
Decision making in advance: Reducing barriers and improving access to advance directives for people with dementia

Alzheimer's Australia
Discussion Paper 8

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Acknowledgments

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Dr Margaret Brown
Research Fellow
Hawke Research Institute
University of South Australia

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Foreword

At the National Consumer Summit in October 2005, one of the many important issues identified by participants was the need to address the legal issues faced by people with dementia and their families and carers.

As a first step, Alzheimer's Australia has commissioned Dr Margaret Brown to write this discussion paper on enduring powers and advance directives. The objective is to provide a basis for discussion by consumers of decision making in advance involving legal documents about health care and financial matters and, most importantly, to identify the action that they would like to see taken at the National and State and Territory levels.

This paper is being circulated widely - to consumers, as well as, to Public Guardians, Attorneys-General, Health departments, legal and advocacy rights organisations and peak bodies who have an interest in aged care such as the members of the National Aged Care Alliance.

Alzheimer's Australia is seeking your comments to help us to better address the problems experienced by consumers associated with advance decision making for people with dementia. Your experiences will provide useful evidence to help us to understand these issues. We are keen to know whether the recommendations in this paper address the major points of concern to you. In particular, we are interested in whether the recommendation to seek to have the issues addressed by the Standing Committee of the Attorneys-General is the best way forward.

If you wish to share your views, please write to Alzheimer's Australia, PO Box 4019, Hawker, ACT, 2614 or e-mail comments to secretariat@alzheimers.org.au by end July. If you would like to join our State based consumer groups in considering these issues, please let us know and we will put you in touch with the appropriate contacts.

Lastly, I should like to thank Lundbeck for their continuing support of our publication program.



Associate Prof Marc Budge
President

Recommendations

1. The use of formal advance directives for people with dementia, as soon as possible after diagnosis should be encouraged by Alzheimer's Australia and other agencies.

2. Alzheimer's Australia should consider working more closely with Guardianship Tribunals to provide support for their clients who need to apply for guardianship.

3. Alzheimer's Australia should provide information seminars for all people with memory loss. This could be open to the public for a fee.

4. Alzheimer's Australia should include an additional module as part of the Living with Memory Loss groups to assist the participants to discuss advance directives.

5. Alzheimer's Australia should consider establishing 'a one-stop shop' service (perhaps through the new Dementia Memory Community Centres) run by well-informed, accredited professionals who understand the difficulties and disruption that a diagnosis of Alzheimer's disease can bring. This would include access to the documents and an appropriate witness as well as professional guidance and counselling.

6. Attorney Generals should convene a forum including Alzheimer's Australia and the National Guardianship Administration Network to discuss the issues associated with the law and practice of advance directive legislation within each state and across state boundaries. Some of the issues that require a national approach include:
 - a. clarification of when legally appointed decision makers are necessary

 - b. need to establish clear pathways to appoint substitute decision makers

 - c. mutual recognition and harmonisation of the respective laws across state boundaries

- d. the lack of consistency in the legislation across and within the states, for example
 - when enduring powers are activated
 - ensuring enduring powers of attorney are properly exercised once the donor becomes legally incapacitated
 - the need for an annual review of all advance directives

 - e. different terminology

 - f. the need for national strategies to improve knowledge about advance directives
 - in the community
 - for health professionals
 - for the legal profession.
7. There is a need to establish a community education campaign with a specific day per year as a prompt for people to consider their future planning.
8. There is a need to initiate discussions about education for health and legal professionals including training for accreditation for all professionals who will be advising on advance directives.

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Introduction

This paper was commissioned by Alzheimer's Australia to promote an informed discussion about the complex and confusing area of advance directives. It addresses the issues associated with decision making in advance of loss of competence for people with dementia, including the barriers that may inhibit the process. A number of recommendations are suggested to improve the process of decision making in advance for people with dementia and their family carers. These will require additional resources and action by a range of agencies including Alzheimer's Australia.

The recommendations made are consistent with views expressed at the National Consumer Summit on Dementia in October 2005. Seven priority actions were developed at this summit, two of which refer specifically to the findings in this report:

- *Action Point 3*, the recognition of the importance of the Living With Memory Loss programs; and
- *Action Point 5*, access to appropriate financial planning including enduring powers as they are integral to good financial planning.

A number of principles underpin the seven priority actions in the Communiqué from the Summit. These principles include:

- 'people with dementia and their carers need to be recognised as partners in decision making about care options' and
- 'to involve people with dementia as far as is possible'.

This principle of respect and self-determination is fundamental to advance care planning, enduring powers and advance directives. This needs to be acknowledged and acted on. It is time to offer a simplified process to assist people with this complex aspect of their future planning.

Background

Decision making in advance of loss of competence has legal, medical and social implications. It is about relationships, communication and families. Appointing another person to make one's decisions is complex and raises questions about trust, responsibility, competence and appropriate timing for the activation of enduring powers.

It also involves acknowledging one's frailty, future loss of competence and ultimately one's death. This confronts individuals with the 'big questions' that the majority of people are reluctant to talk about.

What appears to be a relatively simple process of completing forms and writing down one's wishes about future care is fundamentally about delegating one's decision-making powers to another person. It is investing one's autonomy in someone else. It cannot be simply categorised as a legal matter as many of the decisions that need to be made involve medical and health care and may impact on the dying process.

The aim of the National Framework for Action on Dementia¹ is to improve the quality of life of people with dementia, their families and their carers. The principles underpinning this National Framework and all 'best practice' include the right for people with dementia to be respected and treated with dignity. In order for this to be achieved their wishes need to be known about their future care, financial management and all aspects of their life while they can still participate in the decision making. This provides more opportunity for them to be recognised as *partners in their care* through their decline and end of life.

Alzheimer's Australia represents some of our society's most vulnerable older people. Individuals diagnosed with Alzheimer's disease or other dementias will at some stage during their illness lose decision-making capacity. It is therefore important that these potentially vulnerable, usually older, adults are encouraged and assisted in planning for their future in our complex society while they are still able and have legal capacity.

Not everyone who develops memory loss is aware of the need to plan for future decision making and there are barriers that may inhibit people from proceeding with this process. Few people appoint a substitute decision maker or make an advance health care directive, and once legal capacity has been lost then the opportunity to do so is also lost.

The increasing number of elderly people who will lose decision-making capacity challenges us as a society to address the issues and barriers that currently exist.

Advance directives

For the purpose of this brief discussion paper the generic term 'advance directive' will be used to describe appointing a substitute decision maker and/or making an advance health care directive. The language used throughout the Australian jurisdictions differs and there is some disagreement about what specific terms mean.² It is important, therefore, to establish clear definitions and identify the principals that underpin those definitions so that a national discussion can take place.

An **advance directive** is a generic term that covers:

- Enduring Power of Attorney (EPA), which appoints a substitute decision maker for financial and business matters;
- Enduring Power of Guardianship (EPG), which appoints a guardian to make decisions about lifestyle and health care;
- Medical Power of Attorney (MPA), which appoints a medical agent to make decisions about medical treatment when the person is no longer competent;
- Advance health care directive: a written statement (whether a formal legal document or informal) stating the sort of medical treatment and/or health care the individual may or may not want after he or she is no longer able to make these decisions³

Advance directives are based on the principle of autonomy and provide a way of extending the individual's right to self-determination when he or she is no longer competent to make decisions. The concept arose in the USA during the 1970s as a response to the technological interventions that kept people alive, often in a moribund state, rather than letting them die. People wrote letters to their loved ones asking that they not be kept alive if they were no longer able to communicate meaningfully with their families. These letters became known as living wills and were the beginning of the advance directive movement.⁴ Legislation followed but written statements proved to have limitations and did not always reflect the person's values and principles. Then legislators thought that appointing a trusted person to make decisions for the individual would be a better way of ensuring that his or her wishes were followed once the person was no longer competent. Powers of attorney for health care decisions were then introduced in law. Australia followed this trend in principle, but not consistently throughout the different jurisdictions.

A decision maker can also be appointed for financial and business matters. These are quite separate issues; however this also involves appointing and investing trust in another person. Powers of attorney for financial matters have been in existence for some time but the powers cease when the donor loses capacity. *Enduring* powers were introduced during the 1980s, to continue after the donor has lost legal capacity. More people are aware of enduring powers of attorney for financial matters than any other form of advance directive.

Advance directives: is there a need?

Carer: *"I had no idea that we needed to do this. Who would tell you?"*

Individuals diagnosed with Alzheimer's disease *will* lose decision-making capacity at some stage during their illness. Therefore good future planning is important including appointing enduring powers and discussing future decisions before it is too late.

In many families informal decision making appears to be satisfactory and there may not be a need for any formal advance directive.⁵ The common law and guardianship law in most Australian jurisdictions acknowledge these informal arrangements. This means family members have the right to decide on behalf of an individual who can no longer do so.⁶

The majority of people, especially older people, assume that they can make decisions or have decisions made for them by their next of kin. Not all are aware that they need to appoint an enduring power for financial matters for certain financial matters. Many couples have their home in joint names and this can become difficult if an enduring power of attorney has not been appointed and the person loses capacity. It is increasingly difficult to manage one's financial affairs in a society that demands a legally appointed substitute decision maker.

In some cases when families rely on informal decision making the process breaks down as a result of conflict or power relationships that overrule the older person's decisions.

Many of these cases are referred to the Guardianship Tribunal, where a guardian is appointed to assist with the decision making. The appointed guardian may be a family member or they may be a stranger. In some cases, there are limitations on the types of decisions they can make.

The majority of cases referred to Guardianship Tribunals throughout Australia involve older people with dementia, hence decisions about these vulnerable people's lives move from their private domain into the public arena. This can be a straightforward process in clarifying the powers or it can be very distressing both for the individuals and their families. It also involves considerable cost to the community. It could be argued that many of these referrals could have been prevented if advance directives, especially appointed decision makers, were in place.

It is recommended that:

1. The use of formal advance directives for people with dementia, as soon as possible after diagnosis should be encouraged by Alzheimer's Australia and other agencies.

Access to accurate information and assistance

Currently many people do not understand the advantages of advance directives and the importance of attending to them while they are still able to participate in the decisions. Research in South Australia found that information about advance directives and enduring powers is not readily available and many people are not aware of the need to look for the information.⁷ Most states have the relevant information about their advance directive legislation on websites; however not all older people have access or are familiar with downloading information from the internet.

Planning for the future should involve the opportunity to communicate about one's decisions, life wishes and preferences in a private and trusting environment. The discussion should be intrinsic to the process as it can involve private and sometimes distressing issues, particularly when there is conflict in the family. Some people require assistance to think through their personal situation.

This level of intimacy is rarely acknowledged in association with appointing a substitute decision maker and attempting to express wishes about the refusal of medical treatment. For example part of the discussion may involve decisions about how the individual would want to be cared for when he or she is dying. This includes clinical decisions about resuscitation, life support and the use of antibiotics.

This subject also crosses professional boundaries. It is about relationships, communication and families. Not everyone has a close, trusting family. For those who do the process can be relatively easy, but only if English is their first language, they are relatively well educated and they can afford to consult a lawyer. For those who do not, this process can be just too hard and confronting. Who do you trust? Where can you get advice?

Advance directive legislation begs the question about who people should consult - a doctor or a lawyer. Research has shown that some people are confused about whether to see a lawyer or a doctor when the decisions relate to health care and lifestyle. Discussing end-of-life decisions with a lawyer is hardly appropriate and doctors are often not comfortable with the legal documents. Enduring powers of attorney for financial matters are less confusing and people usually seek assistance from a lawyer, accountant or financial planner. These people are obviously less suited to assist with health and lifestyle decisions.

Legal advice

Those people that visit a lawyer to execute their enduring powers will rarely have an in-depth discussion about their future decisions. Lawyers do not have the skills and knowledge to give advice about medical treatment decisions and are not well versed in decisions around suitable living arrangements or the issues of grief associated with memory loss and a diagnosis of Alzheimer's disease.

Many people do not go to lawyers: some prefer not to, others cannot afford it and many do not know a suitable one to go to. South Australian research has found that lawyers do not give standard information and some only attend to enduring powers for financial matters.

Advice from health professionals

Not all health professionals, including general practitioners, are well informed about enduring powers and advance directives and they rarely raise the topic with their patients.⁸

In 2002, research in South Australia found that general practitioners were unsure about how to advise patients to express their wishes about medical treatment, and they also found that giving advice on future planning was too time consuming.⁹

The 2005 SA research found that memory clinics do not have standard protocols.¹⁰ Some people who were referred to a memory clinic were given the relevant forms and do-it-yourself kits; others were not given any information nor was there any follow-up to assist these participants in completing their enduring powers.

Do-it-yourself kits

There are do-it-yourself kits, but they are not readily available and can be daunting for some people who are not familiar with the process or feel uncertain that they are doing the right thing. People frequently have to rely on a complete stranger to witness these documents, such as a Justice of the Peace (JP) at the local council. This process assumes that the JP has checked to see if the documents are correct and that the individual is competent enough to understand what they were doing.¹¹

Some people find do-it-yourself kits easy to understand and others do not. In the SA research, one woman and those close to her (all with university degrees) had misunderstood the extent of the powers under the EPG and thought that it covered financial matters as well. Others found the wording daunting. This suggests that people not only need advice but also support with the process of understanding, completing and witnessing the documents.

Guardianship Tribunals

Guardianship Tribunals can appoint an administrator of finances or a guardian to make personal and health care decisions if an individual loses capacity and has not appointed an enduring power. The guardian may be a family member if one is appropriate and willing. This service is not well known as an alternative avenue for appointing a decision maker, and its function as a safety net is not well understood. There is, however, a changing paradigm around decision making in society and a much greater need for legally appointed substitute decision makers, for example in dealing with agencies such as gas, electricity, telephone and financial institutions. There is also an increased insistence by residential facilities for powers of attorney to be in place on admission.

A percentage of people who develop dementia do not have someone they can appoint as a substitute decision maker. Once an individual has lost capacity, the Guardianship Tribunal is the only avenue to legally appoint a decision maker. It is therefore important that the process of applying for guardianship is easy and families are well supported with mediation and advocacy services. This requires adequate resourcing if tribunals and Public Guardians are to be available as helpful options for people with dementia and their family carers.

Alzheimer's Australia

Receiving a diagnosis of Alzheimer's disease is often very traumatic for families. It is not always appropriate to delve into a discussion at this time when the individual and their family are struggling emotionally with the meaning of the diagnosis and the potential of losing decision-making capacity. However, it is important that this discussion occurs and strategies need to be devised to see that discussion takes place in a non-threatening environment.

One strategy is to give information about enduring powers at diagnosis, in an informed and sensitive manner, then a follow-up three to six months later with a trained professional sensitive to the accumulated loss that individuals and their families experience. Alzheimer's Australia would be an ideal organisation to provide this follow-up support. If this were the case, then all those diagnosed with memory loss could be referred to this service. This would involve informing general practitioners, geriatricians and specialists involved in memory clinics about the service and the importance of referring their patients as soon as possible.

The Living with Memory Loss (LWML) groups run by Alzheimer's Australia provide helpful information for the participants on this subject. However, not all people who experience memory loss, and not all those who have been diagnosed, find their way to Alzheimer's Australia. Some may receive very little or no support. Some participants of the LWML groups are unsure about their decisions because of complex family needs and require additional support.

Most of the participants in the SA research thought that it would be a good idea for Alzheimer's Australia to run a seminar or forum on enduring powers where people could get information including the relevant forms, and appropriate advice to assist both those who are struggling with memory loss and their families.¹²

Information about advance directives needs to be more readily available and the information should be more accessible for older people and people from other cultures and language groups. Easy access and a non-threatening environment could make a significant contribution to alleviating some of the burdens that Alzheimer's disease and other dementias impose. Having a single venue where people could get information and advice that covers both the legal and medical aspects of the process, as well as, the sensitive personal issues, would encourage more people to put their powers in place and consider their future decisions in a safe environment. It could be open to the public (for a small fee) as well as people with dementia and their families.

It is recommended that:

2. Alzheimer's Australia should consider working more closely with Guardianship Tribunals to provide support for their clients who need to apply for guardianship.

3. Alzheimer's Australia should provide information seminars for all people with memory loss. This could be open to the public for a fee.

4. Alzheimer's Australia should include an additional module as part of the Living with Memory Loss groups to assist the participants to discuss advance directives.

5. Alzheimer's Australia should consider establishing 'a one-stop shop' service (perhaps through the new Dementia Memory Community Centres) run by well-informed, accredited professionals who understand the difficulties and disruption that a diagnosis of Alzheimer's disease can bring. This would include access to the documents and an appropriate witness as well as professional guidance and counselling.

Simplifying the law and practice

Wife: "Is there law governing this? I didn't know."

The law and practice associated with enduring powers and advance directives are complex, varied and difficult for families to understand. There is no consistency across the different Australian jurisdictions. It is not within the scope of this paper to analyse the differences between and within each jurisdiction other than to note that there are serious inconsistencies that will require urgent attention if these laws and policies are to become more user friendly for people as they age, especially those who will lose capacity.

There is also confusion and inconsistency in the language and terminology associated with the law both across state borders and within the states. For example, in South Australia there is overlap between the Enduring Power of Guardianship and the Medical Power of Attorney.¹³ In Western Australia and the Northern Territory people cannot appoint an enduring guardian. This means they cannot appoint a substitute decision maker for lifestyle and health care decisions. On the other hand, Queensland and the ACT have enduring powers that cover financial, lifestyle and health care decisions under the one power. Therefore it is only necessary to appoint one person as a substitute decision maker if the donor so chooses.

Not all people are clear about when the enduring powers are activated. This point needs clarification for all enduring powers in all jurisdictions.

Even when people have attended to their enduring powers and made advance health care directives, it is imperative that they are reviewed regularly, for example once a year. The SA study found several examples of couples who had appointed each other as substitute decision makers some years before the onset of Alzheimer's disease.¹⁴ This could have serious ramifications once the partner loses capacity.

Recently there has been considerable attention given in the media to elder abuse, specifically related to the misuse of enduring powers of attorney for financial matters.

The potential for abuse of enduring powers is a barrier for some people who feel they do not have someone that they can trust. Safeguards need to be put in place to ensure that vulnerable people, such as those with dementia, are protected against financial abuse.¹⁵

Not all states currently recognise other states' advance directive legislation. This can cause considerable anxiety, confusion and additional cost. Many people are very mobile in the twenty-first century; hence consistency and mutual recognition are essential.

It is recommended that:

6. Attorney Generals should convene a forum including Alzheimer's Australia and the National Guardianship Administration Network to discuss the issues associated with the law and practice of advance directive legislation within each state and across state boundaries. Some of the issues that require a national approach include:

- a. clarification of when legally appointed decision makers are necessary*
- b. need to establish clear pathways to appoint substitute decision makers*
- c. mutual recognition and harmonisation of the respective laws across state boundaries*
- d. the lack of consistency in the legislation across and within the states, for example*
 - when enduring powers are activated*
 - ensuring enduring powers of attorney are properly exercised once the donor becomes legally incapacitated*
 - the need for an annual review of all advance directives*
- e. different terminology*
- f. the need for national strategies to improve knowledge about advance directives*
 - in the community*
 - for health professionals*
 - for the legal profession.*

Education

The community

The wider population is not well informed about enduring powers and advance directives. There are no clear markers (prompts) in our community to remind people to attend to their affairs (e.g. getting married, make a will!). Retirement can often be a trigger particularly for businessmen and women. The diagnosis of Alzheimer's and/or the symptoms of memory loss and attending the LWML group can be a trigger for some people to attend to their enduring powers and/or advance directives, but not for others. Many do not find their way to Alzheimer's Australia or any other support. There need to be some clear markers or prompts to remind and assist people who are not in contact with these organisations about the importance of future planning.

Education campaigns need to be aimed at *all* older people to avoid stigmatisation of those with memory loss and to ensure that people have the information before they lose capacity and cannot legally appoint a substitute decision maker.

Community education tends to be limited and ad hoc. It is better developed in some states than others. Queensland has revised its powers of attorney legislation and improved public and professional education. Public education is the responsibility of the Office of Public Advocate or Guardian in each state but is currently limited. More resources are needed to ensure that the public is well informed on these issues.

It is recommended that:

7. There is a need to establish a community education campaign with a specific day per year as a prompt for people to consider their future planning.

Health and legal professions

Health professionals are on the whole not well informed about advance directives. This includes the medical profession as many consider advance directives to be part of the legal domain and therefore not their responsibility.

The Respecting Patients' Choices (RPC) project currently running in Victoria, South Australia and the Northern Territory is one example of training health professionals about the state laws and how to introduce the topic to patients in some acute hospitals.

Training staff to become RPC consultants is a good model and recognises the need for properly accredited personnel to advise people on their future decisions. The plan is to roll the program out to aged care facilities and the community; however this is a slow process and the program is not available to everyone.

An education program designed specifically for general practitioners was developed in the Central Coast of NSW.¹⁶ The program is based on interactive CDs, one of which is *Legal Issues for Older Persons*. The evaluation of this program found that the biggest barrier for GPs was lack of knowledge and skill.

There is little documented evidence on how lawyers advise clients about advance directives nor on the issues associated with capacity assessment. As mentioned above, the SA study found that people's experience with lawyers was variable and generally they did not adequately address health care and lifestyle decisions.

Lawyers are trained to understand the law and the legal process. However they are not trained in capacity assessment nor in how to assist people with early memory loss, and all the ramifications that will ensue for them and their families as their condition progresses.

It is recommended that:

8. There is a need to initiate discussions about education for health and legal professionals including training for accreditation for all professionals who will be advising on advance directives.

Further reading

These documents complement and expand on the material covered in this discussion paper:

1. The National Framework for Action on Dementia, 2005 Consultation Paper; and Response from Alzheimer's Australia.
2. Legal Planning and Dementia, Alzheimer's Australia Position Paper 5, 2005.
3. Palliative Care and Dementia, Alzheimer's Australia Discussion Paper 7, 2006
4. Communiqué: National Consumer Summit on Dementia, Alzheimer's Australia 2005.
5. Margaret Brown and Sue Jarrad, *Putting 'the Powers' in Place: Planning for the Future*, Final Report, Alzheimer's Australia SA Inc, 2005.

Notes

1. National Framework for Action on Dementia, *2005 Consultation Paper*, Australian Health Ministers' Conference, p. 8.
2. See Appendices A and B.
3. See Appendix A.
4. Margaret Brown, *The Medical Power of Attorney: A Benefit or Burden?* Master of Science Thesis, Flinders University, 1995.
5. See Appendix B.
6. There are some exceptions including decisions about larger financial transactions and selling property. For example, many couples have joint ownership of their house
7. Margaret Brown and Sue Jarrad, *Putting 'the Powers' in Place: Planning for the Future*, Final Report, Alzheimer's Australia SA Inc, 2005.
8. H Merl and L Bauer, *Time to Think about Aged Care and Dementia*, 4 CD set; *Legal Issues for Older People*, CD & Evaluation, Legal Issues Working Party of the Central Coast Primary Dementia Care Network (CCPDCN), 2005; Margaret Brown, 'Participating in End-of-Life Decisions: The Role of General Practitioners', *Australian Family Physician*, vol. 31, no. 1, 2002, pp. 60–62.
9. Margaret Brown, 'Participating in End-of-Life Decisions: The Role of General Practitioners', *Australian Family Physician*, vol. 31, no. 1, 2002, pp. 60–62.
10. Margaret Brown and Sue Jarrad, *Putting 'the Powers' in Place: Planning for the Future*, Final Report, Alzheimer's Australia SA Inc, 2005.
11. The Royal Association of Justices of SA Inc. expressed an interest in education about capacity assessment. This could indicate concern about their role in this area.
12. Margaret Brown and Sue Jarrad, *Putting 'the Powers' in Place: Planning for the Future*, Final Report, Alzheimer's Australia SA Inc, 2005.
13. The South Australian advance directive legislation will be reviewed in 2006. The Review Committee will be informed about the some of concerns addressed in this paper.
14. Margaret Brown and Sue Jarrad, *Putting 'the Powers' in Place: Planning for the Future*, Final Report, Alzheimer's Australia SA Inc, 2005.
15. In 2005 the SA Attorney General released a *Discussion Paper on Enduring Powers of Attorney*.
16. H Merl and L Bauer, *Time to Think about Aged Care and Dementia*, 4 CD set; *Legal Issues for Older People*, CD & Evaluation, Legal Issues Working Party of the Central Coast Primary Dementia Care Network (CCPDCN), 2005.

Appendix A

Glossary of terms

Advance health care directives (AHCD)

Similar terms include advance health directive (AHD), advance directive (AD), anticipatory direction (AD) and living will. These are written statements stating the sort of medical treatment and/or health care the individual may or may not want after he or she is no longer able to make these decisions. Some jurisdictions have legal documents (formal advance directives); others do not have specific legislation but encourage individuals to record their wishes in writing (informal advance directives).

For example, Queensland and the ACT have legal documents for recording wishes in advance. SA and the NT have specific legislation that only allows decisions about end-of-life treatments to be made in advance. Victoria has a Refusal of Treatment Certificate that only applies to a 'current condition'.

Enduring Power of Attorney (EPA)

An enduring power of attorney is a legal document that allows an individual to appoint an attorney (substitute decision maker) to make decisions about financial and business matters. This power extends after the person has lost legal capacity, unlike the power of attorney which ceases once the person no longer has capacity.

Each state and territory has specific legislation but there are differences in:

- terminology;
- registration of the enduring powers;
- when the power is activated;
- mutual recognition of the other states' enduring powers.

Both Queensland and the ACT have enduring powers of attorney that can cover financial, lifestyle and health care decisions. The other states and territories specifically do not allow an EPA to decide on health and lifestyle decisions.

For detailed information see: Alzheimer's Australia webpage 'Legal Planning and Dementia' at <http://www.alzheimers.org.au/legal>

Enduring Power of Guardianship (EPG)

An enduring power of guardianship is a legal document that allows an individual to appoint a guardian to make decisions about lifestyle and health care. This power commences after the person no longer has decision-making capacity. The enduring power of guardianship is available in NSW, Victoria, South Australia and Tasmania. Western Australia and the Northern Territory do not have an equivalent power. Queensland and the ACT have one enduring power to cover both financial and health care decisions.

Medical Power of Attorney (MPA)

The Medical Power of Attorney is a legal document that allows an individual to appoint a medical agent to make decisions only about medical treatments when the person is no longer competent to do so. South Australia has a MPA. Victoria's legislation uses a different term, an enduring power of attorney (medical treatment).

Appendix B

Legal resources

The Alzheimer's Australia 'Legal Resources' webpages demonstrate the lack of consistency across the different jurisdictions.

For example, in Queensland if someone has not legally appointed an attorney and that person becomes incompetent, the person's next of kin becomes their Statutory Health Attorney. That person may then make most of the decisions on behalf of the incompetent person. In NSW, the term is 'Person Responsible' and in SA, the guardianship law refers to 'informal decision makers'. In the ACT, however, one's 'spouse or next of kin has no automatic legal right to make decisions about your medical treatment on your behalf. Once your decision-making ability is lost, the Guardianship and Management of Property Tribunal will need to appoint a guardian for you'.

See <http://www.alzheimers.org.au/legal> to follow the links to the resource pages for each State and Territory jurisdiction.

Visit the Alzheimer's Australia website at

www.alzheimers.org.au

for comprehensive information about

- dementia and care
- information, education and training
- other services offered by member organisations

Otherwise, for further information and advice contact:

the **National Dementia Helpline** on **1800 100 500**