why.

Lack of knowledge rather than abusive intent was seen to be responsible for much neglect. This understanding supports those

participants who argued that intent was not necessary to identify a behaviour as abusive. Awareness of limitations to knowledge was key to addressing questions of neglect:

I don't think that you can know everything about everything. I think what you need to be able to do is recognise that it's beyond your scope of knowledge and know where to refer it on to.

4.1.3 Summary

In summary, it is clear that providing a concise definition of what constitutes abuse is extremely difficult if not impossible. Perhaps it is not even useful. Definitions can provide clarification but they can also result in unintended and damaging demarcations. For example a tight definition may result in people defining behaviours as non-abusive. Resources could be wasted on trying to determine whether certain behaviours constitute abuse when they could be used to improve the situation. The evidence presented here would indicate that it is perhaps more useful to think of abuse in terms of a continuum. At one end of the continuum lies poor practice, poor relationships, evidence of lack of respect and so on. At the other end is unambiguous abuse: evidence of bruising, malnutrition, total neglect and so on. This continuum may include situations in which:

- the victim feels abused, the perpetrator intends no harm but society in assessing the situation would 'see' abuse;
- the victim and perpetrator are accustomed to a particular context of verbally 'abusing' each other and do not define the relationship as abusive but society would judge the situation as abusive;
- society judges there to be no problem, the victim is accepting and understands but the perpetrator feels she/he is being abusive because she/he is not meeting her/his own high expectations as a carer; or
- a staff member practices in a way that is the norm in that environment, ignored by society, but totally unacceptable to the carer and to the professional standards of nursing.

It is not sufficient to define abuse as situations where abuse is intended: abuse often results from ignorance not intent. Nor is it appropriate to define abuse as situations where the victim feels abused: the older person may be extremely demanding and regard any departure from their expectations as abuse. Alternatively, for many reasons including learned helplessness, poor self esteem, vulnerability and gratitude, a 'victim' may not define what they are experiencing as abuse even when an objective assessment by any reasonable person would say it is.

No one definition of abuse would cover all situations. What is required it seems is an assessment that always takes account of:

- the experiences and perceptions of the victim;

- the experiences and perceptions of the perpetrator; and
- the contemporary norms and values of society.

It is clear that abuse can take many forms including those previously identified: physical, sexual, psychological or financial, and may be mediated by environmental, systemic, spiritual and cultural issues. How abuse is perceived by those affected is influenced by relationship issues, the severity of injuries sustained and the intent of the perpetrator on a continuum from ignorance to malice.

4.2 Contexts and precipitators of abuse

A variety of issues were suggested as precipitators for abuse of carers, staff and older people with dementia. These included:

- coping characteristics of the individuals and their reactions to personal situations; and
- characteristics of contexts and support external to the individual.

Little attention was given to the precipitators of an older person with dementia abusing carers. Participants seemed to accept that people with dementia could not be 'blamed' and that the responsibility for changing the abuse situation rested with others. The frustration of living with a person with dementia and a history of abuse in the relationship were identified as key precipitators of abuse towards carers.

The precipitators of abuse were largely represented as a process of related rather than discrete issues, such as lack of support services to attend to both staff and carers' needs. The support participants wanted but felt was lacking included:

- respite care;
- access to education and training;
- strategies for addressing the isolation caused by the practical challenges of caring and the stigma related to dementia faced by people with dementia and their carers.

Recognising the precipitators preceding abuse incidents was viewed as vital to appropriate and timely intervention:

[W]hat you are trying to get to that person is that, yes, there is the result of stress. Or, so have you been caring for this person? Are you tired? All those things that might trigger the abuse. So, rather than saying to the person come to us when you are abusing, come to us when you are feeling stressed.

4.2.1 Issues for carers

A major issue for carers was lack of support for their caring roles. Lack of options characterised much of the discussion of issues for family carers:

You know this is the condition, you can't do anything about it, and you have to put up with it basically. There are very few real options.

A tension existed between the weight of responsibility and the devalued role of caregiving. This is best understood in relation to the community and service expectations regarding the provision of informal care and difficulties of accessing appropriate services. Carers were viewed as having rights that were compromised by these issues:

I personally feel that having been a carer for a long while that carers are also denied a lot of their moral rights... I think there is a tendency for agencies to sometimes treat carers with a little bit less respect than they should have... So, yes, I think carers are treated with little respect, even by the organisations that are supposed to be there to help them.

And later:

I feel that when you say you're a pensioner or a carer you automatically go down a bit... when you're dealing with any bureaucracies they think, 'Well, this person's just a pensioner.'

A pressure was felt by some of the participants to maintain at least a façade of being able to successfully manage and cope with the stress attached to the care relationship, even when that relationship involved being subjected to abuse. One participant related how she worked hard to prevent staff from being troubled by her situation:

I act as if, you know, nothing much has happened in front of my husband and the staff when he talks like that to me. So I act as if, you know, I brush it off. And therefore the [staff member] doesn't notice I feel the way I feel. I'm only worried that they feel he, my husband, doesn't want them. And I make sure to tell them that it's not the case, it's just nothing personal. It's just him telling us he doesn't want anyone else but me.

Lack of options when undertaking care relationships was closely related to the level and perceived quality of service provision:

I could have put him in a nursing home a long while ago. That was a choice not to. I guess most carers are in the same position in as much as, well I would say willingly [care], but there is an obligation to do it certainly. You feel it's the right thing to do. And also given the conditions in nursing homes, I don't see them as a viable option really. There must be good ones, but I've seen a lot of awful things in nursing homes.

A closer partnership between carers and services is required if carers are to feel valued in their roles. Inflexible service provision is not capable of fulfilling carer needs:

I'm getting council respite once a fortnight; that's the maximum I can get. But I will never go out when she's here. I can't afford to leave my mother with someone—I don't know how she will handle any situation. I can't risk that again because of her poor health. So, it's useless to me, the respite, but I have to take it because if you refuse council respite you lose everything.

An interdependence exists between staff and carers. Inability of formal care to provide for service users' needs has a profound impact on the day-to-day experience of family carers, who are most often partners or children. As the following participants describe, while not acknowledged as 'professional' and having often been understood as not being able to provide adequate or sufficient care, they may be called upon to accommodate shortcomings in formal care:

I will tell you a small story. A husband and wife, he had dementia... lived on a farm [where] they raised a family. Anyway, he got thrombosis in his leg and they took him to the hospital. He went in the afternoon... [H]is wife stayed with him for a little while and then she had to go and feed the dogs. And they rang her at 11.30pm at night, she is about 40 miles out of town, and said 'Come and get him. We can't manage him.' And she took that man home in the middle of the night in an extremely angry state.

A further example illustrates the relationship between staff and carers:

A story of an old lady... she had been caring for her husband who was quite a large man. And she got to the point where her health had... broken down. He was physically aggressive and they finally got him into this place. And they rang her at eleven o'clock at night and said 'You've got to come and take him home, we can't care for him. He's too aggressive.' And she said 'Here am I, a little old lady being told to go up to the system... and take my husband because with all their skills and knowledge they can't cope!'

Isolation compounds the challenges facing carers. The stigma associated with dementia also contributes to the social isolation of carers and older people with dementia:

Once you mention dementia [people] don't want to know you. It's strange. I suppose it's like Alzheimer's disease—people [want to] get away from it.

4.2.2 Issues for staff

It was expressed throughout the data that staff employed to care for people with dementia work under difficult conditions. Insufficient staff numbers to provide for care responsibilities, lack of education, lack of professional supports, lack of activities for service users, and environments (including systems of care provision) which did not adequately accommodate either carer or service user needs were identified as key issues for staff. These concerns were expressed within the context of abuse, implying that abusive or neglectful relationships were inevitable.

Participants addressed the outcomes for service users when staffing levels are deemed insufficient to provide care on an individual basis:

The frustration! And that because the staff levels [are] too low. Like, two people on night duty!

[regarding depersonalisation of service users] It's passed on from one shift to another.

A lady actually ringing her nephew and saying 'I need to go to the toilet.' And people are so 'on edge' in these facilities.

A number of issues were raised with regard to staff experiences. Frustration with inadequate staffing levels and staff education and training were problems for both carers and staff reflecting on their own situation. There was, however, much sympathy for staff, with others looking for ways to understand—and, importantly, excuse—inappropriate behaviour. As one carer said regarding his suspicions of physical abuse against his wife:

I mean, they're doing a good job. I'm not arguing with that. They've got a job to do, and if the person makes it difficult, well, they've got to deal with it. And how so they go about it anyway, without bruising someone? ... Well, it's a difficult point, isn't it? I mean, they've got to get her to bed and if she resists, well, what do they do? They've still got to get her to bed.

For clarity, staff issues are divided into those specific to nursing and medical care providers, and more general issues including clinical and non-clinical staff.

4.2.3 Nursing staff

Demands for nursing staff with a high level of education and training were expressed in the forums and interviews. A basic level of skill was recognised as essential which includes a core knowledge of dementia specific issues. The traditional culture of little education and skills being required in aged care was seen as contributing to stress and subsequent abuse.

Related to this is the lack of supports for staff within their workplace. One nurse identified insufficiencies in current practices, and expressed the need for management to be proactive in establishing staff supports:

[W]e don't put in stress management strategies for them. We don't identify the signals that people are reaching that can tip them over the edge and that can cause abuse, and you tell someone to 'Shut-up, I'm sick of listening to you' etc. [Y]es, it is due to staffing, it is due to culture. There's all those factors. But, as a manager I see that it is also my responsibility to be able to identify the group that we're caring for and give staff the skills to identify their own needs in which to persist with care. But we don't do that, because we pay you and you're only there for eight hours. So, often we don't give people the skills, I suppose, to work in those very challenging environments.

[Staff] don't acknowledge that they have a problem... [W]hen I've done debriefing for staff, or I've said 'It's time out for you'... that's okay to have that. It's not considered as part of that cultural norm to ... prevent abuse.

4.2.4 Medical staff

General Practitioners (GPs) were identified as a first contact for many carers. Difficulties arise when called upon to offer a diagnosis on the basis of a brief contact: 'Many times people will go to the GP and they will present so well that the GP wonders what on earth everyone is going on about.'

Other professional groups attempt to include medical practitioners in their inservice and ongoing training, but acknowledge the difficulty of having medical practitioners attending:

I think doctors [are] stretched to the limit. I think that is one of the reasons [for non-attendance]... it is very difficult to get them to come at any time of the day to do an education session.

Informal contact between GPs and other service providers was seen as useful networking, but suggests an *ad hoc* approach to service liaison:

I think half the problem is that doctors never get to see half the literature that comes in and I know that they must get blitzed with stuff. But I reckon half the time they are not even aware of what services are. And unless you had some personal contact with a doctor at some time in relation to a client or a consumer then he may not even know you are there.

A wider focus than clinical assessment was advocated by non-medical participants commenting on GP services: 'They are not looking at carers' needs. They are looking at the clinical aspects of this person with dementia.' An exchange between two participants illuminated the tension between time restrictions and expectations of GP practice:

[Person 1] There is a lot of very simple skills, aren't there, but everyone says they haven't got time.

[Person 2] And I say it is part of the treatment.

4.2.5 General (including non-clinical) staff

How staff recognise abuse relationships was identified as an issue:

You've got a moving population of staff which have to be trained ongoing. But also, once the paranoia fits into people with dementia you're also trying to sort out what is [really happening]. [For example], the carer comes in, the professional carer, while the wife goes out and the husband thinks that she has gone off to have an affair. But to know when to distinguish between what actually is abuse and not cause further anxiety for the whole family is not an easy thing to do.

Of considerable concern is the representation of staff taking advantage of the situation of older people with dementia. As one older person shared:

I'm probably a bit mentally affected, as in my brain isn't as fast as what it used to be. So, to a certain extent, people take advantage of that.

This highlights the need for careful and attentive management of formal care relationships. The possibility of personality clashes occurring and the need for an appropriate response to these is necessary to ensure that a formal care relationship does not cause harm:

I would hope that we would have the ability to identify if we are unable to work with a particular client and say up front that 'OK, I can't work with this person any more' and be able to speak to your boss, or whatever, so that it doesn't become an emotional abusive situation. [So] you don't become enmeshed in what should be primarily a professional relationship. It's hard not to get emotionally attached to people, but I think as professionals we have to take some responsibility.

The demand for education and training included clinical and non-clinical staff:

I think it's very important that people in this position ... whether they be assessors or whether they be other paramedical staff or even doctors [they] should have more knowledge of dementia. Perhaps inasmuch as that there are still things they can still understand and they're still capable of being hurt.

An 'ethical component' to education and training was suggested by one participant, advocating a greater understanding of the rights of older people with dementia as well as their physical needs:

They actually have to think a little bit about their rights and that they still have rights.

And I know that HACC workers now have to do a certain course, but I'm just wondering if it should have some sort of ethical component to it instead of just being told what they have to do for the elderly. They actually have to think a little bit about [service users'] rights and that they still have rights... I'm generalising here because there are a lot of good workers too, there seems to be a feeling amongst a lot that 'Well, these people are lucky to get these services. We are doing them a favour.'

Again, the question of neglect was raised:

I think there's a real problem with patients in hospital... which I put under neglect (which is also abuse as far as I'm concerned), where a lot of people with dementia are not even fed. The food is just put there and then just left. They may not be capable of feeding themselves... unless they have a family member come in and feed them they're likely to be left.

4.3 Abusive relationships

A number of features typified the abusive relationships described by the respondents. These were similar for both carers and older persons with dementia who were subject to abuse. A sense of vulnerability and lack of opportunity to negotiate their circumstances characterised the representations of both victims and perpetrators of abuse when informal care was provided, while lack of understanding was central to representations of abuse perpetrated by staff. There was little agreement, however, as to when decision making should be respected in the case of older people with dementia. Some participants advocated the rights of older people with dementia to decide on their participation in activities of daily living (ADLs):

I think the line should be drawn where it's for their health. No-one's going to die from not having a shower one day and particularly if it's in winter... If they're reasonably clean and they don't want to shower, I don't think they should be forced to have a shower every single day.

Others suggested that staff agreeing to let older people refuse showering, for example, was an example of neglect:

I just find that pretty abhorrent, basically ... one day one of the carers said to me 'I won't shower your mother today because I said to her 'do you want a shower?' and she said 'no'.'

It was clear that while respect for carer, staff and older persons' rights was advocated, how rights might be expressed (in the above example the 'right' to decide on showering compared with the 'right' to have daily hygiene attended to) varied widely. Much of this disagreement is the result of differing expectations of decision making responsibility.

4.3.1 Decision making

Limitations on decision making ability or opportunity were central to the discussion of abusive relationships. As dementia is the most common form of cognitive incompetence in older people, the inability to be able to negotiate both the care relationship and the circumstances which frame the relationship were viewed as key features of abusive relationships involving care giving. As one older person with dementia described, relating his lack of involvement in decisions regarding where he was to sleep:

I asked them 'Well, why wasn't I told?' ... I told them I was, at the time, pretty upset about the whole thing. I didn't want to be treated like a lump of garbage. I thought it reflected on me as a person. Yeah, I was crook, but if I was going to be moved I should have been at least asked if I was alright to be moved. And, secondly, at least advised that I was going somewhere else. I shouldn't have been just told 'You're going.' I think that was unreasonable.

And later:

I remember very little about [service] as far as treatment was concerned. At [service] it wasn't a matter of asking what your opinion was or anything, you were assigned a class.

The level of decision making was for some participants a measure of the care relationship. While occasional lack of decision making was not problematic, ongoing constraint of decision making was:

I think it's when you're consistently given no choice about the majority [of] ADLs during the day. Just consistently every day over a long period of time.

The loss of relationship was also poignantly represented in the data, in the case of someone being obliged to provide care: 'For example... she really wants her daughter relationship back. She doesn't want to be a carer.' The lack of decision making and opportunity to negotiate the relationship were raised as an example of both parties' rights being compromised. Similarly, the personality changes sometimes wrought by dementia impact greatly on relationships:

He was always a very gentle, very nice, very respectful [man]. So, all of a sudden it disappears. It's a mixture of not being used to it and of course I know its Alzheimer's. But at the same time I feel bad.

If changes to relationships are included within the parameters of abuse then this suggests that all care relationships are at risk of being framed by abuse. The relationship between powerlessness and vulnerability to abuse warrants close investigation and analysis.

4.3.2 Vulnerability and powerlessness

Older persons with dementia and their families are often unable to challenge formal care parameters and the processes of institutions for fear that they will be unable to direct future care arrangements or be denied care. One respondent described such a situation:

I know of an instance of a ... gentleman who becomes worried at night: he threw his bottle through the window. Staff didn't understand he thought someone was coming through the window. Now, they threatened him and his wife that he had to go to a psych hospital if he misbehaved again. And you know the wife's afraid to say anything because she thinks, well, they'll take away her husband!

The vulnerability of the older person with dementia and or their advocate seriously limits their ability to insist on appropriate care in formal relationships. This situation is exacerbated when staff lack appropriate knowledge of dementia issues and the specific needs of older people with dementia. Despite caring about service users, staff may be unable, through lack of training or insight, to appropriately care for older people with dementia. This, combined with the power inherent in the formal carer position, is seen to leave older people, their advocates and families, at risk.

Social paternalism was also raised as an inappropriate community and service response to the increasing vulnerability that accompanies ageing and dementia, and one that demands attention:

I think that the frail elderly, and the majority of Alzheimer's patients are elderly, are certainly extremely vulnerable and at risk of abuse.

[O]nce society perceives that someone is vulnerable, they then say 'It's our right to take over.' They tend to [take over] along the lines of what would suit [the service or community] best. I think unless we change society's attitude to [recognise] the dignity that should be afforded to the person we're not going to get past that one.

Framing the issues of decision making and vulnerability is the systemic nature of abuse. This was recognised as fundamental to investigations into relationships that featured elder abuse.

4.3.3 Systemic framework for abusive relationships

When there was no clear responsibility for activities that were seen to constitute abuse, the participants discussed this in terms of systemic issues. One issue was lack of adequately trained staff and actions (or inaction) arising from lack of knowledge:

Where it is cases of restraint or other issues like that—where it is proved through no fault of their own—they just don't know any better. The system is at fault there, I think.

Insistence on formal and informal care relationships adhering to organisational demands was also identified as contributing to abusive incidents. This was considered twofold: by denying carers, staff and older people the opportunity to negotiate their own circumstances, and by increasing peoples' vulnerability by reducing the level of control they could exercise with regard to daily activities. As one respondent offered:

I discovered that my mother was being documented as being abusive in the mornings. She was, but I really discovered that [what] was going on was that people were walking in saying 'Good morning!' Blinds up! 'Out of bed!' Of course she was going to be abusive!

And a further example:

[W]hat I also discovered at this facility was that they were still showering them by night staff and they all have to be [finished] by 7 in the morning. I said to them 'You can't do that!'

To return to the issue of showering, how organisations accommodate the older person's decision making is an issue. One nurse noted: 'You have the ones who want to shower every 5 minutes, you know, that's what they want to do. Are you abusing them by not letting them?' And the other extreme of this situation:

A Unit Manager rang me yesterday and they've got a lady who they haven't showered for 80 days in their dementia unit. And she says the

staff are putting it to her that it's the woman's choice that she doesn't have to shower.

Control over residents' intimate relationships was also suggested as indicative of the variety of ways systems facilitate abuse. The social stereotypes associated with older people, especially those with dementia, and the organisation and service structures which place obstacles in the path of people developing and/or maintaining intimate relationships were put forward as examples of systemic abuse.

Contributions to this discussion included:

In hostels there is no place for people to be alone or to have privacy. It's not set up that way.

Even married couples that go into hostels... they often have separate rooms, they don't have the double bed. You know it's really set up so that it makes it very difficult for them to have a sexual relationship.

Also, a lack of funds for people in institutional care... or even at home... No government is going to give the amount of money [necessary] to change things around to make people have a lot more privacy.

The abuse of an older person's rights was also discussed in relation to others 'speaking for' older people and assuming they knew what was 'best' for them. Often this was placed in a benevolent framework and related to protection:

I can't count the amount of times I have said to the person, look, there are day activity centres. There is this, this and this! [And they reply] 'Oh, no, no, the person won't like that. They won't go.' They make the decision on behalf of the person with dementia and you think the person with dementia is not being given a fair go through all this.

It's an overprotectiveness, too, that no one can look after them as well as I can. It's the ability to let go a little bit too [that is necessary].

Carers spoke of the difficulty of negotiating their care relationships within a system that had preconceived expectations of their role:

There's an expectation from the community and also from government policy: it's to keep people at home as long as possible. We do have agencies that have that expectation of carers. And I do think that some [informal] carers are never actually asked if they want [formal assistance]. There's an assumption made by service providers that these people will care.

4.3.4 Summary

In summary, precipitators of abuse centred on a lack of flexible strategies to assist in the acquisition of knowledge and skills and the reduction of stress and vulnerability. Participants emphasised the need for staff to have increased levels of awareness and understanding of dementia and its impact on the person and his or her family. Carer and staff stress could be reduced by equipping them with knowledge of the

biopsychosocial processes common to dementia. This could be achieved by providing resources and skills that would assist them in responding in effective ways to the various challenges associated with the course of the disease.

The rights of the person with dementia—including the right to make decisions—were acknowledged. However, there appears to be a need for greater exposure to materials and information that would assist in considerations of how to translate the rhetoric into relationships with the older person.

Improved partnerships between the older person with dementia, carers and staff were seen as integral to pre-empting, reducing and/or eliminating elder abuse. It was anticipated that better partnerships would facilitate genuinely informed decision making, empower carers and the older person, and reduce the stress and vulnerability.

4.4 Types of abuse

The forums were designed to discuss aspects of abuse. Consequently, issues that may have been raised as examples of stress in other situations were raised in the context of abuse in these forums. The content of the forums and interviews included asking participants what they considered constituted abuse. Despite the difficulty in defining abuse, participants were able to confidently identify instances of abuse. Examples of these are given under the broad categories identified in the data collection process: physical abuse, psychological abuse, financial abuse and systemic issues.

Some participants wondered whether elder abuse should be viewed as a sub-category of domestic violence. Focus on the relationship, history of the abuse relationship and behaviours of carers and older people were central to this discussion:

I mean, if there is [a] history of abuse, where [the] partner has a history of domestic violence, and that partner has stayed there, when does it stop being domestic violence and become elder abuse?

Domestic violence can start anywhere. It can be a whole lot of major stresses in somebody's life, their inability to cope with what's happening in their life.

I am making some parallels [between domestic violence and elder abuse]. [S]omeone with dementia doesn't have the ability to say 'I don't want you to do this to me anymore.' But there are also some parallels with a lot of people who are abused [in domestic violence] to be able to say 'I don't want you to do this to me anymore.'

While not central to the discussion, this issue warrants further consideration. This is especially the case as categories raised in discussion of elder abuse are closely drawn from the wider domestic violence service guidelines and theory.

4.4.1 Physical abuse

Little engagement with issues of physical abuse occurred. While recognised as 'the big one' and defined quite broadly to include rough handling by both staff and carers and interactions between patients lacking supervision, this form of abuse was not discussed in detail. The physical aspects of providing care and their impact on carers' wellbeing were also seen as abusive by forum participants, perhaps exacerbated by lack of supports. However on analysis it was considered that physical abuse included any form of assault such as sexual abuse, inappropriate use of restraint and isolation.

An example of physical abuse was an incident involving two residents, both diagnosed with dementia, of an aged care facility. One resident was repeatedly being physically assaulted by the other. The wife of the resident was distraught and requested that action be taken to prevent any further incidents. Staff at the facility could only suggest the relocation of her husband to another facility. This demonstrated a lack of knowledge of alternative resources and interventions that could be used in such situations. It indicates that staff require more education on strategies to prevent or minimise abuse in residential care.

Sexual abuse

Belittling and/or ignoring the sexual needs and sexual behaviour of older people with dementia were identified along with inappropriate sexual behaviour. Carer discomfort with sexuality figured in discussion around these issues:

Staff don't want to talk about [sexuality]. They don't want to face the issues with it, so that's sort of not recognised in client's needs.

When I worked in psych services... sexuality became this big issue. It was like, we didn't talk about it, or whatever, because if we opened it up it would be like opening a can of worms. And where would we go with it, and all that sort of thing. So, a lot of time it is ignored.

The question of consent to participate in sexual activities was recognised as problematic for carers with partners who have developed dementia:

Like, someone has got dementia, can't often consent to having sex...
Like if that happened to [people without dementia] it would be rape, or whatever.

Lack of privacy and lack of appropriate accommodation were seen as barriers to sexual expression. These ranged from preventing older people from masturbating to discouraging couples from developing or maintaining sexual relationships.

The question of how to address inappropriate sexual behaviour expressed by people with dementia was of concern, particularly as a form of abusive behaviour targeting both staff and carers. People with dementia were identified as both potential abusers as well as being vulnerable to being taken advantage of sexually by carers.

Inappropriate use of restraints

The use of medication was central to discussion about inappropriate use of restraints. Side effects, inaccurate diagnoses and inappropriate prescription drugs were identified as contributing to abuse associated with inappropriate restraint.

Restraint implemented to prevent wandering was recognised as an inappropriate response to dementia behaviours:

[I]t is the intent to care for that person and not have them locked up. And to understand that walking away is part of the dementing process with a lot of people.

Lack of appropriate facilities for medical inpatients with dementia was highlighted as a problem. Without such facilities restraint was seen as inevitable:

I personally had experience back with my uncle when he had to be restrained when he was in hospital once, a small hospital. Now, I can sense an enormous problem because he was a wanderer, he could have got out. They had to protect him, they had to protect themselves, so they had to physically restrain him. And I guess this is an issue... but it is very difficult when someone has to go into hospital for a medical condition.

While locking people in a room can be perceived as restraint, it can also be an example of isolation.

Isolation

Examples of isolation included being ignored and not being engaged in communication as well as physical isolation and lack of social contact:

I say isolation as in communication, depending on what level of dementia they are. Or how to find that key to make that contact. That's no difference at different levels, and to maintain [this communication] and to move with them in that pattern of their physical demise. And not everyone can do that.

Discomfort on the part of the carer with the older person's appearance or behaviour in public may influence the level of isolation experienced:

Well, it can be that the carer is embarrassed or gets stressed with taking someone with dementia out. It is embarrassing to them. They may be incontinent while they [are] out. Or, they dribble food or whatever. So, they basically keep them at home, isolated in the homes.

For this participant, connections between people were central to avoiding isolation and associated negative consequences. Describing the inadequate creation of community in some institutions the participant notes:

[W]e push to ... create normality and where you have a lot of issues of staffing, inappropriate environments, overcrowding, aggression—all in a tiny community that functions twenty four hours a day—the message

gets lost really. I mean the circus carries on and the person in the home is isolated.

The role of the carer in avoiding isolation of the older person and maintaining social contacts is time-consuming. The stigma of dementia combined with increasing age creates a challenge for carers intent on maintaining social networks for the person in their care and themselves:

Because of the age group of people, their social networks can often disappear anyway and maintaining normal social interactions with your friends is often not an option because your friends don't feel comfortable... So those normal associations that people have built up over their life [are] at an age group that tend to fall off anyway because of natural reasons. But, to sustain them is very difficult and because of the demographic of children who live away, we don't all live in nice communities where we have access. So, for that carer, the relentless task of every day providing emotional support is exhausting.

4.4.2 Psychological abuse

Examples of psychological abuse included threats against and inciting guilt in the victim, humiliation, invoking feelings of shame, isolation and powerlessness. The threats are usually verbal and against the older person centred on removal of care, or placement in an institution: 'If you don't do this... we'll put you in a home' or 'If it wasn't for me you would be in a nursing home.' A similar example is telling the older person that they are responsible for the carers' lack of fulfillment and ease: 'If it wasn't for you I could be doing more.'

Inappropriate teasing and taunting was categorised as an example of verbal and emotional abuse. This included ridiculing people in institutions who are developing relationships with each other. Using the older person's belief system against them was also identified in this category, with comments such as 'God is punishing you.'

Lack of respect from carers, especially that founded on lack of communication, was also identified as an example of emotional abuse.

Lack of predicability proved difficult for participants involved in care relationships. One participant described 'doubt' as the crux of the emotional abuse experienced: 'There are things that put you in an area where you doubt about what's going to happen next.' And, further:

[D]oubt about your future, really. Because you've got no idea where you're going in about 5 minutes time. It might be a case of really strewn out. You have no awareness... in my case I had no awareness, no real awareness.

Psychological abuse of carers included accusations of unfaithfulness, stealing from the older person and not caring.

4.4.3 Spiritual issues

It was clear from the data that older persons should expect not only their physical wellbeing to be free of abuse, but also what was termed a

spiritual aspect of individuals. The spirit was seen as the inner distinctive nature which makes the person the being they are. For some, the term was used interchangeably with notions of self; for others it had a more religious connotation. The development of self is influenced by culture, environment, family and ethnicity. For the participants, trust and the confidence engendered by trust was central to spiritual wellbeing:

Well, it's sort of like, I feel the people in residential care ought to have a feeling that they could trust the organisation. [That] they can trust the organisation to cater for them physically, but... also pay attention to their individuality and... just a sense of wellbeing... Where the environment is not looking after the sense of wellbeing for the person so that they can actually have a strong sense of trust in the residential care that they're going to get.

Denial of personal validation by carers—refusing to recognise and connect with them as individuals—was provided as another example of spiritual abuse.

While spiritual abuse was not confined to areas of religious practice, questions of religion figured largely in this category. Recognition and maintenance of religious traditions was identified as essential to avoiding abuse of older persons' spirituality: '[She] really wanted to go into a Catholic facility, but they couldn't find one. So, she's really distressed because no-one provides rosaries or visiting.' A heightened sense of spirituality recognised in people with dementia may make attention to these concerns a priority if abuse is to be avoided:

I think something ... that is often not recognised is, as people [develop] dementia and they go backward, they often do reawaken the awareness of spirituality even though this person hasn't darkened the church door in years!

Denial of access to ritual and the environmental factors which may contribute to that provided examples of spiritual issues. Forced ritual and roles, for example, when religion or religious visitors were forced upon older people, was another example of spiritual issues.

4.4.4 Financial abuse

Financial issues, while inherently related to inappropriate manipulation of economic means of older persons and carers, covered a wide variety of behaviours. These ranged from institutional claims made on residents' income to older people refusing to fund their own care when in informal care arrangements:

[I]t can get very tricky. It's about signing houses and farms over and that sort of isolating people and not providing care... It ties up with all the other [categories of abuse].

It is also denying someone access to care because ... the carer doesn't want to [fund care].

People with dementia were recognised as being vulnerable to financial abuse through compromised decision-making skills combined with lack of an advocate:

I think it could be about not maintaining them at the standard they normally would have been kept at. And, if you are in charge of the money, you are going to decide. It doesn't matter what standard of food, clothing, toiletries, because who is going to question you?

Well, it's about standard of living really. It's not maintaining them the way they would have ought to have been maintained had they been well... but someone else is making the decisions.

Even sometimes... someone may really need to go into care, into residential care. But, financially that's going to put pressure on the family because of assets like farms and things like that.

Having control of the finances of a person with dementia was seen as a tool for exercising control over the older person: 'Sometimes you see someone who's controlling the finances of the person with dementia and they have control of them.' Similarly: 'It's so that they can then direct the care the way they want it. They've got hold of the dollars and the person with dementia has no right.' A further example of the financial or material abuse was described by one participant who spoke of his step-daughter disposing of her mother's 'good clothing' and replacing them with second-hand clothes.

4.4.5 Systemic issues

Systemic issues frame all of the above categories. They include social and institutional structures that give form to the abuse experiences of both carers and older people. One older person described 'the system' as 'bigger than I am, and everybody's got control except you.' Lack of control or influence over their environment and the structures that form their lives are central systemic issues for carers, staff and older people.

One participant said:

It's not a direct abuse. But it comes about because of lack of staff. It comes about because of the lack of understanding, comprehension that this is a very important aspect of how people can be best cared for in these establishments. It comes about because management is unaware of it. Because management maybe are not inputting sufficiently to the wellbeing of their personal carers and so forth. It's a whole.

Recognition of institutional procedures, which worked to the disadvantage of carers and older people, were identified as components of systemic abuse. These included services being unavailable at times when they are most needed, and presentation of choices in a manner that precludes options for carers or the person with dementia:

In terms of people [having] to attain a certain level of incapacity before the service system will say 'Yes, we will provide care.' And so often the carer can be articulating that they don't feel able to care. But the service system is saying 'You have to because they're not eligible for our service.' So, people say things but they're not heard or there isn't a capacity for it to be heard within the service system because of the way we fund it or because of our target groups or whatever.

Systemic issues also included environmental deprivation/overload and related to factors such as being housed in extremely poor accommodation, being exposed to extremes of sensory overload or deprivation (eg. noise, lighting, smells), being deprived of sunshine, external views, good nutrition, privacy and so on. Participants found it difficult to differentiate poor care from abuse however, there clearly was an important issue here.

4.5 Mandatory reporting

Mandatory reporting was, on the whole, not identified as a strategy that could be useful at present. Participants recognised that professional bodies already had strategies for those professionals found guilty of gross misconduct (as a result of poor practice). Many participants saw reporting as punitive rather than supportive. This may reflect a lack of understanding of the process of mandatory reporting. Little is documented on the efficacy of mandatory reporting and that which is recorded only highlights the negative aspects of the process. This suggests more work is required on identifying positive outcomes and benefits to those individuals who are protected when the process is implemented.

Participants suggested that where abuse was perpetrated by staff due to poor practice that management should facilitate appropriate education and training rather than the punitive action of reporting. Specific education on dementia was seen as essential if carers were to understand the complexity of caring for someone with this disease. Continuous ongoing education regarding various aspects of care should be offered to staff and carers, which would hopefully reduce the incidence of inappropriate care which may be misconstrued as abusive.

4.6 Summary

The types of abuse identified included those commonly cited in other reports: psychological, physical and financial, however, participants saw systemic issues as integral to elder abuse. Participants stressed these systemic issues need to be addressed if any success is to be achieved in removing other issues relating to abuse. The need to think about abuse on a continuum and within context was very clear. In the grey area the benevolent—but ignorant—actions of one person could constitute abuse to another. Any approach to abuse should recognise the continuum from poor practice to blatant abuse.

5. Summary of findings

The findings from this project are consistent with previous work and extend this work specifically into the area of abuse and dementia. Attempting to define abuse precisely was seen as an unhelpful and probably impossible exercise. It was very clear that while broad parameters may be agreed, all cases need to be assessed in relation to their unique contexts. Because the discussion was within the context of abuse all responses were framed in that way. However, it is likely that the responses would have been very similar had the context been one of discussing stress.

The major precipitators of abuse were identified as:

- vulnerability;
- overwhelming perceptions of stress; and
- feeling unsupported and lack of relevant knowledge and skills.

Individual abuse was seen to be supported by a system that was often ageist, inflexible and lacked the knowledge, skills, environments, attitudes, structures and processes necessary to prevent vulnerability, stress, ignorance and subsequent abuse.

The types of abuse which were identified were consistent with those previously reported. Mandatory reporting was not supported, as participants generally argued for supportive responses and mandatory reporting was perceived to be punitive and not successful in other areas where it has been introduced.

6. Conclusions

There is potential for abuse across the continuum of care for all people with dementia and their carers, no matter where the caring takes place. If one is to be serious about minimising abusive situations, preventative strategies need to be seen as the priority.

Public stigma regarding both dementia and abuse was seen as an overriding problem which leads to hesitation in seeking advice or assistance. Some carers expressed a feeling of enforced marginalisation because of the manifestations of the disease and a lack of recognition by staff and family members that a change in the individual had occurred. This feeling was expressed as 'No-one is listening'. Participants considered it a priority to raise public awareness of dementia, abuse, the role carers play in providing community care and the impact caring responsibilities can have on an individual. Educating the public in relation to enduring power of guardianship, powers of attorney and generally having one's house in order should cognitive competence diminish was also seen as a potentially useful preventive strategy.

General strategies which the participants suggested would prove beneficial included:

- raising public awareness that abuse occurs not only in the home but wherever care is delivered;
- encouraging carers, staff and, where feasible, people with dementia to seek help;
- establishing a very well known first point of contact; and
- ensuring the contact point can provide useful, non-judgemental and supportive information. For the contact point to be effective it would be essential for each community to have a group of experts to whom the abusers and abused could turn.

Carers identified the need to improve the adequacy of service provision. This included more flexibility in service provision and easier access to information about services and support agencies. Expecting GPs to be the 'fonts of all knowledge' and the people responsible for providing practical support and education has failed in the past and there is no evidence to indicate that GPs will have more time and/or be more able to undertake this role in the future. Nevertheless, GPs are a first contact for many people and should have ready access to experts in dementia and abuse with whom they can consult.

There has been a certain amount of work done in the area of abuse and a number of protocols and policies exist. What seems to be needed is action to ensure all services have policies and protocols based upon the best available evidence. Policies and protocols need to be dynamic, user friendly, embedded in practice, accepted by staff, carers and other relevant members of the community and evaluated in terms of quality outcomes. Teams of multidisciplinary experts/consumers could provide the impetus for initiating anti-abuse strategies and for monitoring and supporting processes and outcomes. There was support for some Statewide co-ordination/ standards but with local implementation. In the USA, the Los Angeles Fiduciary Abuse Specialist Team (FAST) offers specialist financial advice to protective services, community service providers and the general public, and could provide an excellent model for addressing financially abusive situations. The FAST is a multidisciplinary team comprised of detectives, lawyers, health service providers, bankers, stockbrokers, real estate agents and financial planners. Its success in resolving cases of financial abuse has led to upskilling and increasing the confidence of workers who are motivated by the improved case outcomes.

For any strategies to be successful there does need to be flexible, responsive support services in place. Participants in all groups reconfirmed the need for access to 24 hour/seven days a week respite. Such respite could be offered in a variety of ways including respite in the home, formal respite beds and respite holidays for carers with or without the person with dementia. Family carers wanted access to

more education about how to care for the person with dementia, how to care for themselves and about the dementing process.

Poor relationships between the person with dementia, carers and staff were at the centre of many abusive situations. There was a stated need for staff to be more knowledgeable about dementia and appropriate care practices if they were to work in this area. There was also a need for environmental and system support for both family carers and in formal caring contexts. This may include ensuring adequate and appropriate staff mix, providing safe areas as alternatives to restraint use and exploring flexible ways of supporting staff/carer knowledge gaps, for example access to telecare consultancy and/or networks.

While community resources were seen as an essential component in assisting carers, there also emerged the need for dementia specific care. Participants spoke of the need for funding to be set aside for dementia specific units and an increase in the funding for dementia beds in aged care facilities.

An overriding factor in the development and provision of services was the need for the people requiring the services to feel empowered. Empowerment was seen to occur through inclusion in decision making and in partnership between staff and family. The provision of information on the dementia, choice of care provision, and information on services already available were identified as essential in supporting carers, staff and people with dementia. Carers not only identified the need for those caring for their relative be knowledgeable about dementia, but also the need to feel confident that the dignity of the individual would be preserved. It was also important to the carers that they had the opportunity and choice to be as much or as little involved in the care as they desired. Carers recognised that they had expertise in the delivery of care for the person with dementia and this information could be:

- beneficial to the staff in providing more strategies for care;
- beneficial to the person with dementia in reducing the fear of being cared for by a stranger; and
- beneficial to the carer knowing their loved one was safe and receiving optimum care.

Mandatory reporting was, on the whole, not identified as a strategy that could be useful at present. Many participants saw reporting as a punitive rather than supportive action. This may reflect a lack of understanding of the process of mandatory reporting. Little is documented on the efficacy of mandatory reporting and that which is recorded only highlights the negative aspect of the process. This suggests that more work is required on documenting positive outcomes and benefits to those individuals who are protected when the process is implemented. Having supportive communities was seen to be a less threatening response. Such communities understood dementia and assisted with care by, for example, returning wandering people home,

being alert to inappropriate financial transactions, tolerating/distracting unusual and perhaps uninhibited behaviours and so on.

In conclusion, preventative strategies need to be seen as the priority. The analysis of data derived from discussion forums and interviews provided a framework for the development of a model protocol that is dementia specific. It is intended that this protocol be used in conjunction with existing resources and protocols³ which deal with the generic aspects of abuse. The protocol will be evaluated in Phase 2 of the project.

7. References

Austin and Repatriation Medical Centre. (1996). *Elder Abuse Resource Kit*. Melbourne.

Australian Bureau of Statistics. [ABS] (1999). *Australian Demographic Statistics*. June Quarter, Catalogue number 3101.0.

Bright, L. (1997). *Harm's Way: Abuse Experienced by Residents in Homes and Steps to Take to Reduce it*. United Kingdom.

Cahill, S. & Shapiro, M. (1993). 'I think he might have hit me once': Aggression towards caregivers in dementia care. *Australian Journal on Ageing*. 12(4): 10–15.

Comijs, H.C., Pot, A.M., Smit, J.H., Bouter, L.M. & Jonker, C. (1998). Elder abuse in the community: prevalence and consequences. *Journal of the American Geriatric Society*. 46(7): 885–888.

Commonwealth Working Party on the Protection of Older People. (1994). *Protection of Older People in the Community*. Canberra: AGPS.

Coyne, A.C., Reichman, W.E. & Berbig, L.J. (1993). The relationship between dementia and elder abuse. *American Journal of Psychiatry*. 150(4): 643–646.

Department of Health and Community Services, Aged Care Services. (1995). *With Respect to Age: A Guide for Health Services and Community Agencies Dealing with Elder Abuse*. Melbourne: DHS.

Department of Human Services, Northern Metropolitan Region. (1997). *Elder Abuse Protocol*. Melbourne: DHS.

Department of Human Services, Southern Metropolitan Region. (1997). *Dealing with Elder Abuse: A Training Kit*. Melbourne: DHS.

3. Examples of existing resources include: *With Respect to Age*; Duty of Care; Residential Care Rights; Statutory obligations; Aged Care Act; Mental Health Act; Outcome Standards / Accreditation; Resident Classification System; Occupational Health and Safety; any other relevant existing State or Commonwealth guidelines.

- Family and Community Development Committee. [FCDC] (1997). *Inquiry into Planning for Positive Ageing*. Melbourne: Victorian Government Printer.
- Fielding, W.S. (undated). *Responding to Elder Abuse: A Guide for Carers* (Victoria)
- Hall, P.A. (1989). Elder maltreatment items, subgroups, and types: Policy and practice implications. *International Journal of Ageing and Human Development*. 28(3): 191–205.
- Hamel, M., Pushkar Gold, D., Andres, D., Reis, M., Dastoor, D., Grauer, H. & Bergman, H. (1990). Predictors and consequences of aggressive behaviour by community based dementia patients. *The Gerontologist*. 30(2): 206–211.
- Kurrle, S.E., Sadler, P.M., Lockwood, K. & Cameron, I.D. (1997). Elder abuse: prevalence, intervention and outcomes in patients referred to four Aged Care Assessment Teams. *Medical Journal of Australia*. 166(3): 119–122.
- Kurrle, S.E. & Sadler, P.M. (1994). *Assessing and Managing Abuse of Older People: A Handbook for the Helping Professions*. Sydney: Alpha Biomedical Communication.
- Lachs, M.S., Williams, C., O'Brien, S., Hurst, L. & Horwitz, R. (1997). Risk factors for reported elder abuse and neglect: a nine-year observational cohort study. *The Gerontologist*. 37(4): 469–474.
- Lowell, R. (1996) Exploring the private sector in aged in-home care provision. *Lincoln Papers in Gerontology*. 32. Melbourne: La Trobe University.
- Ministerial Task Force on Dementia Services in Victoria, (1997). *Dementia Care in Victoria: Building a Pathway to Excellence, Final Report*. Melbourne: DHS, Aged, Community and Mental Health Division.
- New South Wales Task Force on Abuse of Older People. (1993). *Abuse of Older People in their Homes: Final Report and Recommendations*. Sydney: Office on Ageing.
- Paveza, G.J., Cohen, D., Eisdorfer, C., Freels, S., Semla, T., Ashford, J.W., Gorelick, P., Hirschman, R., Luchins, D. & Levy, P. (1992). Severe family violence and Alzheimer's disease: prevalence and risk factors. *The Gerontologist*. 32(4): 493–497.
- Pillemer, K. & Suitor, J.J. (1992). Violence and violent feelings: what causes them among family caregivers? *Journal of Gerontology*. 47(4): S165–S172.
- Public Trustee (Queensland). (1999). *Abuse of Older People. What is it? What can be done about it? Who can you turn to for help?* Brisbane.

Sadler, P., Kurrle, S. & Cameron, I. (1995). Dementia and elder abuse. *Australian Journal on Ageing*. 14(1): 36–40.

Southern Health Care Network. (1999). *Supporting Older People at Risk: Protocols for the Prevention of Elder Abuse*. Melbourne.

Weeks, E. & Sadler, P. (1997) *Elder Abuse and Dementia*. Sydney: NSW Advisory Committee on Abuse of Older People.

Wolf, R.S. (1988) Elder abuse: 10 years later. *Journal of the American Geriatrics Society*. 36(8): 758–762.

Office of Seniors Interests. (2000). Major initiatives, elder protection. Government of Western Australia. [<http://osi.wa.gov.au/iyop/elders.htm>] Accessed 22-5-2000.

Office of Ageing. (1999). Abuse of older people. Facts about older people information sheet. Queensland Department of Families, Youth and Community Care. [<http://www.families.qld.gov.au/ageing/fact8.html>] Accessed 22-5-2000.

8. Appendices

8.1 Plain language statement

Title of project:

Elder Abuse of People with Dementia and their Carers

There are various forms of abuse perpetrated against older people including physical, psychological, financial, sexual abuse, and neglect. Elder abuse can occur in a variety of settings through both formal and informal carers. It is not always the person requiring care who is the victim of abuse. Carers themselves may be the victims of abuse. The present project is designed to help meet the information needs of concerned individuals and organisations so that they are better equipped to deal with this significant social issue. Information will be collected through discussion forums and interviews with experts and other individuals who have experienced abuse in some way, directly or indirectly. These sessions will be recorded and transcribed for analysis, the results of which will be presented in a report of the project's findings.

There will be no physical risk to participants. Speaking about their experiences may cause some participants to become upset. The researchers have counselling skills and experience working with sensitive issues, including working with people who are dementing and their carers. If further support is needed arrangements have been made with the Alzheimer's Association Victoria to access their counselling resources.

If you agree to participate in the study the researcher will talk with you about your experiences of abuse. It is anticipated that the interview will take no longer than one hour. Your details will be coded so that all information you give will remain confidential. Information that you give will be included in reports and publications on the study but your identity will not in any way be disclosed. You may withdraw consent at any time during the study and information given by you will then be excluded from consideration and publication. If you divulge information during the interview that indicates a life threatening situation, the interviewer will inform your GP or the person who originally contacted you about this research. Should you ask for assistance in relation to an abusive situation the researcher will put you in touch with someone who can provide that assistance.

If you have any questions about the study entitled 'Elder Abuse of People with Dementia and their Carers' please contact Susan Koch, Senior Lecturer at the School of Nursing, La Trobe University on 9479 2898. Any queries or complaints relating to this research which have not been resolved by the researcher may be referred to the Liaison Officer of the La Trobe University Human Ethics Committee at the Research and Graduate Studies Office, La Trobe University, Bundoora, 3083. Telephone (03) 9479 1443.

8.2 Consent form

Title of project:

Elder Abuse of People with Dementia and their Carers.

I (the participant) have read (or have had read to me—*where appropriate*) and understood the information above, and any questions I have asked have been answered to my satisfaction. I agree to participate in this activity, realising that I may withdraw at any time.

I agree that research data collected during the study may be published or provided to other researchers, on condition that my name is not used.

NAME OF PARTICIPANT (in block letters) _____

SIGNATURE _____

DATE _____

AUTHORISED REPRESENTATIVE (block letters) _____

(required only where the participant is not capable of providing his/her informed consent)

SIGNATURE _____

DATE _____

SENIOR INVESTIGATOR (name in block letters) _____

SIGNATURE _____

DATE _____

8.3 Introduction to forum

Welcome and thank you for coming.

As you are aware, we are here to discuss the issues surrounding the abuse of elderly people and their carers. This is an issue of concern to all of us.

These forums are an opportunity to discuss these issues in the company of others with similar interests, experiences or concerns. The information we gather through this study will help to inform the development of policies, guidelines, materials and resources to help address the issue of the abuse of elderly people where dementia is also present.

As researchers we will take every caution to protect the identity of the people present. Information you provide will not be individually identified in any reports or publications resulting from this study. These sessions will be recorded and those recordings will only be available to the research team. You should be aware however, that these are public forums. Any information you give or comments you make will be heard by others present at the forum and the researchers have no control over what other people may do with that information. Having said that I urge everybody here to treat anything you hear here as in confidence and anonymous. Because this cannot be controlled I would like to keep the discussion on a general level. We will discuss issues and thoughts, your suggestions and recommendations for improvements in the way that elder abuse issues are dealt with, and the types of scenarios which could develop into an abusive situation.

If you have more personal experiences that you would like to convey to the research team please approach one of us for a personal interview, where we can explore these experiences in more depth and in privacy.

We respect your right to anonymity but also appreciate that the information you are sharing with us is a valuable contribution to the research. We would like to give you an opportunity to be acknowledged in the final report. Anyone who is happy to be acknowledged for their contribution is invited to sign the register (if you haven't already) and tick the appropriate space. The acknowledgment will not identify what you said or how you contributed but simply that you participated in the study.

Thank you for your attention.

Let's begin.

8.4 Notice of study

The Gerontic Nursing Professorial Unit, School of Nursing, La Trobe University are conducting a study into the **Issues Surrounding the Abuse and Neglect of Older People with Dementia and their Carers.**

Alzheimer's Association Victoria has been funded to carry out a project to look at issues surrounding elder abuse for people with dementia, their families and carers. The project is being conducted in conjunction with La Trobe University's Gerontic Nursing Professorial Unit, School of Nursing.

Elder abuse can occur in both formal and informal caring situations. Caring for a person with dementia can cause a great deal of stress, which can lead to physical or verbal aggression by either the person with dementia or their carer. This project seeks to understand these situations and other forms of abuse against older people with dementia and their carers, with a view to overcoming abuse and better supporting all involved.

People with dementia, their families and carers, and service providers who have an interest in or experience of this issue are invited to participate in this project. Forums concentrating on Formal and Informal Care Issues will be held in metropolitan and rural regions in February and March 2000.

Sale :	15 February	Sale Memorial Hall, 82 Macalister St
Warnambool:	16 February	Lyndoch Home for Aged Care, Hopkins Rd
Echuca:	18 February	Shire of Campaspe Offices, Cnr Hare and Heygar Sts
Melbourne:	21 February	Kingston Centre, Warrigal Rd, Cheltenham
Melbourne:	6 March	Melbourne Extended Care and Rehabilitation Service (formerly North West Hospital), Poplar Rd, Parkville
Wangaratta:	10 March	St John's Retirement Village Hostel, Williams Rd

Formal Care Issues Forums (suitable for GPs, Nurses, Social Workers, other Health Professionals, Industry Groups, Peak Bodies etc.) will be held at 10 am at each location.

Informal Care Issues Forums (suitable for people with dementia, their carers, family members, advocacy, self help and support groups, etc.) will be held at 1pm at each location.

The forum proceedings will be audio recorded and transcribed for analysis, with findings/results published as a report.

See over for more details of the project or contact Susan Koch, Senior Lecturer at the School of Nursing, La Trobe University on 9479 2898.

Further information

There are various forms of abuse involving older people including physical, psychological, financial, sexual abuse and neglect. Elder abuse can occur in a variety of settings through both formal and informal carers. It is not always the person requiring care who is the victim of abuse. Carers themselves may be the victims of abuse by their charges. The present project is designed to help meet the information needs of concerned individuals and organisations so that they are better equipped to deal with this significant social issue.

The aims of the project are to:

- investigate the issue of elder abuse in relation to people with dementia and their carers;
- increase awareness of this issue amongst service providers and the general public; and
- develop more consistent and effective responses by services to elder abuse, with specific focus on people with dementia.

Information will be collected through discussion forums and interviews with experts and individuals who have some form of experience with elder abuse. These sessions will be recorded and transcribed for analysis, the results of which will be presented in a report of the project's findings.

Speaking about their experiences may cause some participants to become emotional or upset. The researchers have counselling skills and experience working with sensitive issues, including those of people who are dementing and their carers. If further support is needed arrangements have been made with the Alzheimer's Association Victoria to access their counselling resources. The research is designed to gain a better understanding of the issues surrounding the abuse and neglect of older people and will be used to help develop materials and policies to minimise the incidence and impact of this abuse.

If you agree to participate in the study the researcher will ask about your knowledge or experiences of abuse or neglect. The information presented at the group forums will be available to all who attend these forums and as such no guarantee of confidentiality can be given except on behalf of the researchers. If you believe that you have expertise in this area or if you have personal experience of abuse or neglect and would like to contribute further to the study through a personal interview, please contact Susan Koch, Senior Lecturer at the School of Nursing, La Trobe University on 9479 2898.

If you would like more information or have any questions about this study please contact Susan Koch, Senior Lecturer at the School of Nursing, La Trobe University on 9479 2898

The information provided by individuals will be treated anonymously. However, if participants wish their contribution be acknowledged in the final report, they will be provided with the opportunity to sign an attendance sheet.

Registration form
for the Elder Abuse Forum

Name: Position:.....

Organisation:.....

Address:.....

Phone:..... Fax:..... email:.....

Forum you are attending: Formal Care Informal Care

at: Sale Warrnambool Echuca

 Kingston Ctr MECRS Wangaratta

Please return this form to: School of Nursing
 La Trobe University
 Bundoora 3083.

or by contacting Ms Catherine Watts on 9479 5936 / fax: 9479 5842 or
email: c.watts@latrobe.edu.au

8.5 Forum and interview participants

Steve Aivaliotis, Residential Care Rights	Marea Davies, Carer Support Services
Abbie Alcock, Carer Respite & Information Service Hume Region	Jean De Lange, Co Care Gippsland
Shelley Andrew, Carer Respite & Information Service Hume Region	Jean Dennis, Hume Region Regional Aged Care Council
Ina Baird, Community Connections Vic Ltd	Betty Diamond, Alzheimer's Association Support Group
Diane Barnes-Jenkins, Royal District Nursing Service	Helen Dimitakis, Carer Links West
Michele Barry, Aged and Disability Services, Hobsons Bay City Council	Sophie Dimitracopoulos, Aust. Greek Welfare Society
Jule Beauchamp, Community Connections Vic Ltd	Teresa Donegan, Dept of Human Services Southern Metro Region
Sharon Blackney, Lyndoch	Chris Dunster, Carer Respite & Information Service Hume Region
Fay Brassington	Anne Elkins, Moonee Valley Council
David Bugge, Community Connections (Vic)	Gwenyth Ellemor, Community Connections Vic Ltd
Maureen Bushell, Lyndoch	Jane Evans, ACAS - Caulfield
Yvonne Byron, Lyndoch	Fran Faulkner, Alzheimers Association
Jill Campbell, Alpine Health	Eileen Fern, Co Care Traralgon
Shirly Carcozza, Community Health Service	Colleen Fitzgerald, Lyndoch
Holly Cardamone, Australian Residential Care Pty Ltd	Louisa Folkard, Aged & Disability Services, Melton
Lynne Chapman, Moonee Valley Council	Andrew Freeman, Aged and Disability Services, Hobsons Bay City Council
Judy Clark, Lyndoch	Blima Frenkel,
Lisa Clinnick, Hepburn Health Services	Morry Frenkel,
Melinda Collins, St. Vincent's Hospital	D.K. Fulton, Lyndoch Nursing Home
Glenys Craig, Bundoora ACAS	Doreen Fulton, Lyndoch Nursing Home
Coral Cramer, Aged & Disability Services, Melton	Margaret Good
Elizabeth Crask, Alzheimers Association	Sue Green, Camperdown & Support Group
Judy Couch	Cathy Halmarrick, Central Bayside Community Health Services
Agnes Cupures, Dutch Care	Karen Hampshire, Carer Respite & Information Service Hume Region

Therese Healy, Parkville Hostel	Maree McCosh, Lyndoch
Christine Hetherington, Lyndoch	Rae McGowan, Community Connections
Ann Heywood, Rural City of Wangaratta	Judy McNally
Eileen Homan, Camperdown & District Support Group	Pia McNamara
E. Hounslow	Kerry Nelson, c/o Lyndoch Warrnambool Inc
Jo Howard, Sunbury Community Health Care	Meghan O'Brien, St. Vincent's Hospital
Jan Hutchinson, Hepburn Health Services	Joy Orr, Kyabram Hospital, The Pat Hayes Centre
Lynne Johnston, Kyabram Hospital, The Pat Hayes Centre	Joan Pepi, South Eastern Region Migrant Resource Centre
Alan Jones, Bayside Council	Denise Pedrotti
Carol Josselyn, Dementia Respite Options	Linda Persey
Evelyn Karlinski	Joanne Pine, Carer Support Services
Ann Kay, Yarran District Health Services	Joan Polglase, Community Connections Vic
Catherine Kearne, Lyndoch	Ken B.E. Raff
David Keilar, Lyndoch	Gil Robertson, Alzheimer's Association Ballarat Support Group
Rosa Lam, Royal District Nursing Service	Kaye Rossborough, Judy Santwyk-Anderson, 'Killara' Peter James Centre
Annette Lamprell	Elaine Scanlon, Royal District Nursing Service
Helen Light	Joyce Sheppard, Lyndoch
Claire Lippardi, Lyndoch	Kath Sheridan, Royal District Nursing Service
Mary Lyttle, Residential Care Rights	Anne Short, Ashburton Carer Support Group
Brodwyn Madder, ABCSI - Elsie Salter House	Brian Sinclair, Central Bayside Community Health Services
Rita Mahony, Moonee Valley Council	Meaghan Stuver, Royal District Nursing Service
Gloria Manu, Grace McKellar_Percy Baxter Lodges Geelong	Trish Stow, City of Greater Bendigo
Elizabeth Markwell, Lyndoch	Vicki Thomson, Engelbert Lodge
Priscilla Mayne, City of Wyndham	Phil Torpy, Lyndoch
Lynn Mogi, Aged Care Assessment Service, Kingston Centre	Cathy Tzoulis, Carer Links West
Sally Moseby, Blackburn Aged Care Facility/Thames St Aged Care Facility	Netty Van Gelder, Age Concern, Albury/Wodonga
Kathleen Mutimer, Mordialloc Aged Service Committee	

Angela Wallace, Peter James Centre	Bev Wilson, Camperdown & District Support Group
Guy Walter, Moonee Valley Council	Anne-Maree Wilton, Silver Circle
Paula Weckley, City of Darebin, Dementia Care Unit	Bianca Winter, City of Casey
Bonnie Williams, Lyndoch Carers Group	Gaye Whitney, Kangan Batman TAFE, Moreland Campus
Kath Williams, Community Connections Vic	Marnie Zakis, ABCSI - Elsie Salter House