



Discussion Paper 4

March 2012

WHAT PREVENTS PEOPLE WITH DEMENTIA

MAKING PLANS FOR THEIR FUTURE?

**TALKING ABOUT ALZHEIMER'S
ACROSS AUSTRALIA**
FIGHTDEMENTIA.ORG.AU

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CONTENTS

Glossary of terms	4
Executive summary	5
Background	8
Fig 1: Leading causes of death in Australia	9
Methodology	11
Table 1: Survey-based research sample breakdown	11
Results	12
Discussion	13
Confusion	13
Advanced Care Directive	14
Person Responsible	14
Dementia is a terminal condition	15
Diagnosis of dementia	15
Assessing Capacity	16
Role of GPs	17
Table 2: GP steps to advanced planning	18
Service implications	19
Policy implications	20
Conclusion	22
Recommendations	23
Endnotes	24
Resource list	27

GLOSSARY OF TERMS¹

Advance Care Planning	Planning future care to ensure that your wishes are known when you can no longer make decisions for yourself or legally complete documents.
Advance Care Directive	A written, legally binding document, which allows you to record your wishes for general or specific treatment to consent to or refuse under certain conditions. It comes into effect only when you are no longer capable of making your own decisions.
Capacity	<p>Legislation throughout Australia is based on the United Nations principle where it is assumed a person has capacity unless it can be proven that they do not. It is usually the responsibility of the treating medical practitioner to determine whether or not someone has capacity. A good way to test capacity to make a decision is to see whether the person can:</p> <ol style="list-style-type: none">1. comprehend and retain the information provided2. believe the information3. weigh the information in reaching a decision4. make the decision and communicate it in some way. <p>Therefore someone with mild or moderate dementia may still have capacity to make their own decisions, or to complete Advance Care Planning documents.</p>
Enduring Guardianship	Authority you invest in a trusted person(s) to make personal, lifestyle and health care decisions for you when you can no longer make those decisions for yourself.
Enduring Power of Attorney	Authority you invest in a trusted person to deal with your financial affairs.
Person Responsible	Where there is no Advance Care Directive, Enduring Guardian or other similar appointment, legislation provides a list of people (in order of precedence) who have authority to make decisions for someone who can no longer make their own decisions regarding medical and dental treatment. A 'person responsible' is not necessarily a person's next of kin.
Power of attorney	A legal document you sign to appoint someone else as your agent with authority to carry out those transactions to do with your business, property and financial affairs. It ceases to have effect when you lose the capacity to make decisions for yourself.
Will	A legal document that a person capable of making a decision signs to express how they wish their property and other assets to be disposed of after they die.

EXECUTIVE SUMMARY

Living well and dying well are inseparable²

What is planning ahead?

In the context of this paper planning ahead refers to:

- making a Will;
- recording future care and treatment wishes in an Advanced Care Directive; and
- appointing people to make decisions about your personal, health, lifestyle, financial, property, or business affairs through Enduring Guardianship and Power of Attorney documents.

Planning ahead is important for the whole population. We all need to make sure that if we get to a point where we can no longer make our own decisions that our wishes about our health care and financial plans have been set out in legally binding documents. Failure to do this can lead to added stress on our family and carers who will not have the legal ability to make sure our wishes are followed or who could be unsure of our wishes.

Why is it an issue?

Estimates on the usage of these documents are that:

- only 55% of people in NSW are estimated to have a Will;
- 49% of Australians have not taken any actions, formally or informally, to prepare for an event where they may lose the ability to make decisions; and
- less than 20% of Australians have recorded their wishes for end-of-life care.

Currently there are 280,000 Australians living with dementia which, without a medical breakthrough, will increase to 943,000 by 2050. Community awareness about dementia has increased but many people are not aware that dementia is a terminal illness, and as a progressive disease, affects a person's capacity to make decisions over time.

People with dementia have the right to make decisions about their future while they still have the capacity to do so. It is therefore imperative in the early stages of the disease that people with dementia are provided with opportunities to plan for their future and record their wishes, while they still have capacity.

In the event of a person losing capacity to make decisions, such as the progression of dementia, there is information available to assist the person to plan ahead for their future health and financial needs. Yet, barriers preventing the use of the information appear to exist.

Recent research Alzheimers Australia NSW (AlzNSW) conducted with consumers, carers and health professionals highlights several factors which hinder people with dementia in making arrangements for their legal, personal and health plans. Consumers and carers told us they had not made future plans because they:

- Did not understand the value of planning ahead;
- Were unwilling to seek out information about planning ahead;
- Did not know where to access information;
- Had difficulty in understanding the terms used in documentation; and
- Did not receive support from GPs and health professionals

The findings of the research by AlzNSW emphasise:

- the importance of early diagnosis and access to information about planning ahead while the person with dementia still has capacity to participate in decision making about their future;
- the importance of accessible easy-to-understand information about the tools available to assist a person with dementia to plan ahead and where to record these plans;
- the importance of raising awareness and understanding of Advance Care Directives for people with dementia, carers, and some service providers;
- the important role of GPs and other primary health care providers as informants and supporters for the rights of people with dementia to make plans for their future care needs and the importance of initiating discussion, even before a person is diagnosed with dementia;
- the importance of a public awareness campaign for the whole community to understand the value of planning ahead; and
- the unwillingness of people to speak with others about their own mortality.

What needs to change?

This paper addresses these factors and aims to:

1. encourage dialogue between people with dementia, their families, their carers and the service providers that care for their health and wellbeing;
2. alert key stakeholders to the barriers that exist and policy changes which can improve the dissemination and understanding of information about advance planning and therefore its

subsequent uptake; and

3. ensure that all people with dementia have optimum access to simple transparent information that ensures their wishes are recorded while they still have capacity and honoured when they no longer do.

To achieve these aims, Alzheimer's Australia NSW recommends:

1. The Federal government instigates a national awareness campaign about the value and importance of people discussing their wishes for their future care and wellbeing in the event that they may lose the capacity to make decisions.
2. The Federal government includes, as part of its eHealth initiative, Advance Care Directive documentation within the Personally Controlled Electronic Health Record (PCEHR) to ensure a patient's wishes are as accessible as his or her medical records.
3. The Federal Government ensures that nationally consistent legislation and terminology for Advance Care Directives is developed.
4. The NSW Government instructs the NSW Law Reform Commission to clarify confusion about the legally binding nature of Advance Care Directives to increase awareness in all practitioners - legal and medical.
5. The NSW Government assist community service providers to include more directed information about advance care planning in their programs for people with dementia who still have capacity to participate in decision-making.
6. The Department of Health and Ageing creates and promotes awareness of a new MBS Item number to appropriately remunerate GPs for the extensive work

that completing advanced care plans involves and then directs GPs, through the GP Guidelines, to include the provision of information about advance care planning to all Australians at the 75 year old age check and patients newly diagnosed with dementia.

7. The Federal Government supports CALD and Aboriginal community groups to distribute culturally appropriate information (and in languages other than English) in their communities and to doctors, allied-health professionals and other agencies regarding the importance of individuals talking to family about their wishes in the event that they lose capacity to make decisions for themselves.
8. The Department of Health and Ageing mandate that people entering a residential aged care facility, or receiving an Extended Aged Care in the Home (EACH) or EACH Dementia package have an Advanced Care Directive, and an Enduring Power of Attorney or an Enduring Guardian appointed as a condition of entry.
9. The NSW Government support ongoing maintenance and upgrades to the 'Planning Ahead Tools' website.
10. The Department of Health and Ageing increase funding to support GPs to achieve early diagnosis of dementia, and thereby support people to plan ahead while they still can.

BACKGROUND

Information to assist a person to make plans for their future health and wellbeing has increased in recent times, yet awareness of the availability of this information is low and confusion exists around terms, points of access and related legalities and responsibilities. For some, a will and Power of Attorney is created early however many people do not understand the value of recording an Advance Care Directive or appointing an Enduring Power of Attorney or an Enduring Guardian.

A Newspoll survey reported that only 55% of people in NSW are estimated to have a Will³. A recent Pfizer study reported one in two people would like to determine the care options that are best suited to them through Advance Care Directives, yet 49% of Australians have not taken any actions, formally or informally, to prepare for an event where they may lose the ability to make decisions⁴. A recent study by Palliative Care Australia confirms low uptake of future planning with findings that indicate less than 20% of Australians surveyed have recorded any sort of care plan for end-of-life care. Shanley et al⁵ also report that in light of available information the large number of people entering residential care without an Advance Care Directive is surprising and needs to be addressed.

Dementia is the third highest cause of death in Australia (see Figure 1). Currently 280,000 people are diagnosed with dementia and 95,000 of these reside in New South Wales. These numbers

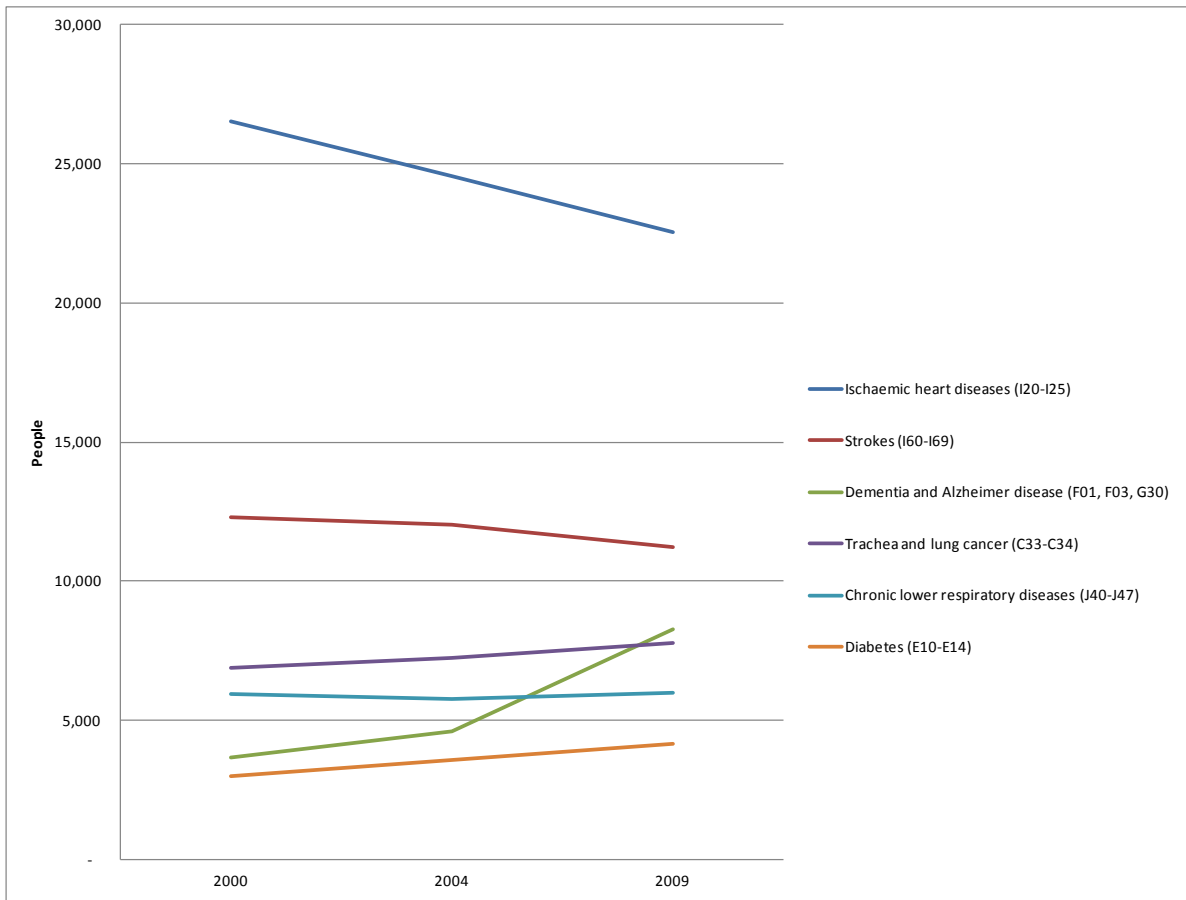
are projected to increase to 943,000 for Australia and 303,500 in NSW by 2050⁶.

Many people are not aware that dementia is a terminal condition. Also, a person diagnosed with dementia will lose their cognitive capacity over time as it is a progressive illness. People with dementia experience a period following the diagnosis when they can participate in decision-making with regard to the rest of their life followed sometimes by many years when they do not have capacity and others will have to make decisions on their behalf. Consequently the need to record the person's wishes for the future, how they wish to be cared for and how they wish their financial situation to progress, should be addressed as early as possible.

Service providers working in the community such as health professionals, accountants and solicitors are often a point of reference for people with dementia and their carers. General Practitioners (GPs) particularly are in regular contact with people as they age. However many of these providers have little current information or understanding about advance planning or do not take the opportunity to discuss with their patients/clients the importance of such action.

People with dementia have the right to make decisions about their future while they still have the capacity to do so. There is a need in the community to expand discussion about the importance of an early diagnosis of dementia and the consequent need to plan ahead, but also, to address the value for all people, to execute a record of their care and financial plans for the future in the event that they may not have the capacity to do so as their condition deteriorates.

Fig 1: Leading causes of death in Australia - selected years 2000-2009⁷



Purpose

This paper documents the barriers that prevent people to plan ahead and makes recommendations which will address these and improve the use of planning ahead tools. It reviews recent and relevant literature and investigates the opinions of AlzNSW consumers and community service providers about the existence of barriers to planning ahead and discusses ways in which these barriers can be broken down.

This paper seeks to encourage dialogue between people with dementia, their families, their carers and the service providers that care for their health and wellbeing. It aims to alert key stakeholders to the barriers that exist which prevent the dissemination and understanding of information about advance planning. It makes recommendations which seek to improve use of legal documents and encourage uptake within the whole population of NSW. Ultimately it aims to ensure that all people with dementia have optimum access to simple, transparent information that ensures their wishes are recorded while they still have capacity and which are honoured when they no longer do.

Current literature

Currently there is a substantial amount of information⁸ and literature^{9 10 11} about the importance of planning ahead for people with dementia; for their own benefit and also the benefit of their carers and families and the health professionals who will assist them in their life with dementia. Good resources also exist (see Attachment 2) that provide valuable information to assist those wanting to make plans for their future. However, as already noted, many people are not aware of information to assist them, due to the existence of social barriers in the community.

The literature reviewed, within the context of barriers to planning ahead, highlighted a number of features that contribute to this situation. A lack of accessible, reliable information about planning ahead was reported consistently in the literature^{12 13} as a barrier. Also, the absence of discussion about instruments such as Advance Care Directives between GPs and the patient^{14 15}; the emotional distress of a diagnosis of dementia^{16 17}; the stigma attached to dementia, especially amongst people from cultural and linguistically diverse backgrounds (CALD)^{18 19 20} were cited. Dementia, some reported, was not acknowledged, by the patient or the GP, as a terminal illness^{21 22} and thus the notion that one loses cognitive capacity with the progression of dementia was not understood²³. Death was reported²⁴ as a taboo subject of discussion for many, with consequent evidence of procrastination and denial of the important inclusion of the person with dementia in decision-making for their future.

METHODOLOGY

In order to further understand the barriers to planning ahead for people with dementia and their carers, AlzNSW conducted survey-based research in 2011. Data was collected from three sources:

1. people with dementia;
2. carers of people with dementia; and
3. community service providers.

Questionnaires were sent to members of the AlzNSW Consumer Committees in Sydney, Wollongong, Port Macquarie, Bega, Wagga Wagga, Armidale, Orange and Newcastle. Two different questionnaires were developed: one for those with dementia and one for those caring for someone with dementia. These two groups were targeted to obtain evidence from people with direct experience of dementia about their perspective on the barriers to planning ahead.

An online survey was created and

promoted to service providers who work with people with dementia or their carers in NSW. Service providers were included in the research in order to:

- gauge their levels of awareness about planning ahead;
- compare their views on planning ahead with consumers; and
- ascertain their views on the promotion of and responsibility for discussions about planning ahead.

The total number of respondents to the three surveys was 77. The quantitative data obtained from the respondents was analysed using SPSS and Survey Monkey, whilst the qualitative comments were analysed using thematic analysis techniques. The breakdown of the sample group, size, the type of data obtained and data analysis method is presented in Table 1 for the three sources.

Table 1: Survey-based research sample breakdown (2011)

	People with dementia	Carers of people with dementia	Community service providers
Sample group and source of data	12 people with dementia from the AlzNSW Consumer Committees responded to a questionnaire conducted in April 2011.	41 carers from the AlzNSW Consumer Committees responded to a questionnaire conducted in April 2011.	24 service providers responded from around NSW using Survey Monkey online.
Data analysis method	Quantitative data was analysed using the SPSS program and qualitative data was analysed using thematic analysis techniques.	Quantitative data was analysed using the SPSS program and qualitative data was analysed using thematic analysis techniques.	Quantitative data was analysed using Survey Monkey online and qualitative data was analysed using thematic analysis techniques.

RESULTS

People with dementia - self-reported questionnaire

Key findings:

- People with dementia had little understanding of the term 'Advance Care Directive' before and after diagnosis and low use of them after diagnosis.
- People with dementia believe the roles of GPs and specialists are integral to conveying the importance of documenting wishes, ensuring the timeliness of decision-making.
- 100% of the people with dementia believe there should be a central point to access information about planning ahead.

Carers – self-reported questionnaire

Key findings:

- Some carers were not aware of the terminal nature of dementia.
- 'Advance Care Directive' is the least understood term amongst carers.
- Carers believed the greatest barrier to planning ahead is the loss of capacity for the person.
- Carers highlighted the importance of early diagnosis.
- Carers believed GPs/specialists are the most appropriate in alerting people to the need to plan ahead.
- Community awareness campaigns can help raise knowledge of the reasons why and how to plan ahead.

Community Service Providers – self reported questionnaire

Key findings:

- Some service providers believed it was not their role to give advice on advance planning, believing it is the GPs responsibility to inform the patient of their rights and the need to make plans.
- Service providers called for community awareness about planning ahead.
- Service providers believed everyone should be recording their wishes no matter how healthy.

DISCUSSION

A variety of factors were identified in the literature, and this research, that contribute to the low usage rates of planning ahead tools by people with dementia and their carers. The accessibility of information about available resources and a delay in decision-making to undertake planning were strong variables that negated the execution of documents by a person with dementia to plan ahead.

Other factors included:

- confusion about the need to plan ahead;
- confusion about information and jargon used;
- confusion about the validity of tools;
- diagnosis of dementia too late;
- misunderstanding of the terminal nature of dementia;
- lack of support from some doctors and service providers to make plans;
- discussion of death and end-of-life care a taboo subject;
- denial of the illness due to stigma; and
- emotional distress.

Confusion

A high level of confusion was evident in the research and the literature around the need for, the advantages of, and the associated legal requirements for a person with dementia to plan ahead while they have the capacity to do so^{25 26}.

I knew they existed but didn't have enough understanding (person with dementia)

Ambiguity also existed around ownership of the responsibility for initiating discussion with the person with dementia about the

value of planning ahead while they are still capable of making decisions.

Many participants in the research claimed to know of the existence of information to assist a person to plan ahead but, as there is no 'one stop shop', explain it is often difficult to locate appropriate information to plan ahead. Further, the content and emphasis of the information can differ according to the source and so become confusing for the individual.

Much of the evidence indicates that there is still a lot of misunderstanding of the legal terminology used in discussion of documentation for planning ahead.

We all need to be better educated about planning our future and encouraged to organise our future earlier in life, not just our will (carer)

For example, anecdotal evidence tells us some people are not aware that a Power of Attorney is not valid once the person loses capacity or that the 'person responsible' is not necessarily the next of kin, and is based on a hierarchical mode of selection.

All too complex, amazingly complex (person with dementia)

In addition, in each state and territory there are different laws about Advance Care Directives and therefore the terminology differs. This can confuse both doctors and people with dementia, particularly if a person transfers to another state. Meisel²⁷ suggests that some doctors overestimate the legal risks of some practices, such as not resuscitating a patient or administering high doses of medication to relieve pain to the detriment of the person's recorded wishes.

At times, ethics, clinical judgment and the law conflict²⁸ (Meisel)

Information in plain language needs to be accessible, easily understood and widely promoted to enable an optimum number of people to record their wishes for their future care and wellbeing.

Advance Care Directive

Amongst the data collected for this research, Advance Care Directives were the least known and understood amongst the range of tools available to assist a person with dementia to make plans for their future. Compared to other tools, Advance Care Directives were the tool with the least number 'in place', the least 'take-up after diagnosis' and the least 'recommended by services'. This is despite service providers reporting a good knowledge of Advance Care Directives. Advance Care Directives are promoted heavily within current literature^{29 30}, and yet our research and anecdotal evidence tells us community awareness remains low.

Many people do not record an Advance Care Directive due to misinformation and ambiguity about the power the document will have when it is needed. Advance Care Directives are legally binding but many doctors and lawyers are uncertain about their status.

In New South Wales, Advance Care Directives are based on common law, and unlike some other states there is no 'prescribed' Advance Care Directive form. However a decision in the NSW Supreme Court³¹ confirmed that decisions that were made and recorded formally or informally are legally binding if there is evidence to prove the person wrote the record themselves, had capacity at the time and did not change their mind after writing it.

In *Planning for the End of Life for People with Dementia*³², Cartwright explains that every person, while they have capacity or through an Advance Care Directive, has the right to accept or refuse treatments, including palliative care. While the person

has capacity, information should be given about treatments available to them, and the consequences of accepting or refusing such treatments, even if the person is in a residential care facility or hospital.

Cartwright explains that first and foremost an Advance Care Directive is based on respect for patient autonomy. 'They can make their decisions for good reasons, bad reasons, no reasons, provided they are competent'³³. Individuals are encouraged to review their Advance Care Directive regularly, but if changes are not made and the directive was made some time ago it should still be accepted as valid. These are the sorts of messages that are often unknown in the general community, despite the available information.

Information about tools to make plans for the future, especially information about Advance Care Directives, needs to be promoted more widely in the community, using plain language which is easily understood. With the relatively short window of opportunity available to a person with dementia between diagnosis and the progression of lost capacity, accessible information is imperative.

Person Responsible

Qualitative evidence suggests that some people with dementia and their carers are unsure of the term 'person responsible'. The 'person responsible' is the person who will make decisions on behalf of a person with dementia who has lost capacity. In NSW this would be the enduring guardian but, in the event of the person with dementia not appointing an enduring guardian the following hierarchy is used.

1. Spouse (including de-facto or same sex partner in a stable, continuing relationship).
2. Non-professional carer who provides regular support to the person and understands their wishes.

3. Close relative or friend who has a close relationship with the person³⁴.

This information needs to be promoted as often people are not aware that the next of kin is NOT necessarily the person responsible.

Dementia is a terminal condition

A person with dementia will eventually lose capacity to make informed decisions. Despite this information, the terminal nature of dementia is not always acknowledged, particularly in the early stages. However, this research and other literature³⁵ confirms that many people with dementia and their carers are not aware of this prognosis which leads to a delay in decision-making and planning and the opportunity for the person with dementia to participate in that process.

“The patient and the carer should be told that dementia is a fatal disease at the time of diagnosis” (carer)

When decision-making is delayed the risk of a person with dementia losing capacity increases and systemic issues to planning ahead are realised. The reasons for delays in decision-making are:

- diagnosis of dementia too late;
- denial of the illness due to stigma;
- discussion of death is avoided due to taboo or cultural issues;
- family conflict about responsibilities; and
- emotional distress following the diagnosis

I was too ashamed about the diagnosis to make enquiries (person with dementia)

Diagnosis of dementia

Emotional distress

Findings from the research indicated that many people found the diagnosis of dementia very distressing and felt that they were not in the psychological frame of mind to deal with the prospect of death or the purposeful task of recording their wishes for a future without cognitive capacity or control of their lives. Service providers in turn reiterated this concern and many did not feel comfortable initiating discussion about end-of-life plans following the diagnosis of dementia.

It may be too much for them to handle at this time (carer)

The person and carer may be too overwhelmed at this stage and may not see the need to plan ahead (service provider)

The advantages of an early diagnosis

While acknowledging the emotional trauma associated with a diagnosis of dementia, for the person with dementia and their families the benefits attached to gaining a diagnosis as early as possible are significant. An early diagnosis allows the person with dementia and their family to set up support systems to help in the future and to access information that will assist their understanding of dementia as an illness and the associated prognosis. Importantly, an early diagnosis allows the person with dementia to maintain their right to participate in informed decision-making about their future financial and care needs, while they still have capacity to do so.

The carer should be told that dementia is a fatal disease at the time of diagnosis (carer)

Timeliness of the diagnosis is integral to reducing the impact of many barriers that prevent the take-up of tools and assistance to plan ahead. Further, timeliness of information, to the person with dementia and the whole community, is integral to raise awareness of the need to set plans in place if people want to remain in control of their lives if their cognitive capacity is lost.

Assessing Capacity

The loss of capacity of the person with dementia was a significant barrier reported in the research. To have capacity to make a particular decision means to have the ability to:

- comprehend and retain the information provided;
- believe the information;
- weigh the information in reaching a decision; and
- make a decision and communicate it in some way³⁶.

Due to misinformation, or a lack of understanding about the progression of dementia, or the stigma associated with dementia, some participants in the research reported that others immediately associate a diagnosis of dementia with an inability to make decisions. However, the capacity of a person with mild to moderate dementia to make decisions can fluctuate from day

to day or over one day. It is therefore imperative to assess the capacity of the person if he/she is to be included in the decision-making process. This ensures the person is not making decisions that are uninformed but also ensures the person diagnosed with dementia has optimum opportunity to participate.

It is usually the responsibility of the treating doctor to determine capacity. Assessment tools are varied, however, Cartwright³⁷ cites the Six-Step Capacity Assessment Tool developed by Alzheimer's Australia as appropriate and reliable.

Role of GPs

GPs play an important role in advance planning as they care, often on a regular basis, for many people with chronic and terminal illnesses. In addition, GPs often have trusting long term relationships with patients based on the provision of trusted diagnoses, information, advice and guidance which supports the patient's care and wellbeing. These factors allow them to discuss personal issues of the nature required for planning ahead and should be embedded into GPs practice.

[The]GP in association with other regular advice should mention 'Advance Care Directives'...in continual chatter mention other paper work that needs to be looked at. (carer)

The evidence from this research shows a high level of expectation of the GP and geriatrician to instigate dialogue about care plans and yet, according to the findings, doctors did not always deliver in this regard.

Agencies such as the Sydney South West Area Health Service have developed a one page document in their My Wishes series called Advance Care Planning: the basics that GPs could give to their patients, whether they have dementia or not, about the value of advance planning and where to find further information.

In addition the My Wishes series highlights five helpful steps to assist GPs which can be seen in Table 2 on the following page.

It was suggested in the findings that following the diagnosis of dementia, and acknowledging the often subsequent distress, a follow-up appointment could be initiated by the GP to discuss care plans and the right of the person with dementia to participate in decision-making and recording these plans while they still have capacity. Hirschman et al⁴⁰ acknowledge the emotional impact of the diagnosis on the person and their family to discuss plans for future care and state that 'discussion sessions over multiple visits' combined with education about the importance of advance directives has been found to be most effective.

There needs to be a period of adjustment. By all means approach the issues early in the diagnosis; however it needs to be followed up at a later stage (carer)

For GPs and other health care professionals, advance care planning is perceived as onerous with necessarily lengthy discussions with patients and their families⁴¹. This can act as a disincentive for them to initiate conversations and processes despite the large range of resources and information available to them and their patients/clients.

Service implications

Services can be confusing, dissatisfying and at times even alienating⁴²

Some respondents in this research reported that they did not feel it was the responsibility of the community service provider to instigate dialogue about Advance Care Directives. Wissow et al reiterated this finding and reported that some service providers avoided discussions about advance care planning due to time constraints, a lack of necessary skills to deal with sensitive issues and a fear that some people with dementia may have 'too many questions'⁴³.

If community service providers are to offer an holistic service they need to be informed about, and understand, the importance of financial and care planning for people with dementia. Service providers need to know the availability and location of appropriate resources which support planning ahead. Ensuring the consumer is aware of his or her right to access support to uphold the plans they make for the future is also important.

Table 2: GP steps to advance planning

	Action	Notes
Step 1	Incorporate advance planning as part of routine care of patients	Provide information and offer advance care planning when doing a comprehensive medical assessment Suggest the representative or family be involved in future consultations about the patient's wishes
Step 2	Assess Capacity of patient to appoint a representative and complete an advance care directive	If patient has capacity, check and witness the representative(s) is/are appropriate and agree and that the appropriate form is being completed If patient does not have capacity, refer to state legislation for who can be representative
Step 3	Support discussion and documentation of advance care directive	Discuss the patient's wishes with patient and carer Provide information on patient's medical status, prognosis and future treatment options Review plan Complete relevant forms
Step 4	Apply the patient's wishes to medical care	Consult directive and representative when major clinical decisions need to be made
Step 5	Review plan regularly or when health status changes significantly	Can be revoked at any time as long as the patient has capacity

Source: Sydney South West Area Health Service, My Wishes: information about advance care planning for General Practitioners³⁹

Central point of information

As a solution to perceived inaccessibility of information, some participants in the research suggested a central point to access information and advice. However, if the information and documentation is standardised, as it is with a Will, a central point to access information may not be necessary but better disseminated across a range of locations to reach a range of consumers. The solution to the problem of inaccessibility lies not just with its location, but also in the promotion of such information and what to do with it once a person has found it.

Disseminating the information

As mentioned above, GPs and other treating doctors would be good agents for promoting information that is standardised and easy to understand. Hirscham⁴⁴ identified non-health care professionals such as lawyers, accountants and financial planners as people who could assist in increasing the use of planning ahead tools within the community. As a person ages, contact with non-health care professionals often increases. This provides a corresponding opportunity for extra support and information about advance planning to be given when a person with dementia has contact with these services.

Educational materials for non-health care professionals would be beneficial and could include information about understanding dementia and suggestions that might enable them to broach the subject of advance planning when other planning tools or arrangements are discussed. These professionals can play an important role in disseminating valuable information about planning ahead as part of their regular business and in some ways have an easier task as they are removed from the diagnosis of dementia.

...there is nothing like the personal touch...where a person can work through issues that may need addressing (service provider)

Issues relating to different cultural groups

All aspects of planning ahead are affected by cultural mores, behaviours and perspectives. Information needs to be sensitive, and easily accessible to all cultural groups including Aboriginal people to ensure an optimum number of people with dementia are aware of, and can exercise, their right to plan ahead while they still have capacity.

CALD groups are often disadvantaged due to a lack of information in their language or treating doctors who speak their language who can advise them. Service providers who responded in this research identified this as an issue regarding planning ahead in NSW. In addition, cultural taboos can significantly reduce discussion about death or end-of-life care between family members and the person with dementia. For example Ng⁴⁵ reports that it is considered disrespectful and insensitive to talk about death with an elderly family member in some Asian communities. Brodaty et al⁴⁶ reported that some CALD communities do not acknowledge or recognise dementia as an illness but see it as a normal part of ageing.

An American study⁴⁷ reported that rates of completion of advance directives are much lower for some CALD groups due to lower health literacy and Triplett et al⁴⁸ argued that white women and people with a higher level of education were more likely to have made an advance directive.

In light of these issues, the Planning for Later Life Forum⁴⁹ suggests that linking the idea of recording a person's wishes for their future care and wellbeing with a Will may be a solution to the problem as many people from CALD communities are comfortable with this aspect of future planning.

Policy implications

A National Framework for Advance Care Directives

As mentioned, misunderstanding about the legal capacity of documents, the lack of consistency across the States/Territories and the confusion with terms all contribute to the barriers that negate a person's ability to make plans for the future. The National Framework for Advance Care Planning⁵⁰ recognises the need for a national scheme for Advance Care Directives. The Framework informs policy-makers and aims to:

- assist the community, via advance care planning, to recognise the limits of modern medicine;
- facilitate the harmonisation of formats and terminology across all states and territories;
- encourage all adult Australians to appreciate the benefits of planning ahead in the event they may lose their capacity to make decisions regarding their health and wellbeing;
- enable respect for decisions made by substitute decision makers, appointed under an Advance Care Directive; and
- ensure the recognition of Advance Care Directives as part of routine practice in health and aged care settings.

Central Repository

Once a record is made of a person's wishes for their care, accessibility to those records is imperative. Directives may be required urgently, away from the person's normal place of residence or without family or trusted friends available.

At the time of writing legislation is being tabled in the House of Representatives to initiate the Personally Controlled Electronic Health Record (PCEHR) which will roll out its eHealth initiative to record, with the patient's permission, the health information of Australians in an accessible and streamlined system of healthcare management. eHealth will enable coordinated holistic care within a secure and controlled environment⁵¹.

As a person ages, or if they are diagnosed with a terminal illness, they will require treatment from a number of doctors and specialists. If the person is diagnosed with dementia they are often supported by a carer at home or live in a residential aged care facility. eHealth will coordinate information and provide carers, doctors and specialists access, with the patient's permission, to a clear and up-to-date summary of health information⁵².

The Australian eHealth framework could include an Advance Care Directive within the PCEHR to ensure a patient's wishes are as accessible as his or her medical records, and concurrently reduce the burden of medical staff to make decisions on behalf of the person with dementia.

CONCLUSION

Awareness

Awareness of the availability and importance of planning ahead needs to be increased. It seems that many people know about some tools available to assist them but are not aware of the point of access, while others are not aware of the importance of making these decisions and recording them until it is too late.

These issues are just as relevant for younger people and should be discussed by lawyers etc when drawing up a will (service provider)

In response to the need for more information about planning ahead and the need to negate death as a taboo subject, a national awareness campaign to stimulate discussion amongst the community would assist on a number of fronts. Such a campaign would be a vehicle for information about the range of planning tools available, what they are and how to access them; it would generate discussion amongst individuals and alert them to the importance of recording their wishes in the event that they lose the capacity to make decisions about their care and wellbeing and it would help reduce the stigma associated with dementia that can deny a person their right to participate in their own care and financial plans.

A campaign similar to the Australian government's Donate Life promotion⁵³ which encourages dialogue with loved ones about organ donation in the event of death, would be beneficial.

Everyone should be aware of the need to make plans and record their wishes for their future wellbeing to ensure continued control of their lives and alleviate potential tension and concern for those that love and care for them. This requirement is imperative for anyone diagnosed with a terminal illness, especially one such as dementia, whereby their capacity for decision-making will eventually be lost.

Following a diagnosis of dementia, the person, their carer and families should be honestly informed about what lies ahead. The person should be supported and encouraged to retain control of their lives by 'putting things in order' while they still have capacity to express their wishes. To realise optimum outcomes, the barriers that currently exist to effective planning should be acknowledged and initiatives developed to reduce their impact and existence.

The factors contributing to barriers to planning ahead for people with dementia that are outlined in the findings by AlzNSW align closely with much of the literature reviewed. These findings confirm the need for increased awareness and understanding of the range of tools available to plan ahead. Further, and of equal value, is the need to increase awareness of the importance of early diagnosis of dementia so that people with dementia are given their rightful opportunity to make decisions about, and record, their wishes for their life with dementia, particularly end-of-life care when they will no longer have cognitive capacity.

RECOMMENDATIONS

Alzheimer's Australia NSW makes the following recommendations to improve community awareness, increase usage of legal and health care planning tools and ultimately ensure the right of people with dementia to participate in their own decision making.

1. The Federal government instigates a national awareness campaign about the value and importance of people discussing their wishes for their future care and wellbeing in the event that they may lose the capacity to make decisions.
2. The Federal government includes, as part of its eHealth initiative, Advance Care Directive documentation within the Personally Controlled Electronic Health Record (PCEHR) to ensure a patient's wishes are as accessible as his or her medical records.
3. The Federal Government ensures that nationally consistent legislation and terminology for Advance Care Directives is developed.
4. The NSW Government instructs the NSW Law Reform Commission to clarify confusion about the legally binding nature of Advance Care Directives to increase awareness in all practitioners – legal and medical.
5. The NSW Government assist community service providers to include more directed information about advance care planning in their programs for people with dementia who still have capacity to participate in decision-making.
6. The Department of Health and Ageing creates and promotes awareness of a new MBS Item number to appropriately remunerate GPs for the extensive work that completing advanced care plans involves and then directs GPs, through the GP Guidelines, to include the provision of information about advance care planning to all Australians at the 75 year old age check and patients newly diagnosed with dementia.
7. The Federal Government supports CALD and Aboriginal community groups to distribute culturally appropriate information (and in languages other than English) in their communities and to doctors, allied-health professionals and other agencies regarding the importance of individuals talking to family about their wishes in the event that they lose capacity to make decisions for themselves.
8. The Department of Health and Ageing mandate that people entering a residential aged care facility, or receiving an Extended Aged Care in the Home (EACH) or EACH Dementia package have an Advanced Care Directive, and an Enduring Power of Attorney or an Enduring Guardian appointed as a condition of entry.
9. The NSW Government support ongoing maintenance and upgrades to the 'Planning Ahead Tools' website.
10. The Department of Health and Ageing increase funding to support GPs to achieve early diagnosis of dementia, and thereby support people to plan ahead while they still can.

ENDNOTES

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RESOURCE LIST

Alzheimer's Australia

Cartwright, C. (2011) Planning for the End of Life for People with Dementia: a report for Alzheimer's Australia, Paper 23, Part One, March 2011.

Available at: http://www.alzheimers.org.au/common/files/NAT/20110404_Nat_Paper_23EoLP1.pdf

NSW Health

Using Advance Care Directives (2004) - To provide advice to health professionals on the best practice use of advance care directives within an advance care planning process.

Available at: <http://www.health.nsw.gov.au/pubs/2004/pdf/adcaresdirectives.pdf>

Advance Care Planning Useful Links page

Available at: http://www.health.nsw.gov.au/patient_care/planning/useful_links.asp

ADHC

Planning Ahead Kit.

Available at: http://www.adhc.nsw.gov.au/individuals/ageing_well/planning_for_the_future

NSW Trustee and Guardian
(Attorney General and Justice)

Available at: <http://www.tag.nsw.gov.au/>

Planning ahead tools website.

Available at: <http://www.planningaheadtools.com.au/>

TAG Booklets

A Guide for Wills AND A Guide for Powers of Attorney.

Available at: <http://www.tag.nsw.gov.au/Content+Menus/About+Us/Publications/default.aspx>

TAG "Life Planning Tool"

Available at: <http://www.tag.nsw.gov.au/lifeplanning+tool/default.aspx>

Law Society of NSW

Planning Ahead.

Available at: <http://www.lawsociety.com.au/community/publicationsandfaqs/legalquestions/Planningahead/025903>

The Advanced Care Directive Association

<http://www.advancecaredirectives.org.au/index.html>

A Plan of Care: A book to help people make health and personal care decisions for a person in NSW who has dementia

By Anne Meller, Sara Graham, Elizabeth Hindmarsh, Barbara Squires and Sharon Wall

Available at: <http://www.advancecaredirectives.org.au/pdf/ACD-Plan-Of-Care.pdf>

My Health, My Future, My Choice

Available at: <http://www.advancecaredirectives.org.au>

Carers NSW

Planning for the Future.

Available at: <http://nsw.carersaustralia.com.au/?/article/view/111>

The Sydney South West My Wishes Advance Care Planning Program

Further information about this program and copies of the ACP forms can be obtained from www.mywishes.org.au or by calling (02) 9612 0646.

Planning what I want

An Australian primary health care website that has information for the general public as well as healthcare professionals. It includes general information on a range of ACP-related topics, examples of forms and several video clips from experienced practitioners. Available at:

Available at: <http://www.planningwhatiwant.com.au>

Online ACP program from RACGP

The College has a 2-hour online program about advance care planning that attracts CPD points.

Available at: <http://www.gplearning.com.au>

Medical care of older persons in residential aged care facilities (4th ed)

A comprehensive resource providing information on a range of issues, including ACP.

Available at: <http://www.racgp.org.au/guidelines/silverbook>

ASLaRC – Southern Cross University (Colleen Cartwright is Director)

Advance Care Planning Documents

Available at: <http://aslarc.scu.edu.au/downloads.html>

This Centre at Southern Cross University has a range of information and forms associated with ACP as well as PowerPoint presentations by Professor Colleen Cartwright

Benevolent Society

Your Future Starts Now – A guide for the over 50s (2008)

Available at: <http://cms.bensoc.org.au/uploads/documents/YourFutureStartsNowMar08.pdf>

OTHER PUBLICATIONS

Social Research Publications by Alzheimer's Australia NSW

[Building Dementia and Age-Friendly Neighbourhoods - Discussion Paper 3 July 2011](#)

The needs of people with dementia and other types of cognitive impairment have helped shape the design of residential facilities, but the issue of accessibility to public places and spaces for people with dementia and their carers has been almost completely neglected. In a series of focus group consultations we asked members of the eight Alzheimer's Australia NSW regional consumer committees to describe how they experienced their surrounding neighbourhoods once they stepped outside the safety and familiarity of their front gate and made their way to the local shopping centre, park, doctor's surgery or club.

[Building Dementia and Age-Friendly Neighbourhoods - Discussion Paper 3 July 2011\(PDF\)](#)

[Addressing the stigma associated with dementia - Discussion Paper 2 Sep 2010](#)

The purpose of this paper is to raise public awareness about the effects of stigma associated with dementia, to address the need to change the way we, as a society, approach dementia, and to make recommendations for further action.

[Addressing the Stigma associated with Dementia Discussion Paper 2 \(PDF\)](#)

Dementia is a condition that carries a heavy burden of stigma. People's attitudes, perceptions and understanding of the nature of dementia can determine how a person diagnosed with dementia, their carer and family accept and learn to live with the condition. The stigma associated with dementia can often lead to social exclusion, discrimination and disempowerment.

[Alzheimer's Australia NSW – Addressing the Stigma associated with Dementia - Executive Summary \(PDF\)](#)

[Driving and dementia in New South Wales - Discussion Paper 1 Apr 2010](#)

A new discussion paper, Driving and Dementia in NSW, indicates there is little clear, accessible information about the rights and responsibilities of a driver after a diagnosis of dementia.

[Driving and Dementia in New South Wales Discussion Paper 1 \(PDF\)](#)

Issues raised include:

- Driver testing for people with dementia must be improved
- Legal obligations for a driver with dementia are unclear
- Call for improved transport alternatives for a person with dementia
- Need for better support for transition from driver to non-driver in NSW

[NSW Discussion Paper Key Recommendations \(PDF\)](#)

[Quality Support Groups Research Project](#)

There is little knowledge of the way support groups in New South Wales are currently functioning, or how effectively they are providing support to their participants. The purpose of the Quality Support Groups Research Project is to understand the operation and structure of dementia support groups in New South Wales; ascertain what constitutes a quality support group; and determine how a quality support group can be achieved.

Quality Support Groups Research Project - Phase 3 The purpose of Phase 3 is to analyse findings from Phase 1 and Phase 2 of the Project. The Quality Support Groups Research Project provides a comprehensive understanding of quality in a support group and formulates best practice guidelines to enhance the delivery of quality service

to carers of people with dementia. This research upholds the mission of Alzheimer's Australia NSW to minimise the impact of dementia through leadership, innovation and partnerships. This is the third and final report into a research project that spanned 5 years and looked at what comprises a quality support group. This is the first comprehensive state-wide Australian study of ongoing support groups for carers of people with dementia. Over the five years of the project more than 350 people took part, including leaders of the groups and carers who had at some time attended a support group.

Significant findings of the report are:

- Huge benefits of supports groups for people who attend on a regular basis
- The uncelebrated capacity of mutual aid amongst group members to assist each other
- The unexpected finding of the profound impact of grief and loss on the health and well-being of a carer of a person with dementia
- Some carers reported the grief and loss felt at the time of diagnosis was equal to or even greater than the grief felt when the person with dementia dies

[Quality Support Groups Research Project - Phase 3 Executive Summary \(pdf 45 KB\)](#)

The full Phase 3 report is available to purchase from Alzheimer's Australia Online Bookshop.

[Quality Support Groups Research Project - Phase 2 \(pdf 1.92 MB\)](#)

This report presents the second phase of the Quality Support Groups Research Project, which acknowledges the voices of past and present members of dementia carer support groups.

[Quality Support Groups Research Project - Phase 1 \(pdf 764\)](#)

The focus of phase one of the Quality Support Groups Research Project is a

literature review of research conducted into dementia support groups and a survey of existing support groups in New South Wales to investigate the views of support group leaders.

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