



RESPONSE TO THE NSW ABUSE OF OLDER PEOPLE INTERAGENCY PROTOCOL

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Opening comments

Carers NSW (CNSW) is the peak body in NSW representing 750,000 people caring for a family member, friend or neighbour who has a disability, chronic condition or mental illness or who is frail aged. Whilst each care situation is unique, carers provide a range of practical assistance, health care, emotional support, supervision and advocacy that support older people to remain living at home.

Overall, CNSW welcomes the NSW Government commitment's to supporting the wellbeing of its older residents. Further, CNSW considers the abuse of older people as a serious community issue that requires a coordinated response and partnership to ensure consistent, timely and effective interventions that are in the best interest of the older person.

However, CNSW believes that one of the key challenges in this emerging area of policy practice and research is recognition that informal carers who support the older person to continue to live at home experience varying degrees of abuse themselves.

In this situation, the needs of the carer in terms of health and well being as well as rights and protection must be addressed so they can continue in their caring role without detriment to themselves and the people they care for. Carers may also be providing support and acting as an advocate on behalf of their care recipient where abuse has occurred in the community care setting. In line with this, CNSW asserts that the revised Interagency Protocol needs to take into account the growing body of evidence surrounding carer stress and carer abuse, and the interactional nature of elder abuse and its implications to new models of intervention and prevention.

The abuse of older people is a complex problem that can emerge from multiple causes and factors including family situations, carer issues, and cultural issues. Family situations include discord in the family created by the older person's presence, a history and pattern of violent interactions within the family, social isolation, stresses on the carer or carers, and lack of knowledge of care giving skills.

This submission provides information about some of the issues that carers face in relation to the Protocol and highlights the need to provide better and more timely responses to informal carers, who are themselves ageing and faced with the challenge of caring for an increasingly complex and dependent care recipient. Areas where it is recommend that there should be better inclusion of carer's needs, rights and protection have been identified and practical questions are raised around the implementation, monitoring and updating of the Protocol.

A series of recommendations have been provided in the last section of the submission - ideas on further research topics that CNSW believe will inform future thinking and direction in supporting vulnerable adults in our community.

Key Issues For Carers in Relation to the NSW Abuse Of Older People Interagency Protocol

The bulk of care to older people takes place in the community and care needs are met by unpaid family carers. Without the care provided by family members, the current system of community care would not be unsustainable.

- Like all people, carers have a right to be treated with dignity, respect and to be able to provide care in a safe environment.
- Different care situations and carers from different community groups will require different inventions and Protocols.
- Carers are often at risk of abuse themselves in their caring role.

- Many carers themselves are ageing and their health and well being is deteriorating and their ability to continue care is at risk.
- The Protocol assume a link between carer stress and abuse of the care recipient by the carer.
- Carers need education, training and support to provide ongoing care.

Elder Abuse – the issues

Definitions and Language

CNSW proposes that the definition section within the Protocol be expanded to include unintentional neglect, intentional neglect and self-neglect.

The complexity of defining the abuse of older people, or elder abuse, and debate over classification of types of mistreatment compound the task of evaluating the magnitude of the problem. Definitional disputes and the continuing search for definitions of elder abuse and neglect remains an important issue. Thus accurate definitions of abuse and neglect will ensure accuracy in screening, classification and appropriately targeted interventions.

CNSW also proposes that an alternative term to *elder abuse* be considered.

The term 'elder abuse' encompasses behaviours outside of physical acts such as financial abuse and emotional abuse. CNSW suggests the use of the term 'Vulnerable Older Adults' as this reflects more accurately the risk factors that older people and their carers face, the context in which the caring is taking place, and addresses the importance and challenge of balancing autonomy with the safety of vulnerable adults. In line with this suggestion, CNSW would support a renaming of the interagency Protocols to *NSW Abuse of Vulnerable Older Adults Interagency Protocol*.

NEGLECT- INTENTIONAL OR UNINTENTIONAL AND SELF NEGLECT

Carers NSW supports the definitions and description of the different types of abuse that older people may face. However, we strongly recommend that it is important to qualify, acknowledge and articulate the difference between the various types of neglect within the Protocol.

Neglect can be defined as intentional or unintentional harmful behaviours on the part of an informal carer paid or unpaid in which the older person has placed his or her trust.

Unintentional neglect involves a failure to fulfil a care taking responsibility, but the carer does not intend to harm the older person; **intentional neglect** occurs when the carer or care worker consciously and purposely fails to meet the needs of the older person, (McDonald 1996)

Neglect typically refers to the refusal or failure to provide an older person with the necessities of life such as water, food, clothing shelter, personal hygiene medicine comfort, personal safety and other essentials.

CNSW also supports the inclusion of **self-neglect** in the Protocol.

Self-neglect is characterised as behaviour by an older adult that threatens his or her own health and safety. Self-neglect usually means that the older adult refuses to or fails to provide him or herself with the necessities of life noted above. This newer definition of self-neglect excludes situations in which a mentally competent older person knowingly makes a voluntary decision to engage in acts that threaten his or her safety.

Although there are some scholars who question as to whether self neglect should be included in consideration of the abuse of older adults because no relationship of trust exists, alternatively some would argue that it is important to consider it as part of the different types of abuse that occur.

The focus of the Protocol is not only about responding reactively to situations where there is suspected abuse, but to anticipate and where possible prevent such abuse as well as provide support and education to adults who are vulnerable in our community.

Carer Abuse

CNSW suggests there is a clear statement and recognition within the Protocol that carer abuse exists and it is often unrecognised and unspoken in policy and practice.

Carer Abuse is not a new phenomenon in the field of literature on elder abuse. Carer abuse occurs when the carer is abused by the person they are caring for. Usually there has either been a long history of domestic violence or the recent onset of dementia.

CNSW receives over 1000 calls per month through the Commonwealth Carer Resource Centre carers' 1800 telephone line. CNSW collects data and case histories on calls made to this number. In the last 12 months the number of calls received on the subject of abuse was a total of 109. Of these, 73 calls were from carers about carer abuse and the remaining 36 calls were regarding the abuse of the care recipient by family members.

This indicates that there are significant numbers of carers and those they provide care for that require better support to enable them to continue in their role as a carer and prevent the breakdown of the caring role and relationship.

This information points to the need to continue with a range of support, education and provision of respite services for carers to have a decent break from their caring role. Assessment becomes critical in determining the balance between providing services to supplement carer contributions or to substitute for those inputs for individuals without carers.

CARER STRESS

Despite the popular image that elder abuse is primarily caused by stressed carers and dependent elders, evidence is accumulating that neither carer stress levels nor victims levels of dependence may be core factors leading to elder abuse (Wolf, 2000). Nonetheless carer stress remains a significant concern. Carers, who are quite often ageing themselves or caring for more than one family member, face the personal challenges of ageing while addressing the needs of their care recipient. While carers' stress may not directly lead to intentional or unintentional abuse and neglect of others, it may lead to a decline in the physical, emotional and financial wellbeing of the care provider.

Furthermore, the carer is at risk and vulnerable to abuse by the elders for whom they care. Some scholars have belatedly questioned whether spouse abuse is ever first time abuse in old age (Eckley & Vilakazi, 1995; Knight; Neysmith 1995). Most of the literature has ignored the history of relationships across the life span and there is a great variability in the ways in which families react to the progression and the context of their caring role. Families and carers benefit from interactions with providers who understand that individual members' comprehension may be uneven, and who can also help ease the difficult transitions that accompany decline, grief and loss.

Carer stress and its outcomes may be mediated or moderated by the social support and coping resources of the carer and the care recipient (Aneshensal, CS; Pearlin, LI; Mullan, J.T).

The primary function of support programs should be to promote the wellbeing of carers in their ongoing role and to identify early, those carers with ineffective problem

solving and coping styles, and provide them with appropriate problem solving interventions.

It is more appropriate to look at the situation as one in which there are two vulnerable adults (victims), rather than a victim and an abuser. There appears to be very little evidence to link caregiver burden and stress with violence and abuse (Coyne 2001; salderet al 1994:38) however, many of the interventions and Protocols around dementia and abuse appear to be underpinned by the assumption that there is a direct correlation.

Older people, family members and carers need to receive education about the signs of carer stress and about their own rights not to be abused.

This education should have the objective of raising awareness and identifying sources of support and assistance. Consideration needs to be given to funding through carer organisations for such carer education.

FINANCIAL ABUSE

The Protocol needs to explore in depth particular strategies that provide support to carers in asset management interventions and responses. As close relatives and friends are the main source of support for older people informal carers are likely to be the first source of help with financial matters. The provision of assistance with managing finances and assets by relatives and friends raises questions of probity and propriety. Conflicts of interest and risks of financial abuse may arise especially where help with finances is embedded within close care relationships that involve high levels of trust and privacy.

The extent of deliberate financial abuse is unclear. Doubtful practice may reflect carers ignorance or misunderstanding of the complexities of managing someone else's financial assets. Older people, carers and frontline staff lack knowledge and understanding of issues involved in managing older people's financial affairs, especially how legal and administrative arrangements affect their choices, decision making and independence. Making sound decision about the management of resources and assets in older age is an increasingly complex task.

Assisting informal carers with asset management and protecting older people from financial risks and abuse requires various strategic policy and practice responses that extend beyond substitute decision making legalisation.

Policies and programs are required to:

1. Increase awareness of the tasks, tensions and practices surrounding asset management.
2. Improve the financial literacy of older people, their informal carers and service providers.
3. Ensure access to information, advice and support services.
4. Develop better accountability practises.

In summary, although there is a wealth of information available on managing the finances and assets of an older person, this is fragmented, not widely known or easy to access; is often poorly understood by the public in general and by older people and their relatives in particular. There is a need for a single, comprehensive and easily understandable guide that brings together existing information from a wide range of organisations and sources.

Careful evaluation of the accessibility, relevance and usefulness of such a guide is essential. Both policy actions and further research are therefore urgently needed in order to improve the levels of financial literacy, accessibility of information and support available to older people and their informal carers.

Context and the Role of Caring

In section 4.1 of the Protocol, there should be recognition of the notion of responsibility, particularly when the person with dementia is perpetrating the abuse of the carer.

Research has indicated that carers are concerned about their ageing status, their deteriorating health and their ability to continue to care for their dependents. (O'Connell, Bailey & Pearce 2003). In addition, as older carers are often caring for someone in their own age group, they may also have to cope with the growing dependence of the care recipients, and at the same time, they are increasingly likely to have at least one chronic health condition themselves.

Dementia is already a significant health, social and economic problem for Australia and will increase to epidemic proportions. The projections of the incidence of dementia are overwhelming. There are currently 200,000 people diagnosed with dementia in Australia per year and by 2050 this number is projected to grow to 730,000. In terms of current government policy and the preference of older people to remain living in their own home, the need for informal carers will also continue to grow.

The interface/relationship of dementia to experiences of abuse by either the person with dementia or their carer requires careful consideration. CNSW believes there are some complex and critical issues that need to be addressed within the context of the Protocol.

Within the dementia specific literature, there is debate about the notion of responsibility, particularly when the person with dementia is perpetrating the abuse. Questions are raised about how they can be held responsible when they have a cognitive impairment, given that intent is seen to be a crucial focus for definition of abuse. Violence and aggression in the context of dementia are not uncommon and can be observed as one of the most serious behavioural symptoms relating to dementia.

There is some evidence reported in the literature that service providers may inappropriately seek to maintain the community care situation, even where there is evidence that the carer is being abused. Of relevance is the 1997 study in Adelaide by Gilbertson & Bull. Seventy two percent of caregivers only relinquished care at the time of a crisis- "notably a threat to the safety of the care giver". However, there are some voices advocating a change:

"In the field of dementia it has been suggested that, as a basic starting point, there must be a shift away from the goals of care being to simply reduce institutionalisation and sustain caring relationship. Rather the aim should be to enhance the quality and meaning of life for both the person with dementia and their carers" (Gilbertson & Bull 1997)

The interface of dementia, elder abuse and domestic violence can result in situations where the:

- Older person with dementia is the abuser where there is not a history of domestic violence power /control issues
- Older person with dementia is the abuser where there is a history of domestic violence before the onset of dementia
- Older person with dementia is the victim of abuse where there is not a history of domestic violence

- Older person with dementia is the victim of abuse where there is a history of domestic violence before the onset of dementia
- Person using violence or the victim of violence is an unpaid carer (family member) a paid carer (within the community) or an institutional carer.

Where the person with dementia is the abuser, the reason for the abuse is often conceptualised as a behavioural or psychological symptom of dementia. This can result in responses that do not consider the needs, rights and protection of the carer, especially when the carer is a partner or family member.

Research has concentrated on the abused and the abuser at the expense of exploring the wider implications of age, gender, race, ethnicity and class, all of which influence people's positions in the social structure and their opportunities in life (Ogg & Munn Giddings, 1993).

Options for Intervention

The Protocol needs to specify the different options that exist, and the types of Protocols and assessment process that will provide better support to assist carers in their caring role.

Elder abuse requires a multilevel response, one that promotes the rights and autonomy of the individual as well as supporting the carers of older people. This multifactorial response needs to be monitored and evaluated to assess its ongoing effect. It is important that the major cause be identified in each case of abuse, so that interventions can be designed accordingly. There is agreement in the literature that the best approach involves multi-disciplinary teams and coordinated intra and interagency Protocols.

During the past 10-15 years energy has been invested in developing instruments to identify older people and their carers who are at risk and there a number of screening tools that have been used and successfully trailed and tested overseas.

However, many of the assessment Protocols used currently are based on assumptions founded in domestic violence models/Protocols and therefore contain several weakness, such as discounting the interactional nature and aspects of abuse. To date, there has been no concrete evidence that the Protocols actually do facilitate accurate identification of abuse.

The existing Protocol:

- assumes a caregiver/situational model of abuse , which persists despite contradictory evidence emerging in the literature
- fails to provide adequate definitions of what strategies should be used with whom and under what circumstances
- points to little or no evidence of the efficacy of treatments or interventions

Education and Training Evaluation

The Protocol should include ways to address the training, education and support needs of carers in their caring role and include the strategies to be used to evaluate the outcomes of different interventions.

CNSW asserts that an evaluation of current practice /effectiveness of the Protocol across NSW is required. It is important to be able to provide front line workers with feedback about what works, and to evaluate the outcomes of different interventions,

as well as be able to collect and offer evidence for relevance of particular interventions.

The evaluation questions noted below should be included in the revised Protocol as a tool to assist and support agencies in the implementing the Protocol.

1. Does the intervention stop the abuse or reduce its severity?
2. Is there a change in how often the abuse occurs following interventions?
3. Does the victim feel that there has been an improvement in the situation?

These questions are fundamental to assessing the ongoing effectiveness of the Protocol and interventions and ensuring positive outcomes for both the carer and care recipient.

As such, education and training is a fundamental preventative strategy for carers and plays a pivotal role in the prevention of abuse to both the carer and care recipient. Carer support groups have a long and distinguished history as a resource to assist carers, typically offering a combination of social support, education and training, stress reduction and problem solving strategies.

In addition to training professionals, carers and older people themselves, it is essential to promote a general public awareness of elder abuse. Public education campaigns should be geared toward raising awareness of both the potential for elder abuse and carer abuse and highlighting the warning signs of abuse.

Recommendations

1. Establish a statewide service to respond to requests for assistance, specialist information and support, education, referral support to older people experiencing abuse and their carers.
2. Develop a centrally maintained database, clearinghouse and advisory service on best practice models in prevention and interventions for elder abuse and carer abuse.
3. Develop a public awareness campaign around elder abuse and carer abuse with a focus on prevention and intervention.
4. Convene an interdepartmental working party on elder abuse to monitor the performance of agencies in regards to the implementation of Interagency Protocols.
5. Develop a comprehensive guide on the management of older people's assets to increase financial capabilities and promote good practise.
6. Develop and pilot a screening tool / checklist of warning signs of abuse that can assist in the early detection of carer stress and elder abuse and carer abuse.
7. Undertake research into an incidence study and prevalence study on elder abuse and carer abuse.
8. Undertake research into the needs of CALD and Aboriginal and Torres Strait Islander carer populations with respect to vulnerable older people and their carers.
9. Promote ongoing education and training of professionals and others working with older people and their carers who are or have been abuse
10. Investigate the options for crisis care and supported accommodation where vulnerable adults need to be removed from the situation.
11. Increase the number of designated respite places available for the purpose of providing carers with a break in cases of carer stress, suspected carer abuse or suspected elder abuse, and provide training and support in advocacy for both the older person and their carer.
12. Develop a through understanding of the different types of responses required for different types of abuse. ie does the behaviours or symptom of dementia require a specific response? How effective are current responses to abuse where dementia is a factor?
13. Include Carers NSW as a key contact in the *Useful contact list page 20 Revised Protocol*.

Conclusion

Communities that are well connected and inclusive of older people assist to create an environment where the abuse and neglect of older people can be reduced.

At a broad level, an empowering and supportive approach should underpin the revised Protocol and one that recognises that fundamental is about effectively minimising the risk of abuse and neglect to both older people and their carers.

At a practical level, the interagency Protocol needs to identify the types of support and training that both the older person and their carer may require in the community setting in order to prevent the breakdown of the caring role and relationship.