DECEIVE 1 2 DEC 2006 BY: LACA

Submission	No. 81
Date Recei	ved



Placing Carers First

Submission from:

Carers Queensland

To:

The House of Representatives Standing Committee on Legal and Constitutional Affairs

Inquiry into Older People and the Law

December 2006

About Carers

Carers provide support to family members or friends who require assistance due to disability, mental illness, chronic conditions or frail age.

There are approximately 2.6 million carers in Australiaⁱ. Around 1 in 8 people are carers.

Carers make a substantial contribution to the care and support of people with disabilities or illnesses, providing around 80% of the assistance receivedⁱⁱ. In 2005 carers provided 1.2 billion hours of care. The cost to replace this care with formal services would be at least \$30.5 billion annuallyⁱⁱⁱ.

Unpaid carers provided support to $711\ 000$ people aged over 65 years living at home^{iv} or approximately 30% of the older population.

About Carers Queensland

Carers Queensland is dedicated to supporting the 535 800 carers in Queensland that provide assistance to a family member, friend or neighbour who has a disability, physical or mental illness or is frail aged.

The purpose of Carers Queensland is to enhance the quality of life of those Queenslanders in a caring role, promote their rights and needs and provide information and support services

This submission is also endorsed by Carers Australia.

Introduction

Legislation for older people can have important implications for their family members and friends and the assistance that they provide to them. Increasingly, legislation such as that which considers Enduring Powers of Attorney and other substitute decision-making arrangements, are acting to regulate natural relationships. As a consequence, personal and domestic matters are being transferred in to the public domain rather than remaining private. In this way, the moral and ethical character of carers is being increasingly prescribed.

In addition, solutions for complex issues facing families and relationships are sought through legislation, often in isolation, rather than exploring underlying social issues and addressing these with both legal and social remedies.

TERMS OF REFERENCE

This submission will address the Terms of Reference of the inquiry, examining carers' major concerns with the current legislative regimes in addressing the legal needs of older people aged 65 years and over.

1. Financial abuse

Prior to an examination of the issue of financial abuse it is important to be reminded that, in the main, families support and protect older people and keep them safe and well. Where a family member or friend is assisting an older person with their finances these arrangements, on the whole, serve people very well. The overwhelming majority of families are 'doing the right thing' – acting with probity and integrity. Intentional abuse is not common. Family members and carers generally have a deep and abiding concern for the older person.

<u>Asset Management</u>

Providing assistance with asset management is a common task. A large number of carers provide support to an older person to manage their finances. A national study that explored the prevalence and nature of asset management found that over one quarter of Australian adults assist an older person to manage their assets^v. This assistance is mainly provided to older parents, but also to friends or neighbours and other relatives.

Assistance is provided with routine as well as complex and major financial tasks including the day-to-day management of finances such as paying bills, banking, cashing pensions, payments of fees and charges; long-term management of finances including investments, superannuation and property; and, the dispersal of major assets such as the family home.

Interestingly, carers do not just support older people who have impaired capacity. Assistance is also provided due to variety of attitudinal and practical reasons such as lack of confidence, unfamiliar technology, limited mobility, and failing eyesight^{vi}. There are both formal and informal means to assist older people with their financial affairs. Most arrangements (approximately 83%) are not formal legally sanctioned appointments such as an Enduring Power of Attorney or administrator. Rather, assistance with assets most commonly occurs outside of the legal realm, in the private sphere, using informal processes. In the main, they involve carers paying bills with their own money (and then, mostly, being reimbursed). These informal processes were considered much more convenient by carers.

Although acceptable and preferred by those involved (i.e. the older person and the carer), these practices are often considered 'risky' in that they employ limited accountability processes that potentially leave the older person open to abuse and do not provide the carer with protection from unwarranted allegations of abuse.

It is important to recognise that difficulties are more likely to arise in the management of older people's affairs as a result of limited expertise or support for carers rather than deliberate abuse^{vii}.

Responses to financial abuse

- Legal response: The main response to abuse has largely been concerned with protective legal frameworks for substitute decision making such as EPAs and guardianship. However, as noted above, given that most asset management occurs outside of the legal realm, and that abuse occurs within both formal and informal arrangement, this is an insufficient response. The other legal interventions are primarily reactive: after the older person has endured some harm (deliberate or not). This regulation does not address the issues underlying possible abuse. Obviously, there is also a place for facilitative and supportive strategies to protect both older people and their carers from harm.
- Information and support for older people and carers: Clearly, assisting with assets can be a complex activity that sometimes requires high levels of specialist skills. It is, understandably, a responsibility for which some carers may feel under-prepared and can report difficulties^{viii}. However, most people who assume the role receive little support or information. There is a clear dearth of financial and legal advice to assist carers who find themselves in the position of managing someone else's assets. Timely and affordable specialised financial and legal education and support is required.
- Resources: Simple tools and management systems would be of assistance to carers. These mechanisms would increase accountability but would also, importantly, simplify the task for carers in addition to protecting them from unwarranted allegations of abuse.
- Mediation: Asset management does not occur in a vacuum but in a complex web of existing family relationships. For this reason, access to mediation to address family dynamics will be of particular assistance to some families. It can provide a forum for families to develop their own solutions to issues that they may face.
- Other services for carers: Recognising that carer stress, sleep deprivation, poor health and other factors can sometimes contribute to abuse, timely and appropriate general support services for families and carers, is also appropriate.

Examples that incorporate some of these responses:

- Seniors Advocacy Information and Legal Service (SAILS)^{ix}: SAILS is a service for people over the age of 60 who are experiencing, or are at risk of experiencing, domestic (non-spousal) and family violence. It is a multidisciplinary model that employs both a social worker and lawyer to work together to address legal and social concerns associated with abuse or potential abuse.
- Assisted Asset Management Community Demonstration Project: Carers Queensland has been involved with the Queensland University Asset Research Team for Seniors (QUARTS) in a Community Demonstration Project, recognising the strategic importance of carers' involvement in asset management and seeking out solutions to support carers in this important role. The project has developed and delivered Community Education for older people and their carers as well as Service Protocols for those workers in relevant service sectors such as banking and community care.

<u>Summary</u>

While there is a requirement for the judicious application of measures that protect older people and their assets (because a very small minority of family and carers will not always do the right thing), our main responsibility is to assist carers in the sometimes difficult task of managing another person's assets.

While carers may not be a fail-safe, they are safer than any other option.

2. General and Enduring Powers of Attorney

The responsibility to make decisions on behalf of another person – in matters related to finances, lifestyle and health care – is arguably the most significant responsibility that one can assume. For most adults without capacity, these decisions are made with assistance from, or by, close family members or friends. Those people close to us who have an intimate knowledge of our history, experiences and preferences are, without doubt, the best placed to make decisions on our behalf.

Consideration is given in this section to the broad range of substitute decisionmaking arrangements when people are deemed to have an impaired decision-making capacity – that is, informal substitute decision-making arrangements, Enduring Powers of Attorney (EPAs) and appointment as a guardian or administrator by a relevant authority.

Informal substitute decision-making

Some legislation encourages the formalisation of substitute decision-making arrangements, most notably through EPAs

However, where older people have not established an EPA, guardianship and administration legislation in most jurisdictions supports the role of informal substitute decision-makers in assisting people with impaired capacity. The system recognises that, for most adults with impaired capacity, decisions relating to personal, health

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and financial matters can be made with assistance from, or by, family members or friends. For instance, in Queensland, formal guardian or administrator appointments are only necessary when informal arrangements are inadequate or inappropriate and there is no other way to ensure that the interests of the adult concerned are protected and their needs met.

Family and friends are usually the best substitute decision-makers

There appears to be a misplaced belief, especially in some guardianship and administration regimes, that appointment of a statutory authority as a substitute decision maker is a safer option than families or friends.

Older people and their families though prefer for these types of decision to remain in the family. Where family of friends are able and willing to provide support and assistance with decision-making then it is essential that they be allowed to do so rather than appoint a statutory authority to perform that role. Such intervention should only be contemplated when all other options have been tried or reasonably considered. This includes appropriate support to enable families to undertake the role.

However, guardianship and administration has an important role to play in supporting and protecting people with a decision-making disability in those instances where the family is no longer able or willing to act as a substitute decision maker or where the family has been <u>proven</u> to be acting inappropriately or inadequately.

Limited awareness or understanding of substitute decision-making arrangements-

Currently, there appears to be very limited knowledge amongst older people, their family members and carers of the range of substitute decision-making arrangements available.

Confusion over the necessity for legal appointments

There appears to be considerable uncertainty amongst older people, their families and the wider community over whether and when legally appointed decision makers are necessary.

Many people – either because of a distinct preference or due to a lack of knowledge, informally manage the affairs of older people. However, in attempting to manage older people's affairs through informal means, family and friends increasingly experience obstacles. Public, non-government and commercial organisations such as utility companies and aged care facilities fail to acknowledge the authority of informal decision-makers and will only deal with legally appointed decision-makers. This (often incorrect) belief can create unnecessary barriers for families and carers in their attempt to provide support to older people.

Formal substitute decision-making arrangements are not honoured

Even when people do go to the trouble to arrange formal appointments, they are not always acknowledged by entities such as banks. This is particularly true of EPAs. Instead, older people and their families are sometimes asked to complete additional 'semi-formal' processes for the organisation's own use. This places additional demands on the older person and the carer and negates the purpose of establishing a legal appointment.

It would appear that those organisations who do not acknowledge EPAs do so out of concerns concerning their authenticity. In particular, concerns over whether the person had capacity when they signed the EPA, if it is the most recent EPA, if the EPA has been revoked, etc. Registration of EPAs may improve acceptance of the attorney's authority on relevant matters.

Cross-jurisdictional differences

Different jurisdictions employ different substitute decision making instruments that confer different powers (for financial, lifestyle and health care decisions), employ different processes and use different terminology. In addition, these instruments are not always mutually recognised. This can cause particular difficulty when the attorney lives in a different state to the principal. It is becoming more of an issue as the population becomes increasingly mobile and more people provide care at a distance. The harmonisation of laws across jurisdiction would be beneficial in such situations.

Associated issues

The notion of substitute decision-making is often bound up with other emotive issues for the older person and their family such as poor health, fears about incapacity, family relationships, trust and mortality. These issues are obviously sensitive and need to be dealt with as such. Assistance may be required by older people and their families to work through these issues.

3. Family Agreements

Family agreements are a relatively new concept that considers the distribution of the older person's wealth to the family member or friend who chooses (or is chosen) to care for an older person.

The most beneficial thing about such agreements is that they provide an avenue for people to discuss and consider their, often previously unstated, expectations and assumptions regarding the provision and receipt of future care for older people.

These family agreements, in considering the transfer of assets to carers, also recognise that people may give up a career and financial security in order to care for older people. The expense incurred by families in providing care is often not acknowledged or compensated for. Family agreements can, in some respects, redress that debt.

However, there are many limitations to the family agreement. There are things that quite simply can not be provided for in a written contract. Such contracts can oversimplify arrangements and fail to acknowledge the complexities involved in providing care, the uncertainty often inherent to care situations and the fact that other factors in a person's life also change and may have implications for care.

There is great merit in assisting families to devise their own informed solutions for the future. However, this need not necessarily occur within a legal framework.

4. Barrier to older Australians accessing legal services

Where there is an issue of the older person's capacity but a formal appointment has not been made for someone to act on their behalf, the older people can be disadvantaged in their ability to access legal services. Without an appointment, lawyers are often not able to take direction. There is merit in providing the authority for those carers acting informally to act with or for the older person in a legal sense.

5. Fraud

Relationships and connections with family and friends provide security and safety and are the greatest safeguard for older people. Older people are more vulnerable when they are not supported to belong to families, neighbourhoods, other natural networks and the wider community. For this reason, support for families and carers which ensures the integrity of the family unit and encourages resilience is essential.

¹ Australian Bureau of Statistics (2003) Survey of Ageing, Disability and Carers: Summary of Findings (Cat. No. 4430.0). ABS: Canberra

¹ Australian Institute of Health and Welfare (1999) Australia's Welfare. AIHW: Canberra.

^{III} Access Economics (2005) The Economic Value of Informal Care, Report by Access Economics for Carers Australia

^{iv} Australian Institute of Health and Welfare (2003) Australia's Welfare. AIHW: Canberra.

^v Tilse, C., Setterlund, D., Wison, J. & Rosenman, L. (2005) Minding the Money: a growing responsibility for informal carers. Ageing and Society, 25. Cambridge University Press: UK.

^{vi} Setterlund, D., Tilse, C. & Wilson, J. (1999) Substitute decision making and older Australians. Trends and Issues in Crime and Criminal Justice, Volume 139. Australian Institute of Criminology: Canberra. ^{vii} Tilse, C., Setterlund, D., Wison, J. & Rosenman, L. (2005) Minding the Money: a growing

responsibility for informal carers. Ageing and Society, 25. Cambridge University Press: UK.

^{ix} http://www.caxton.org.au/services.html#sails