Taking Charge

Making Decisions for Later Life

Report for the NSW Committee on Ageing
prepared by the Benevolent Society of NSW and the
Centre for Education and Research on Ageing
December 1999

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nsw committee on ageing

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This report was prepared for the NSW Committee on Ageing by the Benevolent Society of NSW and the Centre for Education and Research on Ageing.

The project was guided by the Taking Charge Project Sub Committee of the Committee on Ageing. Its members were George Zdenkowksi (Chair), Heather Johnson, Les MacDonald and Henry Brodaty. The Project Coordinator was Margaret Tucker. Many others also provided input into the preparation of the report. Their names are listed on page 42.

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The NSW Committee on Ageing advises the Government on matters affecting the needs, interests and wellbeing of older people in NSW. The 14 members of the Committee come from diverse backgrounds and have skills and interests in many different areas of public policy. For details of previous Committee on Ageing publications see page 48.

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The Benevolent Society of NSW, founded in 1817, is Australia's first charity. Its work is organised through four centres that focus on ageing, children, women's health and social leadership. The Centre on Ageing provides a range of services, from healthy ageing to intensive support, throughout Sydney. This includes low and high care aged care facilities, self care units, Community Aged Care Packages, Community Options and support for carers and homeless older people.

The Centre for Education and Research on Ageing (CERA) is a joint centre of the University of Sydney and Concord Hospital. It conducts a multi-disciplinary research program on ageing. This includes epidemiological, clinical, laboratory and health service perspectives looking at normal and abnormal ageing. CERA complements its research work with an active education and resource development program.

Disclaimer

Foreword

There are several steps people can take to plan ahead for a time when they are unable to make health and financial decisions for themselves. Making a will is a well known step, but awareness and understanding of some of the other steps one can take to, for example, cover decisions about medical treatment, are not nearly so widespread. How important it is to formally appoint someone else to take such decisions may depend greatly on a person's circumstances as well as on their own personal views.

Others in the community, including legal and health professionals, are also often not well informed about the legal provisions that exist in NSW for carrying out the wishes of an older person who can no longer manage their own affairs. They may also face a number of obstacles and dilemmas in trying to carry out those wishes.

As part of its *Taking Charge Project*, the Committee on Ageing commissioned the Benevolent Society and the Centre for Education and Research on Ageing to write this Discussion Paper.

Our aim in producing this paper is to:

- provide information about current policies, practices and services that can enhance the autonomy of people reaching the end of their lives who become unable to make decisions about health and financial matters for themselves
- encourage informed debate about end-of-life decision making
- identify gaps in policy and practice that need to be addressed, in order to maximise the quality of life and choices available to people seeking to make decisions about their future lifestyle, health care and financial arrangements.

The Committee will then advise the Minister of what changes, if any, it feels are needed. Feedback from readers will help us do this and so I urge you to let us know what you think. Our contact details are on the opposite page.

John Mountford

John Mountford
Chairperson
NSW Committee on Ageing

This report is dedicated to Patrick,

who by his living and dying

taught us much.

Contents

1. Executive Summary

This report focuses on planning for the future. It is a complex area, made even more so by the use of confusing terms. Section 2 highlights some of these terms while Section 4 gives an overview of the legal, administrative and informal ways that people may choose to plan both their financial affairs, and their health and lifestyle affairs.

It suggests that the mechanisms that deal with financial issues are generally better understood than those dealing with health and lifestyle issues. The section notes a considerable variation in the arrangements across Australian states and territories, an issue that may be of concern to, for example, people who move interstate or have responsibilities for a person who lives in another state or territory.

Section 5 of the report looks at current research on health and lifestyle issues in Australia and overseas, and focuses on three areas — the level of knowledge among stakeholders, take up rates and barriers to take up.

The research suggests that most Australians are open-minded about the idea of making decisions about issues affecting their health and lifestyle in readiness for a time when they may not be able to do so. This is in line with the trend overseas where there has been considerable debate over end-of-life issues. However, Australians face a number of barriers including a lack of community knowledge and skills in this area. Other barriers include poor communication between health professionals and their patients, lack of trust, cultural influences, and fear and other emotional barriers.

This report raises a number of issues which are discussed in Section 6. They are grouped under the headings:

1. **Legal issues.** What legal problems do we need to address?
2. **Systems and structures.** What arrangements do we need to put in place to make the system work?
3. **Communication**. How can we think strategically about communicating with stakeholders?
4. **Skills and knowledge.** How do we develop the skills and knowledge we need?

What emerges at this preliminary stage is the need for further research in a number of areas and a focus on communication including, for example, further dissemination of information to stakeholders.

2. Glossary of Terms

In this complex area, a number of terms exist that have, at best, vague and, at worst, misleading meanings. The following is a list of terms as they are used in New South Wales, though they may also be applicable in other states and countries.

Abuse of older people is any pattern of behaviour which causes physical, psychological, sexual or financial harm or results in neglect.

Advance directive is synonymous with 'advance health care directive' in this paper, although it can mean any written statement that expresses in advance a person's wishes about their financial, medical or lifestyle affairs.

Advance health care directive (or advance care directive) is a document in which a person gives instructions about their future health care. It comes into effect only when the person is no longer capable of making their own decisions.

Capacity (competence) is determined by whether an individual can understand the nature and effect of the decision they are making. It is not determined by whether an individual can perform a certain task or the 'wisdom' of the decisions they make. Capacity and incapacity (incompetence) are not absolute concepts. A capable adult can include someone with a mild intellectual disability or in the early stages of dementia. In general, the more complex the legal document or decision, the greater the capacity to reason would need to be.

Elder abuse – see abuse of older people

Enduring guardian is someone that a person appoints to make personal or lifestyle decisions and/or decisions about medical treatment on their behalf, when they are not capable of making those decisions themselves.

Enduring power of attorney is a legal document signed by a person appointing someone else as their agent with authority to carry out those instructions relating to their business, property or financial affairs that the person has asked them to carry out. Unlike a power of attorney, it remains in force even if the person becomes unable to make their own decisions.

Euthanasia is the active and deliberate intervention by a second party to end life, with the expressed wish of the first party. It is quite different from discontinuing or not starting a treatment at a patient's explicit request given verbally or through an advance directive. Euthanasia is illegal in all states and territories of Australia and is not discussed in this paper.

Guardianship Tribunal is a legal tribunal. It appoints guardians and financial managers for people aged 16 years and over who are incapable of managing their persons or affairs and have no appropriate or safe informal mechanisms in place for this purpose. The Tribunal may also act as a substitute decision-maker in relation to medical and dental treatment proposed by others for adults sixteen years and above who cannot give a valid consent to their own medical or dental treatment.

Living will is sometimes used to mean an advance health care directive, to be followed when the person is not able to make their own treatment decisions.

Palliative care is care that aims to provide comfort and relief from pain but does not aim to cure the illness.

Person responsible is a substitute consent provider for medical and dental treatment for a person aged 16 years old or over who is unable, for some reason, to give valid consent for their own medical or dental treatment.

Physician assisted suicide is when a physician supplies a patient with the information and/or means to take their own life. It is illegal in all states and territories of Australia and is not discussed in this paper.

Power of attorney is a legal document signed by a person appointing someone else as their agent with authority to carry out those transactions to do with their business, property and financial affairs that the person has asked them to carry out. It ceases to have effect when the person loses the capacity to make decisions for themselves. (See also ‘enduring power of attorney’)

(The) Protective Commissioner is an independent statutory official, separate from the Guardianship Tribunal, who can be appointed to protect and administer the financial affairs of people who are unable to manage for themselves. The Protective Commissioner may be appointed by the Supreme Court, the Guardianship Tribunal, a magistrate or the Mental Health Review Tribunal.

(The) Public Guardian is an independent statutory official, separate from the Guardianship Tribunal, who can be appointed as a guardian for a person with a disability in circumstances where it is appropriate to appoint some other person as guardian.

Stakeholders includes all levels of governments, professionals from the health care, legal and financial sectors, peak organisations, religious organisations, ethicists and members of the community.

Will is 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.

3. Introduction

‘I’d hate that to happen to me if I’d lost it…but what can I do about it?’

This 55-year-old man’s sense of concern and frustration echoes the feelings of many as they contemplate life in their later years. Their feelings of powerlessness are compounded by their lack of knowledge about how to go about planning for their future.

Australia’s population statistics confirm that the proportion of older people in our community is increasing, a trend that is set to continue in the next few decades as the baby boomer generation moves into its sixties and seventies. Their life expectancy is also greater than that of previous generations. Advances in medical science worldwide and a dramatic rise in Australia’s standard of living have seen to that.

During the last 20 years, Australians have witnessed remarkable technological, economic and social changes that have significantly affected all areas of their lives. We are encouraged to take increasing responsibility for ourselves throughout our lives. Superannuation is compulsory for those in the workforce, no longer the preserve of the few. Work for the dole schemes that reflect the concept of ‘mutual obligation’ are expanding. The ‘user pays’ principle is common practice and ‘empowerment’ is one of the buzzwords of the 1990s. Australians, whether they embrace the changes or are more reluctant, are taking greater control over their lives than ever before.

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It is little wonder, then, that we are also beginning to look at taking responsibility for the end stages of our lives. But we are in unfamiliar territory. While for some time, the medical and legal professionals have been grappling with issues that arise from changes in medical technology and the blurring of issues surrounding life and death, the general community is less well informed. Their search for information on the choices available to them about financial management and medical decisions is likely to be tough. Information exists but it is often scattered and difficult to access. Even when people know about their options, it is not clear that existing mechanisms satisfactorily deal with the range of problems that people face.

To fill these gaps and to raise awareness of the issues, the NSW Committee on Ageing proposed a four-part plan. It aimed: first, to develop fact sheets on relevant subjects; second, to write two issues papers to complement the fact sheets; third, to hold two consultation sessions with leading Canadian practitioner Dr Willie Molloy; and fourth, to commission a short discussion paper entitled ‘Taking Charge: Making Decisions for Later Life’. This document is the fourth element of the Committee’s plan.

The issues raised in this report apply to people of all ages. However, as its title suggests, it focuses on older people. Implicit in the report is the need to understand the impact of cultural diversity.

This report groups topics on advance decision making into three main areas:

- Current arrangements
- Current research and its implications
- Issues for discussion.

It aims to stimulate broad community discussion on a range of key issues relating to advance decision making.

4. Planning for your future: a snapshot of current arrangements

This snapshot gives an overview of the legal, administrative and informal ways to make a plan about what you want for your future. It looks at:

- Financial decisions
- Health and lifestyle decisions
- Mechanisms that protect people who lack decision making capacity.

Mechanisms that facilitate financial decisions

Australians are much more familiar with the ways to deal with their financial affairs when they are no longer around to deal with them themselves — or are no longer capable of doing so — than with their health and lifestyle affairs. They can choose one, or more than one, of five options:

- Make a will
- Sign a power of attorney
- Sign an enduring power of attorney for financial matters
- Use informal mechanisms
- Do nothing.

The first three options involve legal documents. As the upper section of Table 1 highlights, this situation is consistent across all Australian states and territories. Making a will and signing a power of attorney have been around for enough years for people to be aware of their existence, though they may be less aware of an enduring power of attorney. For some people, it may be quite appropriate to rely on informal mechanisms. If a person does nothing, they may lose the opportunity to have their wishes carried out, although there are safety net provisions to protect their wellbeing.

TABLE 1: Comparing mechanisms for competent decision makers in Australian states and territories, 1999

	Queensland	New South Wales	Victoria
Finances Future **(After death)**	**Will**	**Will**	**Will**
Finances Now (Effective immediately and ends when person no longer competent)	**Power of Attorney** Powers of Attorney Act 1998	**Power of Attorney** Conveyancing Act 1919	**Power of Attorney** Instruments Act 1958
Finances Future **(Before death)**	**Enduring Power of Attorney for Financial Matters** 1998 Powers of Attorney Act – Effective when person chooses and remains effective when person no longer competent	**Enduring Power of Attorney** Conveyancing Act 1919 – Effective immediately and remains effective when person no longer competent	**Enduring Power of Attorney** Instruments Act 1958 – Effective when person chooses and remains effective when person no longer competent
Health Now	**Right to refuse medical treatment** Common law	**Right to refuse medical treatment** Common law	**Right to refuse medical treatment** Medical Treatment Act 1988
Health Future **(Who)** (Effective when person not competent)	**Enduring Power of Attorney for Personal/Health Matters** 1998 Powers of Attorney Act – Can appoint one or more people to make health decisions	**Enduring Guardian** 1997 Amendments to 1987 Guardianship Act – Can appoint one or more people to make health decisions	**Enduring Power of Attorney (Medical Treatment)** Medical Treatment Act 1988 – Can appoint one or more people to make health decisions
Health Future **(What)**	**Advance Health Directive** 1998 Powers of Attorney Act – Enables people to give directions about future health care – Standard forms issued by Dept of Justice	**Informal advance health care directive** Not enshrined in legislation – Enables people to give directions about future health care – Various forms e.g. Let Me Decide	**Informal advance health care directive** Not enshrined in legislation – Enables people to give directions about future health care
Personal Future	**Enduring Power of Attorney for Personal/Health Matters** – Can appoint one or more people to make personal decisions	**Enduring Guardian** – Can appoint one or more people to make personal decisions	Not available

SA	WA	Tasmania	ACT	NT
Will	**Will**	**Will**	**Will**	**Will**
Power of Attorney Powers of Attorney & Agency Act 1984	**Power of Attorney** Common Law	**Power of Attorney** Power of Attorney Act 1934	**Power of Attorney** Power of Attorney Act 1956	**Power of Attorney** Power of Attorney Act 1980
Enduring Power of Attorney Powers of Attorney and Agency Act 1984 – Effective when person chooses and remains effective when person no longer competent	**Enduring Power of Attorney** Guardianship & Administration Act 1990 – Effective when person chooses and remains effective when person no longer competent	**Enduring Power of Attorney** Power of Attorney Act 1934 – Effective immediately and remains effective when person no longer competent	**Enduring Power of Attorney** Power of Attorney Act 1956 – Effective immediately and remains effective when person no longer competent	**Enduring Power of Attorney** Power of Attorney Act 1980 – Effective immediately and remains effective when person no longer competent
Right to refuse medical treatment Consent to Medical Treatment and Palliative Care Act 1995	**Right to refuse medical treatment** Common law	**Right to refuse medical treatment** Common law	**Right to refuse medical treatment** Medical Treatment Act 1994	**Right to refuse medical treatment** Common law
Medical Power of Attorney & Enduring Power of Guardianship Consent to Medical Treatment and Palliative Care Act 1995 & Guardianship & Administration Act 1993 – Can appoint one or more people to make health decisions	Not available	**Enduring Guardian** Guardianship and Administration Act 1995 – Can appoint one or more people to make health decisions	**Enduring Power of Attorney** Medical Treatment Act 1994 – Can appoint one or more people to make health decisions	Not available
Anticipatory Direction Consent to Medical Treatment and Palliative Care Act 1995 – Enables people to give directions about future health care	**Informal advance health care directive** Not enshrined in legislation – Enables people to give directions about future health care	**Informal advance health care directive** Not enshrined in legislation – Enables people to give directions about future health care	**Advance Health Care Directive** Medical Treatment Act 1994 – Enables people to give directions about future health care	Natural Death Act 1998 – Enables people to give directions about future health care but only for terminal illness
Enduring Power of Guardianship – Can appoint one or more people to make personal decisions	Not available	**Enduring Guardian** – Can appoint one or more people to make personal decisions	**Enduring Power of Attorney** – Can appoint one or more people to make personal decisions	Not available

Making a will

Most people are familiar with the idea of making a will. It is the most common form of advance planning that gives specific instructions about how people would like their assets dispersed after they die.

They also know how to go about making a will. It is an accessible process and it can be cheap. Advertisements appear regularly in the pages of the national and metropolitan press urging consumers to make a will ‘free of charge’ if they use the services of a trustee company. The Law Society of NSW and other bodies carry out public information campaigns. Do-it-yourself will kits are readily available in stationers, bookshops and newsagents. A will does not have to be witnessed by a solicitor, although it is wise to seek legal advice when making a will.

However, making a will does not cover all future scenarios. It cannot be used to:

- Give any instruction about how a person wants their financial affairs managed while they are alive.
- Appoint someone to look after a person’s financial affairs while they are, for example, on holiday overseas.
- Appoint someone to look after a person’s financial affairs when they are no longer capable of making decisions themselves.

To cover the first two of these scenarios, a person must sign a power of attorney. The third is dealt with under an enduring power of attorney.

Signing a power of attorney

A power of attorney is the legal document people sign if they want to appoint someone they trust, perhaps a relative or friend, to manage their financial affairs — or some parts of them — while they are alive. Often they do this because it is convenient. They may be going into hospital or want something dealt with in another state or territory.

A power of attorney must be witnessed by a suitably qualified legal person. In New South Wales, as in other states and territories, it must also be registered with the Land Titles Office or its equivalent in other states and territories, if a land transaction is involved.

If the person signing the power of attorney becomes incapable of making their own decisions the authorisation then ends. This is not widely understood which perhaps points to a need for an increased effort on community information and awareness programs.

Signing an enduring power of attorney

An enduring power of attorney is a legal document that deals with a person's finances while they are alive. It is an extension of the power of attorney that continues even if they are no longer capable of making their own decisions.

Australians are still much less aware of *enduring* powers of attorney than they are of powers of attorney and wills.

Someone who wants to sign an enduring power of attorney must have it witnessed and explained by a suitably qualified legal person. This legal requirement may make it 'all too hard' for the person contemplating this step, although how much of a barrier this presents is difficult to determine. Certainly, the barrier is greater for this person than for someone who simply wanted to make a will.

Australians are still much less aware of enduring powers of attorney than they are of powers of attorney and wills. This is probably because wills and powers of attorney have been around much longer than enduring powers of attorney.

Using informal mechanisms

A number of informal mechanisms exist whereby a person can ask others to assist them in managing their finances. These include having a joint signatory on a bank account or having someone else as a nominee for their pension so the nominee receives it on their behalf. Informal mechanisms work best where the person's finances are straightforward and there is no risk of the person being exploited.

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Doing nothing

If a person dies without making a will, written authority from the court may be needed to allow a person to act as an administrator of the estate. This may be a time consuming and expensive process and sometimes causes considerable unnecessary anguish for grieving relatives and friends. When there is no will, the estate is distributed according to the laws of intestacy. This could mean that a person's assets are not distributed according to their wishes.

If a person loses their decision making capabilities and has not signed an enduring power of attorney and informal mechanisms for managing their financial affairs are not sufficient, then someone may need to apply to the Guardianship Tribunal or Supreme Court. The Tribunal may then make a Financial Management Order appointing someone, perhaps a family member or a suitably qualified friend, to make financial decisions on the person's behalf. If the family disagree on the best person, if there is no one available to take on the financial management role or if the circumstances of the case otherwise require, the Protective Commissioner may be appointed.

CASE STUDY

1. Helen and Michael — No will

Helen and Michael married against the wishes of Helen's parents, who belonged to a strict religious group. Her parents refused to attend the wedding or speak to either of them. Helen was very angry with the religious group for what she saw as their role in breaking up her family, and with her parents for signing over their house and savings to the group. A year after Helen and Michael were married, both were killed in a head-on collision with a semi-trailer. Neither had made wills and they had no children.

Under the laws of intestacy, Michael's estate passed to Helen, as he was older and presumed to have died first. Helen's estate (plus Michael's) went to her parents, who promptly handed it over to the religious group. This was the last thing that Helen wanted to happen, but because she had not left a will, she had no say in it.

The formal mechanisms for making financial decisions involve authoritative legal documents. They cover a broad range of scenarios dealing with a person's wishes before and after death and some remain effective regardless of the person's decision making capabilities. The picture is not so clear cut with health and lifestyle matters.

Health and lifestyle decisions

'Every day for many years, Irene, a nursing sister, witnessed the distress of older patients who were kept alive against their wishes. She then suffered a stroke herself and became paralysed down one side of her body. Determined to avoid a similar fate, she appointed her two daughters as her enduring guardians and added an advance health care directive to the paperwork. She wanted to make sure that if she had another stroke and could not communicate her wishes, she would only receive palliative care if she developed problems such as bowel obstruction.'

Some Australians would agree with Irene's actions; others would not. Every adult Australian has the right to refuse medical treatment (Table 1). But how can people make sure they live the lifestyle they want and receive the health care they want when they are not in a position to make those choices clear themselves? They can choose to do one or more of four things:

- Tell people
- Appoint an enduring guardian
- Write down their preferences
- Do nothing

Some of these ways involve informal mechanisms, such as telling people, their family perhaps, what they would like to happen to them. Others involve formal legal arrangements such as appointing an enduring guardian. Writing down preferences, while not legally recognised in some Australian states and territories, may guide other people making decisions for a person who is no longer competent. The lower section of Table 1 compares the mechanisms for making decisions about health care across the states and territories. Table 2 indicates types of care, from palliative to intensive.

Table 2: Stages of care — The level of care a patient may wish ranges from palliative care to intensive care

	Palliative	**Limited**	**Surgical**	**Intensive**
Aim	To maintain comfort only and prevent pain	To provide some care, non-surgical	To provide surgical care	To maintain life
Treatment	Tests and treatment only to relieve pain or improve comfort, not as a cure	**Yes:** • Antibiotics • Blood tests • Intravenous lines • X Rays • Oxygen **No:** • Life support • surgery • general anaesthetic	**Yes:** • Antibiotics • Blood tests • Intravenous lines • X Rays • Kidney machine **No:** • Ventilator unless surgery demands	**Yes** • Biopsies • Surgery • Life support systems • Transplant surgery
Where	Home preferred	Home preferred	Home to hospital	Home to hospital to bigger hospital
Case example Bleeding stomach	• No blood • No drugs	• Blood • Drugs	• Blood • Drugs • Procedural and surgical intervention	• Blood • Drugs • Procedural and surgical intervention • Life support

Telling people

At the most simple and informal level, people may make their wishes about lifestyle and health known to people who they trust would act in their best interests if the need arose. These may include their doctor, family members and close friends.

Problems may arise when people have no one to tell, no one to discuss their health and lifestyle preferences with.

However, problems may arise when people have no one to tell, no one to discuss their health and lifestyle preferences with. This may mean that no one with any knowledge of the person's views is around to make sure their wishes are followed. In some states and territories, the people they tell may not have the legal authority to see that their wishes are carried out.

Appointing an enduring guardian

Appointing an enduring guardian or, in some states and territories, signing an enduring power of attorney for health and lifestyle matters, deals with the ‘who’ in the process of making views known. It does not, however, deal with the ‘what’.

In NSW an enduring guardian is someone a person chooses to make personal or lifestyle decisions on their behalf when they are no longer capable of doing so. The person chooses what sort of decisions they want the enduring guardian to make. These are called functions. The person can give their enduring guardian directions on how to carry out the functions. Enduring guardians cannot make a will, agree to marriage or override the person’s objections to medical treatment. Neither can they manage their financial affairs unless the person has given them an enduring power of attorney.

The signatures on enduring guardianship forms, like those on powers of attorney and enduring powers of attorney, must be witnessed before a solicitor or Clerk of the Local Court.

Writing down preferences

Enduring guardianship deals with the ‘who’ of the process. But how does a guardian know what the person’s wishes are? He or she may choose to rely on their guardian to make decisions in their best interests. Or they may prefer to write down the ‘what’ of the process — their preferred lifestyle and medical choices.

The higher the value people place on autonomy (being able to control what happens to them) the more likely they are to write down their preferences about health care treatment. Because these choices are written ahead of time, anticipating the moment when they need to be put into effect, these documents are called ‘advance health care directives’. Like wills, they deal with matters in advance but, unlike wills, they deal with health and lifestyle matters before death rather than financial matters after death.

Advance health care directives, (sometimes known as living wills), contain written instructions about a person’s care in case they cannot make those decisions themselves. In New South Wales these directives are not backed by legislation, unless they form part of the appointment of an enduring guardian. In practice however, doctors take them into account when treating the patient and may face penalties if they do not do so. This is reflected in *‘Dying with Dignity: Interim Guidelines on Management’* produced by the NSW Health Department in 1993 which states that “the wish of the patient expressed in this way should be respected”.

Those who argue in favour of advance health care directives suggest that:

- Patients have the right to say what can and cannot be done to their own bodies. The medical profession should not be allowed to impose medical treatments contrary to the wishes of the patient.
- Patients are the people who must live with the consequences of the medical treatment. They have a right to make their own choices.
- To counter the argument that people cannot decide about an advance health care directive because they lack all possible information, those in favour of directives suggest that people readily make other decisions in life when they do not have all possible information available.
- When a person is making decisions about their future finances and health and lifestyle matters, they often choose to involve their family, their friends and their doctor. This involvement can benefit everyone as it can be an opportunity for open discussion, to voice concerns and to find out the wishes of the person involved. Knowing a person’s preferences lessens the burden on family and health care professionals who may be asked to make decisions on their behalf. It can also help to prevent arguments among family members.

Those who argue against advance health care directives suggest that:

- Some advance health care directives are biased towards refusal of treatment. This may lead people to believe they should refuse treatment.
- A healthy person who has completed an advance health care directive may, in some way, be a different person with different values if they are no longer able to make decisions. For example, a rocket scientist with dementia may still lead a happy life because they no longer have the same values as when they were a rocket scientist.
- It is impossible to anticipate all possible research and medical developments.

Some states and territories, including Queensland, South Australia and the Northern Territory have passed legislation about advance health care directives (Table 1). The legislation covers the right to refuse or withdraw treatment. The question arises whether similar legislation should also be introduced in New South Wales and, if so, what treatment it should cover.

Currently in New South Wales, people wanting to document their health and lifestyle preferences when they are capable of doing so may complete one of the model versions that exist or simply use the form as a thought starter to creating their own model. They may attach the advance health care directive to their enduring guardianship so that it forms part of a formal document. Or they may prefer to keep their directive as an informal document.

Various model forms of advance health care directives exist[1] including:

- *Let Me Decide: Health and Personal Care Directive, NSW Version.* Based on the Canadian model *Let Me Decide,* this version has been developed by the Central Sydney Division of General Practice. (See Appendix – page 44)
- *Let Me Decide* form developed in Canada by Dr Roger Clarnette and Dr Willie Molloy. This is available in bookshops and by direct mail order in multiple languages. It is part of a package of material including videos, cassette tapes, colour slides, booklets and publications targeted to specific audiences.
- *Advance Health Directive* form developed by the Queensland State Government. It may be used to document a person's general wishes or their specific directions for various medical conditions and types of treatment. It is widely available through newsagents, bookshops and legal stationers in Queensland.

CASE STUDY

2. Elsie – Appointing an enduring guardian and making an advance health care directive

American born Elsie had been living in Sydney for over 30 years. She had never married or had children. She had no family in Australia although she had developed some special friendships here. Approaching 80 years of age and maintaining very good health and independence, she had recently started to think about her health choices for the future. Because of her determination and interest in this area, she had sought information about advance health care directives and enduring guardianship. She talked to her family and friends about these issues and shared this information with her GP and solicitor.

She discussed her health and personal care decisions with two friends who agreed to be dually appointed enduring guardians. This process took much longer to finalise than she had expected because of the need to educate all the participants along the way. An additional difficulty was the requirement of getting everyone together to sign the necessary documents in the presence of her solicitor.

While a number of model advance health care directives exist, people are not necessarily aware of their existence although in some states, such as Queensland, the Government has committed significant resources to communicating the new mechanism to stakeholders.

Do nothing

'Well, it'll never happen to me.' This is the common reaction if people contemplate a time when they are no longer capable of making their own health and lifestyle choices. There may also be a range of other reasons why people choose to do nothing. These include a fear of discussing death, a higher value being placed on communal rather than individual decision making, or an individual may feel comfortable that their family will talk to their doctors and make the right decisions on their behalf.

So what happens when someone needs medical or dental treatment but cannot give a valid consent to that treatment? For example, they may be unconscious after a car accident or they may have advanced Alzheimer's. The law, in the form of Part 5 of the Guardianship Act, swings into action with a process that aims to identify the best person to make those health decisions that the patient can no longer make for themselves. The NSW Guardianship Act 1987 sets out a hierarchy for 'person responsible', beginning with:

- **The person's guardian or enduring guardian** with the function of giving substitute consent to medical or dental treatment. If there is no guardian or enduring guardian,
- **The most recent spouse, de facto spouse or same sex partner** with whom the patient has a close and continuing relationship. If there is no spouse, de facto spouse or same sex partner,
- **An unpaid carer** who is now providing support to the patient or provided this support before the patient entered residential care. If there is no carer,
- **A relative or friend** who has a close personal relationship with the patient.

  If no one is able to fill this role,

  — No one needs to give consent if the situation is life threatening.

  — **The Guardianship Tribunal** may act as the substitute decision maker for major or minor medical or dental treatment. The Tribunal must act as the substitute decision-maker if special treatment such as sterilisation or abortion is proposed.

The ‘person responsible’ gives consent if minor medical (such as antibiotics) or dental treatment is required. If this person is not available, the doctor or dentist may go ahead without consent if they note in the patient’s record that the treatment is necessary to promote the patient’s health and wellbeing and that the patient is not objecting to the treatment.

Health practitioners have a legal responsibility to give the ‘person responsible’ the same information they are required to give a patient who would be giving their own consent.

The ‘person responsible’ also gives consent if major medical treatment (such as surgery) is required. If this person is not available, only the Guardianship Tribunal can give consent.

Health practitioners have a legal responsibility to give the ‘person responsible’ the same information they are required to give a patient who would be giving their own consent. A ‘person responsible’ must be told the:

- Particular condition requiring treatment
- Alternative sources of treatment that are available in relation to the condition
- General nature and effect of each course of treatment
- Nature and degree of any significant risks associated with each course of treatment or no treatment
- Reasons why the particular course of treatment is proposed.

In all cases, consent given by the ‘person responsible’ or the Guardianship Tribunal must promote the health and wellbeing of the person concerned. Consent cannot be given for treatments which are administered for the benefit of carers or health professionals. For example, a nursing home that is short staffed should not ask for consent to sedate residents to make it easier to care for them.

But what if the ‘do nothing’ option or the other legal, administrative or informal mechanisms dealing with financial, and health and lifestyle matters break down for some reason? What mechanisms exist to protect people? This is the focus of the following section.

Protecting people from abuse and exploitation

There is growing concern about abuse and financial exploitation of people who are in vulnerable situations through, for example, age or disability. People with dementia are particularly vulnerable. It is difficult to know the extent of abuse and exploitation because of inadequate research data and disagreement over definitions of categories of abuse. However, it is estimated that around 5% of older people are abused.[2]

Several informal and formal mechanisms exist that aim to prevent and alleviate such abuse and exploitation. In NSW, there is a multi-pronged approach including:

- **Protocols** for service providers in line with the '*Abuse of Older Persons: Inter-agency Protocol'* [3]
- **Education and training** for stakeholders including, for example, front line staff in community care services. Training kits are available including '*Dealing with Abuse of Clients and their Carers: A Training Kit'* [4]
- **Advocacy** through, for example, The Aged-care Rights Service
- **Publications** aimed at promoting community awareness such as the brochure *'Abuse of Older People: The Hidden Problem'*, available in a range of languages.[5]

These mechanisms focus on grassroots involvement — a 'bottom up' approach. They emphasise equipping service providers to identify and respond to abuse, community awareness, mutual obligation, creating community bonds and reducing the isolation of older people. Education campaigns and communication strategies have gone some way to putting the issues of abuse and exploitation on the national, state and territory and local agendas. Some would argue, however, that more remains to be done.

Formal arrangements

The guardianship and disability laws in all Australian states and territories protect people who are unable to make decisions for themselves. It is also possible to use the criminal justice system to report abuse or financial exploitation as a crime (for example if an assault, fraud, or theft has occurred). However, no legislation in Australia specifically deals with the abuse and exploitation of older people.

The strategy behind this has been carefully thought through. It is a reaction against the American model that places the issue firmly in the criminal justice system by specifically targeting abuse of older people and requiring mandatory reporting. By contrast, in Australia, cases of abuse often come to the attention of the health and welfare services thus placing the issue in the health and welfare systems rather than the criminal justice system.

Which model works best? As yet research on the US model is inconclusive and Australian professionals working in this field say the lack of concrete data only highlights the need for caution. They argue that mandatory reporting may see the older person's autonomy compromised. It can also be an intrusive strategy.

The challenge is to enhance the quality and range of research in the field to better understand the problem and, therefore, the direction to take. It may be necessary to review how the current approach is working and to look at issues such as alternative care arrangements and how to make the problem more visible.

Complaints mechanisms

Several formal mechanisms exist to handle complaints about ill treatment of older people. At the Federal level, they include the Aged Care Complaints Resolution Scheme which is run by the Commonwealth Department of Health and Aged Care to handle complaints about Commonwealth-funded aged care services. At the State level, they include the NSW Health Care Complaints Commission, the NSW Ombudsman and the NSW Community Services Commission.

This snapshot giving an overview of the legal, administrative and informal ways to plan for the future, highlights a number of concerns including, most importantly, a lack of awareness of the mechanisms involved. More research may need to be undertaken to plug the gaps in the current research. This is the subject of the next section.

5. What does the current research suggest?

This section focuses on the current research on advance planning for health and lifestyle issues in Australia and overseas. In particular, it focuses on the level of knowledge among stakeholders, take up rates and barriers to take up. There appears to be much less research available on advance planning for financial matters. This is possibly because the issues are less contentious and arrangements such as power of attorney have been available for much longer than those which apply to health, such as advance health care directives.

The current research on advance planning for health and lifestyle issues suggests that:

- Most members of the community and their doctors want the choice of using an advance health directive
- An increasing number of people outside Australia are completing advance health care directives
- There are several barriers that prevent people from signing an advance health care directive.

1. Most members of the community and their doctors, here and overseas, want the choice of using advance health care directives to indicate their future health and lifestyle care.

When people are made aware of mechanisms like advance health care directives and enduring guardianship provisions, they are overwhelmingly positive. This is the anecdotal experience of the NSW Office of the Public Guardian which is conducting information sessions on enduring guardianship and the Tasmanian Guardianship Tribunal which has held information sessions on advance health care directives.

When people are made aware of mechanisms like advance health care directives and enduring guardianship provisions, they are overwhelmingly positive.

More extensive research on advance health care directives confirms this view. For example, a 1995 Queensland study of 860 health professionals and nearly 500 members of the community found that both groups believed that advance health care directives would make a useful contribution to medical care. Only 10 percent did not support their use.[6]

Similarly, a recent survey in Sydney, conducted by the Centre for Education and Research on Ageing (CERA), found that among nearly 500 respondents, approximately two thirds believed that they would complete advance health care directives, now that they knew about them. The study found that the older people were, the less interested they were in the issue. It also found that the less healthy people were, the less interested they were in advance health care directives.[7]

Overseas research with doctors paints a similar picture. More than four out of every five GPs in a Canadian survey of 1000 GPs living in Ontario favoured the use of advance health care directives.[8] Similarly, since the early 1990s the British Medical Association has strongly supported the use of advance health care directives.[9]

Advance health care directives and enduring guardianship have more direct relevance and urgency for people who do not have close personal or family relationships.

The Centre for Education and Research on Ageing study also showed that family relationships influence a person's level of interest in advance health care directives. Families come in many shapes and sizes. They can include people related by blood or marriage, de facto relationships and same sex partnerships. Changes in families because of death or the breakdown of relationships can have an impact on a person's interest in, and willingness to complete, an advance health care directive. The CERA research suggests that advance health care directives and enduring guardianship have more direct relevance and urgency for people who do not have close personal or family relationships. It found that divorced people were more likely to seek information on advance health care directives than other people.[10]

Implication: The positive response that Australians have towards advance health care directives suggests that the time is right for an informed debate on the issues involved. They have indicated their openness and willingness to listen. Future communication strategies need to take into account the factors which influence when people are most likely to show an interest in advance health care directives.

2. An increasing number of people outside Australia are completing advance health care directives.

While it is difficult to gain accurate figures, it appears that in the US more Americans than ever before are signing advance health care directives or living wills. Part of this may be due to the introduction of the Patient Self-Determination Act in 1991. Under this Act all states and territories have to recognise living wills and durable powers of attorney for health care, which are similar to Australia's powers of enduring guardianship. Every publicly funded hospital has to provide training for health care professionals and information for patients on advance health care directives.

The Act's focus on patient autonomy in health decisions encouraged efforts to highlight the benefits of signing a living will. For example, in 1994 one national organisation, Choice in Dying, conducted an extensive campaign to persuade one million Americans to sign up while President Bill Clinton and First Lady Hillary Clinton also joined the call to ask Americans to sign living wills.

A number of US studies have compared the number of patients completing advance health care directives before and after the introduction of the Act. While the results vary, from a low of 4 percent in some studies to a high of 31 percent, they seem to indicate a trend towards more people signing advance health care directives when the information is made accessible.[11]

Implication: The trend towards the increasing popularity of advance health care directives in countries like the US is one that Australia is likely to follow, though not necessarily mirror. We now have an opportunity to critically examine the mechanisms available in Australia to ensure they facilitate personal choices about financial, health and lifestyle matters and that they are appropriate and accessible for all Australians.

3. Several barriers may exist that prevent people from signing advance health care directives, if they wish to.

Considerable research has been conducted into the reasons why people do not complete advance health care directives. These include:

- Lack of awareness
- Time constraints
- Poor communication between health professionals and their patients
- Lack of trust
- Cultural influences
- Fear and other emotional barriers

Lack of awareness

Few Australians are familiar with the existence and use of advance health care directives. For example, in a 1995 Queensland study less than one-fifth of patients knew that advance health care directives were not legally enforceable in the state at that time. Close to seventy percent of the patients in the survey thought that lack of knowledge about advance health care directives and about the processes involved prevented them from making one. GPs were even more sceptical about patients' level of knowledge. More than 90 percent thought that patients lacked sufficient knowledge about advance health care directives.[12]

Many health care and legal professionals also lack detailed knowledge. In the Queensland study, only a quarter of GPs knew that advance health care directives were not legally enforceable in the state at the time.[13]

A study conducted with GPs in South Australia showed that even eight years after legislation for living wills was enacted, nearly half the GPs were still unfamiliar with the legislation and even fewer felt competent or comfortable with raising the issue of living wills with their patients and families.[14]

Studies in the US in the years following the introduction of the Patient Self-Determination Act confirm that many physicians did not fully understand what an advance health care directive was or how to enact one. Further, physicians who did know what the directives were all about appeared to generate more advance health care directives and to initiate more discussions.[15]

The evidence suggests that lack of knowledge is one issue which prevents health professionals assisting their patients to complete advance health care directives.

Implication: The fact that a particular mechanism is enshrined in legislation does not necessarily mean that it will be acted on. Lack of knowledge among members of the community as well as other stakeholders, such as health care and legal professionals, highlights the need for an extensive education and training program to raise awareness.

Time constraints

Some US studies investigated whether people felt unable to discuss advance health care directives with their GPs due to a lack of time. They found that time constraints were a factor in dissuading physicians from initiating discussions, though less of a factor than the physician's level of knowledge. However, time constraints were not an issue if patients initiated the discussion. In these circumstances physicians were willing to discuss the issues regardless of any time pressures.[16] Only 22% of GPs in the 1995 Queensland study indicated that a lack of time was a problem in their discussing advance health care directives with their patients.[17]

Implication: The lack of readily available data makes it difficult to draw conclusive implications from the current research. It does seem, however, that time constraints may be less of a barrier than the level of knowledge among doctors and, importantly, the level of communication between them and their patients.

Poor communication between health professionals and their patients

Extensive research exists to suggest that positive communication between patients and their primary health carers, especially their GPs, is vital if advance health care directives are be used effectively.

A study in the US looked at the behaviour of physicians in discussing advance health care directives with their patients rather than simply asking them to complete a survey. The physicians were given a 5-week course on the law relating to advance health care directives and asked to discuss the directives with newly enrolled patients and to help interested patients to complete directives. Despite being given extra time to spend with patients, physicians did not approach any patient during the first two months of the trial.[18] Clearly lack of knowledge was not their problem, rather a lack of comfort in initiating potentially sensitive discussions about advance health care directives.

The Queensland study also highlighted the fact that GPs and patients are not always on the same wavelength. GPs, who were asked to give the answers that they thought patients would give, and patients, who were asked to answer on behalf of themselves, consistently came up with widely different answers. For example, GPs underestimated patients' willingness to discuss end-of-life issues with 80 percent of GPs but only a third of patients listing this as a barrier to making an advance health care directive.[19]

Positive communication between patients and their primary health carers, especially their GPs, is vital.

Implication: While detailed knowledge of advance health care directives is certainly important, the willingness and ability to communicate that knowledge are also crucial. This role does not have to be limited to GPs but could include, for example, nurse practitioners who could educate people about advance health care directives.

Lack of trust

In some cases, the nature of communication between the medical profession and patients has changed. Some patients, for example, are sceptical that doctors will carry out their wishes. The Queensland survey found that members of the community were twice as likely as GPs to think that advance health care directives should be legally binding on health professionals.[20] These patients clearly felt they needed the authority of the law on their side to increase their comfort level and belief that doctors would carry out their wishes.

Perhaps patients are justified in this view. Some research shows that nearly one quarter of all deaths in Australia were preceded by treatment that did not receive the explicit consent of the patient.[21] However, US research gives the doctors' perspective. A study of 72 hospitals and nursing homes found that administrative glitches often meant that the doctor did not know a directive existed.[22]

The Central Sydney Division of General Practice is currently undertaking a pilot project with GPs in central Sydney which should throw more light on a range of patient-GP issues around completing an advance health care directive. The project is providing education on advance health care directives to a small number of GPs and a hospital within a designated local area. The pilot hopes to identify a range of issues, including the positive and negative aspects of a patient completing an advance health care directive with their GP, the barriers for patients and GPs in completing such directives, the support needs of patients and GPs in making advance health care directives, and ways of making the process more accessible for both patients and GPs.

Implication: The lack of trust that some feel towards members of the medical profession reflects broader community concerns about the honesty and integrity of the nation's leaders in many walks of life. The 'relaxed and comfortable' days of the 1950s when a doctor's authority was beyond question are long gone. While this scepticism will not change overnight, it raises questions about what skills doctors should learn, what can be done to match differing perceptions and what systems need to be put in place to facilitate good communication.

Cultural influences

US research into different cultural groups and their attitudes to end-of-life decision making suggests that a person's cultural background has a considerable influence. For example, one study looked at the attitudes of 800 European Americans, African Americans, Korean Americans and Mexican Americans. The Korean Americans and the Mexican Americans were more likely to think that patients should not be told if they had a terminal disease and that families, not patients, should make decisions about the use of life support.[23]

In Australia, the research is inconclusive. For example, a recent Sydney study of nearly 500 people including eight older men and women who had a Chinese background and eight older women from a Portuguese background proved interesting but inconclusive. Asked how likely they would be to fill out an advance health care directive, the former group veered to the negative, while the latter group veered to the positive. In such a small sample, however, it is not possible to say whether — or to what extent — the different outcomes were influenced by gender, educational background, religion or culture.[24] To our knowledge, there is no information available about the attitudes of indigenous communities in Australia to end-of-life decision making.

Implication: Further research needs to be completed before we fully understand the influence of cultural background on the attitudes of Australians to advance health care directives.

Fear and other emotional barriers

Most Australians are open-minded about the idea of making decisions about issues affecting their health and lifestyle in readiness for a time when they may not be able to do so.

Fear is a considerable emotional barrier for some people and at its most extreme can lead to paralysis of action. People's fears may range from issues arising from the legal and medical implications of advance directives to issues of potential abuse.

Implication: Further statistically valid research needs to be conducted in this area, both on the emotional barriers and ways to address these concerns.

The story that emerges from the current research is simple. Most Australians are open-minded about the idea of making decisions about issues affecting their health and lifestyle in readiness for a time when they may not be able to do so. This is in line with the trend overseas where there has been considerable debate over end-of-life issues. However, Australians face a number of barriers including a lack of community knowledge and skills in this area. These research findings raise a number of implications for how to go about addressing the gap.

6. Issues for discussion

Australians are on unfamiliar territory when looking at planning for their future years.

Australians are on unfamiliar territory when looking at planning for their future years. While the medical and legal professionals have been grappling with the issues for some time, the general community is less well informed. How can we make sense of these issues so that Australians in all their diversity are in a position to make informed choices?

This section canvasses a number of issues, many of which have been identified in early parts of this report. Some may have long term implications, others may be potential roadblocks so will need to be dealt with in the short term. In most cases, the issue is framed as a question, followed by discussion. This report aims to foster discussion. It does not claim to have all the answers — or even to have noted all the issues.

The issues are grouped into the following areas:

1. **Legal issues.** What legal problems do we need to address?
2. **Systems and structures.** What arrangements do we need to put in place to make the system work?
3. **Communication**. How can we think strategically about communicating with stakeholders?
4. **Skills and knowledge.** How do we develop the skills and knowledge we need?

1. Legal issues

1.1 Is there a need to fine tune the NSW legislation covering enduring power of attorney?[25]

- *Should there be a requirement that the person being appointed under an enduring power of attorney sign a statement that they understand the nature and scope of their responsibilities?*

In NSW there is presently no requirement that a person appointed under an enduring power of attorney must receive any information on their duties. In contrast, in Queensland the person being appointed as an enduring power of attorney is given information and required to sign a form indicating that they understand their responsibilities.

- *Should the NSW legislation be amended to include options as to when it becomes effective?*

In NSW, an enduring power of attorney is effective immediately and remains effective when a person is no longer competent. However, legislation in some states such as Queensland, allows a person to choose whether an enduring power of attorney is effective:

- immediately, or
- at some future time, or
- only when the person becomes incompetent.

1.2 Is there a need to fine tune the NSW legislation covering enduring guardianship?

- *Is the requirement that if more than one person is to be appointed as an enduring guardian they must all be present when it is signed in front of the solicitor too restrictive?*

Currently in NSW, the person making the appointment of the enduring guardian and the person(s) being appointed, must all be present at the same time when the solicitor or Clerk of the Local Court witnesses the form. This may work well in many cases, such as when a married couple wish to appoint each other as their enduring guardian. But is it too restrictive when someone wishes to appoint two or more people (e.g. adult children or friends) who may live some distance away, or even interstate? Could there be an option for a person being appointed to sign a form indicating they understand what the appointment involves and are willing to accept it? Queensland has such a provision when someone is appointed as a power of attorney for personal/health matters.

- *What about people who have no one to appoint as an enduring guardian?*

The problem of having no one to appoint as their enduring guardian was raised by a number of people who attended one of the two information and consultation sessions held by the NSW Committee On Ageing in September 1999. A number of older people do not have partners or adult children. Their friends may also be elderly and not physically or emotionally close enough to take on the responsibility of being an enduring guardian. One option is to make it possible to appoint someone like a solicitor or someone from a private trustee company. This, however, would seem to defeat the whole purpose of having someone who knows you well to speak on your behalf if you become unable to do so. It may be an argument for “stand alone” advance health care directives.

CASE STUDY

3. Margie — No one to appoint as enduring guardian

Margie attended a public consultation about end-of-life decision making. She had a long standing concern about her future health planning and who would make decisions on her behalf. She wanted to maintain her independence and thought that attending the consultation would provide useful information about how she could do this. Her questions highlight some salient points for people who are more isolated.

"I live on my own and have been widowed for over 40 years. We did not have any children and my husband and I both came from very small families. I have no living members of my extended family left. Although my health has been fairly good, I know that I'm becoming frailer. My good friends are deteriorating in the same way. Two of my good friends died recently and the others are quite sick and frail and are likely to die before me. I don't think that any of these friends would be prepared to be my enduring guardian. And I don't think that any of them would really be able to do this task. So who could be my enduring guardian in this position? I would like to have some control over these issues in my life but how can I, under these circumstances?"

In order to meet the diverse needs and circumstances of people, the choices could be:

- Enduring guardian — the person(s) who can make decisions on your behalf on personal/health matters if you cannot, or
- Enduring guardian plus advance health care directive — the person(s) who can make decisions on your behalf on personal/health matters if you cannot PLUS your specific written wishes, or
- Advance health care directive — your specific written wishes

1.3 Does the current enduring guardianship legislation discourage people from updating their advance health care directives regularly?

Advance health care directives only have legal force in NSW if they are part of the appointment of an enduring guardian. Those who advocate the use of advance health care directives suggest they should be updated regularly. This gives you the opportunity to think about whether what you wanted in the past still applies. If it does, and the directive is signed and dated to show that you have considered the issues and your wishes are the same, the doctor treating you will be more confident that you have not changed your mind since you originally signed it.

However, what if you do want to change it? You would have to go to the solicitor again with your enduring guardian(s) and appoint them all over again, as your instructions to your enduring guardian have changed.

- *Should the law allow people to make an advance health care directive separate from their enduring guardianship to allow for easier updating?*

1.4 Should advance health care directives be enshrined in legislation?

In NSW, advance health care directives are not backed by legislation, unless they form part of the appointment of an enduring guardian. However, in some countries and other states and territories in Australia, these directives have a legislative base.

Those in New South Wales who support legislation suggest that:

- Legislation would clarify the legal ramifications and liabilities for stakeholders such as government departments and doctors.
- Legislation makes people more confident that doctors will carry out their advance health care directives.
- An increasing number of Australians are living alone and have no appropriate family member or friend who they would like to ask to take on the role of carrying out their wishes when they are no longer able to do so.
- It would make it easier for people to update their advance health care directive regularly.

Those in New South Wales who do not support legislation suggest that:

- The current situation is working well.
- Doctors do have to take note of advance health care directives and could be sued for failing to do so.

1.5 How is capacity to make decisions defined?

In the past, people were considered either capable of making *all* decisions or not capable of making any. There is now an understanding, however, that capacity (or competence) is not an absolute concept. A person could lack capacity to manage their financial affairs, for example, but retain capacity to make personal care decisions.[26] Incapacity is also not necessarily permanent — illness can temporarily impair capacity and it can be regained when the person recovers.[27]

The issue of capacity is of particular concern for people with dementia. In the early stages of dementia people may still be capable of making decisions and be able to sign documents such as enduring powers of attorney, enduring guardianship or advance health care directives.

Assessing a person's capacity has a bearing on whether they are able to complete an advance directive, such as a will. It also determines when arrangements which take effect on incapacity should start.

At present in NSW, there is no clear indicator as to when an enduring power of attorney should begin to operate. It can be difficult to establish when someone is no longer competent. However, the same problem does not apply to enduring guardianship. A medical practitioner can give a certificate to say that a person who has appointed someone as their enduring guardian has lost capacity. There

CASE STUDY

4. Audrey and David —
Enduring Power of Attorney

Audrey is a widow with an only son, David. Audrey gave her enduring power of attorney to David five years ago. She has now developed Alzheimer's disease and is losing her sight. She began to have great difficulty with managing her finances, losing money and accusing the community support worker of theft. David took over paying her bills, but after a few months, Audrey became suspicious of him and started going to the bank herself, drawing out large sums of money. David talked to the bank, but they explained that they had no legal authority to stop her operating her bank account, although he could operate on it as well. David was considering an application to the Guardianship Tribunal to be appointed her private financial manager when Audrey fell, fractured her hip. She was then so clearly confused that there was no question about David's authority to manage her finances.

is a similar provision in Queensland for enduring powers of attorney for financial matters as well as for personal/health matters.

- *Should NSW legislation have a provision that the enduring power of attorney becomes effective when a doctor gives a medical certificate to indicate that the person has lost their mental capacity?*

2. Systems and structures

2.1 How do we put in place a system that ensures that a person's wishes are known to the right person at the right time?

The NSW Registry of Births, Deaths and Marriages is currently setting up a pilot register of wills. The register will enable people to record the existence of their will, whilst continuing to store their will wherever they choose. A similar register in Canada receives about 50 000 notifications each year.

- *Should the wills register be extended to apply to enduring guardianship and advance health care directives?*
- *Are there other ways to ensure a person's wishes are known to the right person at the right time?*

In Canada, for example, advance health care directives are registered with organisations like the local hospital or local consumer groups. People can also use medi-alert bracelets or an identity card carried in a wallet to alert health professionals to the existence of their advance health care directive.

2.2 Should Australian states and territories recognise the legal and administrative arrangements of other states and territories?

This issue concerns people who sign a legal document such as an enduring guardianship, or an administrative document such as an advance health care directive, in one state or territory and then move to another. It also impacts on those who have responsibility for a person who lives in another state or territory. How should their choices be protected?

3. Communication

3.1 Are there any special issues around making people aware of the choices available to them for future decision making?

Some people may find it difficult to understand the legal and medical terms currently used in decision making mechanisms. They may also not be fully aware of the implications of various arrangements. They might not realise, for example, that giving a person an enduring power of attorney puts a very high level of trust in that individual.

People are also less likely to be familiar with mechanisms that have been most recently introduced, such as enduring guardianship and advance health care directives, than with those that have been around for much longer, such as wills and powers of attorney.

3.2 What are the best ways to make people aware of the choices available to them about future decision making?

Successful initiatives in other states and territories for informing people of these options have included making forms for advance health care directives widely available through, for example, newsagents and doctors' waiting rooms. Banks and financial institutions could be used to disseminate information about enduring power of attorney. Existing communication channels such as newsletters from organisations like Centrelink and the Department of Veterans' Affairs could also be used.

In addition, there may be a case for arguing that greater emphasis should be put on advocacy from the various peak organisations. Better informed consumer groups and frontline health care, legal and financial professionals would also allow consumers and other stakeholders, such as carers, to receive help when it was most needed, when they were making decisions.

3.3 How do we ensure that all groups in Australian society receive the information and help they need to make informed choices?

This suggests, perhaps, specific communication strategies to meet the needs of particular groups. For example, consultations with leaders of specific groups, print and electronic media made available in languages other than English etc.

4. Skills and knowledge

4.1 Frontline communicators lack the appropriate skills and knowledge.

One way to ensure that messages about available choices reach consumers is to equip frontline communicators with the skills and knowledge they need to do the job. Frontline communicators could include solicitors, GPs and other health care professionals, financial advisers and bank tellers. There may also be a role for specialised people, such as nurse practitioners with detailed knowledge in this area, who could give information to people interested in making advance health care directives.

In addition, doctors in particular, need to fully understand their legal responsibility to obtain a valid consent before treating a patient. They also have a critical role in supporting 'persons responsible' in making very difficult decisions. Further, they can help patients to think about future decision making in health areas. Moves to increase specific communication training for young doctors are welcome and could be expanded to include other health professionals.

Feedback

It is hoped that the issues and questions raised in this discussion paper will stimulate broad and lively discussion across the community on advance decision making.

The NSW Committee on Ageing is keen to receive comments on the issues raised so that it may consider them in formulating its recommendations to the Minister for Ageing. Any such comments may be addressed to:

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Endnotes

1 Steinberg et al, 1997. This report comprehensively analyses 36 sample advance directives from around the world.
2 Kinnear and Graycar, 1999
3 *Abuse of Older People: Inter-Agency Protocol* NSW Advisory Committee on Abuse of Older People, October 1995
4 *Dealing with Abuse of Clients and their Carers: A Training Kit* NSW Ageing and Disability Department, 1996
5 Published by and available from the NSW Ageing and Disability Department.
6 Steinberg et al, *Healthy Ageing, Healthy Dying,* February 1996
7 Wall and Shanley, 1999, 11
8 Hughes and Singer, 1992
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10 Wall and Shanley, 1999
11 *Autonomy and the Patient Self-Determination Act* , www.med.upenn.edu
12 Steinberg et al, *End-of-life Decision Making,* July 1996
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15 *Autonomy and the Patient Self-Determination Act*
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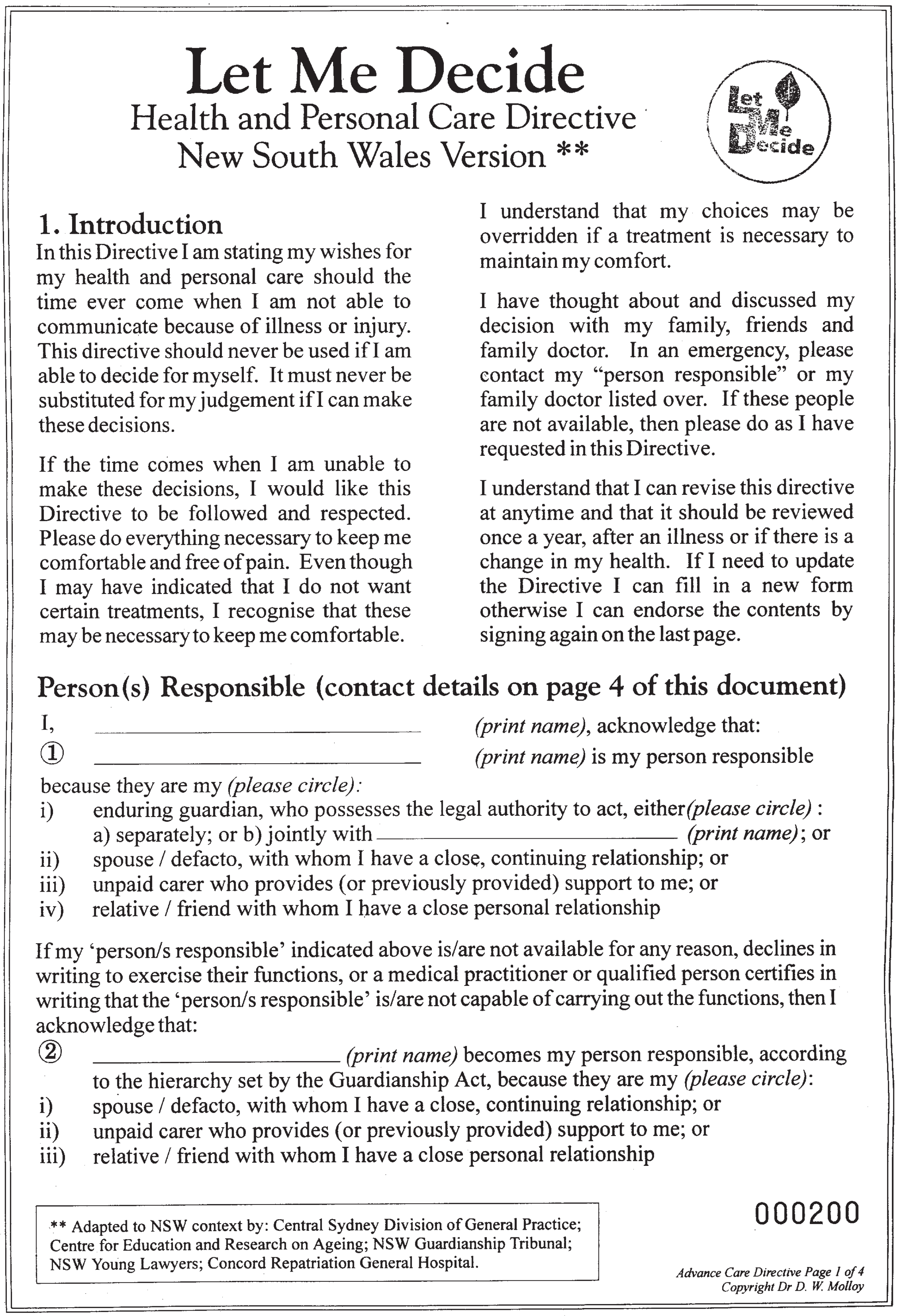
20 Steinberg et al, *Australian Family Physician*, 1997
21 Kuhse et al, 1997
22 *Autonomy and the Self-Determination Act*
23 Blackhall et al, *Ethnicity and Attitudes Toward Patient Autonomy,* 1995
24 Wall and Shanley, 1999, 13
25 A 1999 Green Paper on Powers of Attorney recently released by the Land Titles Office, Department of Information Technology and Management, discussed some possible changes to the legislation covering powers of attorney.
26 Molloy et al, 1999
27 Molloy et al, 1999

Appendix



Let Me Decide

Health and Personal Care Directive
New South Wales Version **

1. Introduction

In this Directive I am stating my wishes for my health and personal care should the time ever come when I am not able to communicate because of illness or injury. This directive should never be used if I am able to decide for myself. It must never be substituted for my judgement if I can make these decisions.

If the time comes when I am unable to make these decisions, I would like this Directive to be followed and respected. Please do everything necessary to keep me comfortable and free of pain. Even though I may have indicated that I do not want certain treatments, I recognise that these may be necessary to keep me comfortable.

I understand that my choices may be overridden if a treatment is necessary to maintain my comfort.

I have thought about and discussed my decision with my family, friends and family doctor. In an emergency, please contact my "person responsible" or my family doctor listed over. If these people are not available, then please do as I have requested in this Directive.

I understand that I can revise this directive at anytime and that it should be reviewed once a year, after an illness or if there is a change in my health. If I need to update the Directive I can fill in a new form otherwise I can endorse the contents by signing again on the last page.

Person(s) Responsible (contact details on page 4 of this document)

I, ______________________________ *(print name)*, acknowledge that:

① ______________________________ *(print name)* is my person responsible

because they are my *(please circle)*:

i) enduring guardian, who possesses the legal authority to act, either *(please circle)*:
a) separately; or b) jointly with ______________________________ *(print name)*; or

ii) spouse / defacto, with whom I have a close, continuing relationship; or

iii) unpaid carer who provides (or previously provided) support to me; or

iv) relative / friend with whom I have a close personal relationship

If my 'person/s responsible' indicated above is/are not available for any reason, declines in writing to exercise their functions, or a medical practitioner or qualified person certifies in writing that the 'person/s responsible' is/are not capable of carrying out the functions, then I acknowledge that:

② ______________________ *(print name)* becomes my person responsible, according to the hierarchy set by the Guardianship Act, because they are my *(please circle)*:

i) spouse / defacto, with whom I have a close, continuing relationship; or

ii) unpaid carer who provides (or previously provided) support to me; or

iii) relative / friend with whom I have a close personal relationship

** Adapted to NSW context by: Central Sydney Division of General Practice; Centre for Education and Research on Ageing; NSW Guardianship Tribunal; NSW Young Lawyers; Concord Repatriation General Hospital.

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Advance Care Directive Page 1 of 4

2. Definitions

A. Loss of Functioning that is *NOT* acceptable AND *NOT* reversible

An *un*acceptable and *irr*eversible loss in my ability to function may result from:

a) an illness or injury that is *not* reversible and that leaves me with a loss in ability to function that I consider to be *not* acceptable.

B. Loss of Functioning that *IS* acceptable AND/OR *IS* reversible

An acceptable and/or reversible loss in my ability to function may result from either:

a) a life threatening illness or injury that is reversible. This is curable, meaning that losses in my ability to function are not permanent; *OR*

b) an illness or injury that is *not* reversible, but that leaves losses in my ability to function that I consider to be acceptable.

C. Cardiac Arrest (CPR)

☐ **CPR**

Use cardiac massage with mouth-to-mouth breathing; may also include intravenous lines, electric shocks to the heart (defibrillators), tubes in throat to lungs (endotrachial tubes).

☐ **NO CPR**

Make no attempt to resuscitate.

D. Feeding

☐ **Basic**

Spoon-fed with a regular diet. Give all fluids by mouth that can be tolerated, but make no attempt to feed by special diets, intravenous fluids or tubes.

☐ **Supplemental**

Give supplements or special diets (eg. high calorie, fat or protein supplements).

☐ **Intravenous**

Give nutrients (water, salt, carbohydrate, protein and fat) by intravenous infusions.

☐ **Tube**

Use tube feeding. There are two main types:

Nasogastric Tube: a soft plastic tube passed through the nose or mouth into the stomach.

Gastrostomy Tube: a soft plastic tube passed directly into the stomach through the skin over the abdomen.

E. Levels of Care

☐ **Palliative Care**

Keep me warm, dry and pain free. Do not transfer to hospital unless absolutely necessary. Only give measures that enhance comfort or minimise pain (eg. morphine for pain). Intravenous line started only if it improves comfort (eg. for dehydration). No x-rays, blood tests or antibiotics unless they are given to improve comfort.

☐ **Limited Care (includes Palliative)**

May or may not transfer to hospital. Intravenous therapy may be appropriate. Antibiotics should be used sparingly. A trial of appropriate drugs may be used. No invasive procedures (eg. surgery). Do not transfer to Intensive Care Unit.

☐ **Surgical Care (includes Limited)**

Transfer to acute care hospital (where patient may be evaluated). Emergency surgery if necessary. Do not admit to Intensive Care Unit. Do not ventilate (except during and after surgery ie. tube down throat and connected with machine.)

☐ **Intensive Care (includes Surgical)**

Transfer to acute care hospital without hesitation. Admit to Intensive Care Unit if necessary. Ventilate me if necessary. Insert central line (ie. main arteries for fluids when other veins collapse). Provide surgery, biopsies, all life support systems and transplant surgery. Do everything possible to maintain life.

Advance Care Directive Page 2 of 4
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TO THE MEDICAL OFFICER

3. Health and Personal Care

Personal Statement.

I would consider an unacceptable level of functioning for me to include:

____

____

____

____

____

____

____

so,

If my loss of functioning is *NOT* acceptable AND *NOT* reversible
(Definition A.) **then please treat me as I have indicated below**

⇩

Cardiac Arrest (Definition C.)	**Life-threatening illness** (Definition E.)	**Feeding** (Definition D.)
CPR No CPR	Intensive Surgical Limited Palliative	Tube Intravenous Supplemental Basic

(Write your choice in the box provided)

If my loss of functioning *IS* acceptable AND/OR *IS* reversible,
(Definition B.) **then please treat me as I have indicated below**

⇩

Cardiac Arrest (Definition C.)	**Life-threatening illness** (Definition E.)	**Feeding** (Definition D.)
CPR No CPR	Intensive Surgical Limited Palliative	Tube Intravenous Supplemental Basic

(Write your choice in the box provided)

I would agree to the following procedures *(write yes or no)*	Blood transfusion	_____
	Organ transplant	_____
In the event of my death, I consent to the following procedures *(write yes or no)*	Organ donation	_____
	Post Mortem	_____
	Cremation	_____

Advance Care Directive Page 3 of 4

4. Signatures

NOTE: This Directive can either be completed on its own, or in conjunction with Enduring Guardianship forms, available from the NSW Guardianship Tribunal, phone: 1800 46 3928 (tollfree) or (02) 9555 8500

Person Completing the Directive

I, ____________________ *(print name)*

Of **address:**

____

____

am voluntarily completing this Advance Care Directive document of my own free will on this **date:** ______________

Signed: ____________________

Person(s) Responsible

I/we have read, understood and agree to act in accordance with the contents of this Directive:

1) Name ____________________
Signature ____________________
Date ____________________
Address ____________________
____
Ph: (hm) ___________ (wk) ___________

2) Name ____________________
Signature ____________________
Date ____________________
Address ____________________
____
Ph: (hm) ___________ (wk) ___________

3) Name ____________________
Signature ____________________
Date ____________________
Address ____________________
____
Ph: (hm) ___________ (wk) ___________

Enduring Guardian/s

If I have an enduring guardian/s, they were appointed on the **date:** ______________ and the document is held at:

____

____

General Practitioner

Name ____________________
Signature ____________________
Date ____________________
Address ____________________
____
Ph: (hm) ___________ (wk) ___________

Witness

I am the witness to this Directive. I verify that ____________________ *(print name of person completing Directive)* signed this Directive on this **date:** ________ of his/her own free will, without threats or offered inducements. I am not a relative of the person completing this Directive nor of the person(s) responsible and I am not involved in the person's medical treatment.

Name ____________________
Signature ____________________
Date ____________________
Address ____________________
____
Ph: (hm) ___________ (wk) ___________

Updating this Directive *(In 12 months time)*
If, after reviewing this document in 12 months time, I wish to endorse the contents, I do so by signing below:

Signature ______________ Date: ________

Advance Care Directive Page 4 of 4

Previous publications from the NSW Committee on Ageing

A Two Way Street: Older People and Volunteering
Sarah Fogg

Building Community Trust
Margaret Tucker

Over the Hill or Flying High: An Analysis of Age Discrimination Complaints in NSW
Sol Encel and Helen Studencki

Who Pays: The impact of user pays and economic policy on older people
Elizabeth Savage, Michael Fine and Jennifer Chambers

Older People and Crime: Incidence, fear and prevention
Robyn Gilbert and George Zdenkowski

Never Too Late to Learn: A report on older people and lifelong learning
Ingrid Fitzgerald

Gendered Ageism: Job Search Experiences of Older Women
Sol Encel and Helen Studencki

When Families Break Down: Rights of Grandparents and Grandchildren
NSW COA and Council on the Ageing (NSW)

Retirement: a Survey
Sol Encel and Helen Studencki

Local Government Services for Older People
John Toon and Diana Loges

Keeping in Touch: Older People Living Alone
Sol Encel, Margaret Kay and George Zdenkowski

Volunteering and Older People
Sol Encel and Penny Nelson

Job Search Experiences of Older People
Sol Encel and Helen Studencki