Dying with Dignity

Tasmania (Inc)

END-OF-LIFE PLANNING

A SUMMARY GUIDE TO DOCUMENTING YOUR WISHES AND CHOOSING AN ENDURING GUARDIAN OR PERSON RESPONSIBLE

NOTE:

While the principles underlying end-of-life planning are fairly universal, the law and support structures available differ between countries and, within Australia, from State to State. This document is written around Tasmanian law and institutions and will need interpretation when read elsewhere.

While the full document can be read on its own, it is designed primarily as supporting documentation to an interactive end-of-life planning seminar developed by DwD Tasmania.

New edition February 2017

DYING WITH DIGNITY TASMANIA (INC)

Dying with Dignity Tasmania (DwDTas) is a community organisation with a focus across end-of-life issues.

Our objectives are to support, promote and work for:
(1) the right of everyone to make decisions about their death and dying with the same freedom of choice, personal autonomy and human rights that they have in other aspects of their lives
(2) the right of everyone to die with dignity, as they see it
(3) end-of-life and advance care planning to enable everyone to express their wishes and to have them respected
(4) accessible, quality services, including palliative care, that assist people to have a dying process and death they regard as dignified, and
(5) law reform consistent with the above.

To achieve these objectives, we:
- promote improvements in end-of-life planning, services and practices
- advocate and lobby for law reform
- research and maintain up-to-date information on the legal, ethical, political and practical issues surrounding end-of-life reforms
- provide information and advice on end-of-life planning and other issues, and
- work cooperatively with other organisations with similar aims, including YourLastRight.com, the national alliance of State and Territory dying with dignity and voluntary euthanasia societies.

One of our major priorities is to improve timely end-of-life and advance care planning across the community. This includes promotion of the preparation of Enduring Guardianships and their registration with the Guardianship and Administration Board. Our core belief is that individuals should be able to undertake their own planning and be able to exercise choice in accordance with their own ethics and beliefs.

We are strong supporters of palliative care which can provide many people with sufficient comfort and relief from suffering for them to have a dignified death. We promote and support access to quality palliative care for all Tasmanians in their own homes or in a caring and appropriate facility. We are actively involved in palliative care networking.

However, not everyone is fortunate enough to have their suffering adequately relieved by even state-of-the-art palliative care. We believe that people should not have to suffer through a prolonged dying process against their wishes. We are therefore working for dying with dignity legislation that:

- allows aid-in-dying to be provided by doctors who are willing to provide it;
  - for those with terminal or advanced incurable conditions and suffering they find intolerable;
  - for adults who are making a choice which is voluntary, and are competent and well informed about the options;
- has strict terms and conditions with at least two doctors involved, and
- ensures there is formal supervision and transparent reporting of the entire process, as exists in places like Oregon, the Netherlands and Belgium.

We are working in cooperation with MPs who support dying with dignity legislation for the development, passage and implementation of effective legislation, after community consultation.

END OF LIFE PLANNING DOCUMENTATION

CONTENTS

ATTACHMENTS

Acknowledgement

In preparing this document we have received invaluable assistance from the Public Guardian, members of the Palliative Care Clinical Network and other professionals working in the field. We are very grateful for this help, while acknowledging that any errors or omissions are wholly our responsibility.

Cautionary Note

While this manual has been prepared using the best advice available, it is written as a general guide only. We believe it to be applicable in most normal situations. However, in particular cases a number of issues may arise which require expert professional advice, whether legal, medical or financial. In these situations it would not be safe to rely on this manual alone and you are advised to seek professional advice in the relevant field.

Summary

There are major advantages to you and the people you care about if you have sensible plans in place to ensure that your wishes are known and will be followed in a situation where you are not yourself able to state what you want. More and more health bodies and organisations are promoting better advance care and end-of-life planning and demonstrating the benefits for individuals and for their families and friends.

This booklet and its attachments provide a simple guide to the documents to consider in your end-of-life planning, how to ensure they are readily available at need and how to ensure that there is no confusion about who you want to make decisions on your behalf if you are no longer able to act for yourself.

Key points

- It is never too early to get the documentation and organisation right. You never know what life has in store and all the legal documents have to be completed while "of sound mind". If you complete forms early in life and change your mind later, you can always change the document.
- If you do nothing else, talk to those close to you about what you think and what you would wish in different health and other end-of-life circumstances.
- There are advantages in documenting your wishes and it is particularly important where you know there are differences of opinion within your family.
- Each of the key documents you need to consider is described in this booklet. These are mostly legal documents that need to be properly prepared, signed, witnessed and lodged.
- Those that relate to your health care provide for you to state your health care wishes in circumstances where you cannot speak for yourself and for you to nominate one or more people who you would want to act for you in any necessary decisions.
- It is very important to think through what your wishes are, to discuss these with the person you nominate to act for you and to document them clearly. This booklet includes detailed suggestions on how to go through this process and issues to consider in choosing a person to act for you.
- When completed, these documents have legal force and must be observed.
- It is also important to store your copy of these documents in a place where they can be easily found and to supply copies to relevant people such as your doctor and any hospital at which you have been treated or have a personal file.

Note that much of the legislation to which these notes refer is State based and differs from State to State. These notes refer to Tasmanian law.

The Need

It is fair to say that most of us are interested in this subject because of a background fear of an unnecessarily unpleasant end to our lives. The fundamental objective of this booklet is to go through ways of minimising this risk, so that we can focus, as we should, on enjoying life.

So it is important to have sensible plans in place to minimise the trauma, inconvenience and plain muddle that can occur, and to ensure that your wishes are known and will be followed in a situation where you are not yourself able to state what you want - for example as a result of trauma or dementia.

Good end-of-life planning requires us to understand a number of legal and quasi-legal documents and provisions. The key is to keep a clear focus on the outcomes that you want and to be willing to seek advice where you need it. Relatively simple provisions will meet the needs of most of us.

To start with three key messages:

> **IT IS NEVER TOO EARLY TO GET THE DOCUMENTATION AND ORGANISATION RIGHT. WRITE IT FOR NOW – YOU CAN CHANGE IT IF YOUR VIEWS CHANGE.**
>
> **IF YOU DO NOTHING ELSE, TALK TO THOSE CLOSE TO YOU ABOUT WHAT YOU THINK AND WHAT YOU WOULD WISH IN DIFFERENT HEALTH AND OTHER END-OF-LIFE CIRCUMSTANCES.**
>
> **WHERE THERE IS ANY RISK OF 'FAMILY POLITICS' GETTING IN THE WAY OF OUTCOMES IN ACCORDANCE WITH YOUR WISHES, EXTREME CARE IS NEEDED IN DOCUMENTING YOUR WISHES, CHOOSING THOSE WHO WILL ACT FOR YOU AND ANY LIMITS TO THEIR POWER TO ACT IF YOU ARE NO LONGER ABLE TO ACT FOR YOURSELF.**

A fourth useful message is to carry with you a means by which your wishes can be identified in an emergency. The Guardianship and Administration Board issues a (free) wallet card upon registration. A body called MedicAlert based in South Australia also (for a modest fee) issues a wallet card and will provide a wristband or necklet engraved with key data. It is not really necessary to go to the lengths of the gentleman who had his details tattooed on his chest!

The three key messages above need to be kept in mind when considering all the documents covered in this paper. There are connections between all of them, so thought may be required to ensure that they are consistent with each other.

Where all the family understand and agree with your wishes and with each other, the documents can be simple and straightforward, but particularly where there are serious tensions and disagreements with or between those closest to you or your heirs, great care and sound professional advice may be needed. It can be difficult to find the right time to discuss our wishes and beliefs in the depth needed to ensure full understanding by those who may be called on to make decisions on our behalf; and it is too easy to try to put off paperwork about something that we vaguely hope will not happen – and certainly not yet. If the worst does happen, the result can be messy for our loved ones and also result in us receiving forms of treatment that we don't want.

The other serious risk from delay in an age when we are tending to live longer is that of dementia overtaking us before we get our end-of-life planning sorted out. All the legal documents have to be completed while “of sound mind” and, while the precise stage at which we may be deemed to be not of sound mind is not entirely clear, it is important to settle our wishes while there is no doubt

that we are "of sound mind". Note that, in law, we are presumed to be of sound mind unless and until we are professionally diagnosed to be otherwise. Even then, we can be of sound mind for certain decisions, but not for others. The requirement is that we can fully understand the consequences of our action or decision.

Document storage and accessibility

It is extremely important that your documents should be easy to find. You should hold a copy of all relevant end-of-life documents in one place and ensure that those you want to have access to them on your behalf know this place. Copies (e.g. of your Will) should be clearly marked with the location and contact number of whoever holds the original.

If travelling interstate or overseas, it is sensible to carry a reference card with key details (including the contact of a family member/friend *not* travelling with you) with or in your passport/wallet.

The Will

It is advisable for a number of reasons to use a lawyer or the Public Trustee to prepare your Will and to ensure that the lawyer holds the original and you a copy. Your copy should be marked to show where the original is.

If you have a lot of minor possessions that you want various friends or members of the family to have it is wise to prepare a list of things not included in the Will and indicate who you want to have each. While this aims to save potential disagreements, it is important to recognise that such a list is not a legal statement. In law these things would go to your residuary beneficiary unless that person chooses to distribute them according to your request. It is sensible to hold the list with your copy of the Will.

If your Will was made over 10 years ago (or whenever there is a major change in your situation) it is wise to review it to ensure that it expresses your current wishes.

The need for a Will is sufficiently well known not to require more than a brief mention. There is a useful document on the Internet at http://www.legalaid.tas.gov.au/factsheets/Wills.html This explains, among other things, the events (e.g. marriage or divorce) which invalidate any current Will so that a new one must be made.

Joint ownership of Assets

Note that, where this arrangement suits both partners, ownership of property, including house, bank accounts, shares, superannuation assets etc in joint names greatly eases procedures on the death of one of the partners as ownership automatically transfers to the surviving partner without being subject to probate. (Note also that joint ownership overrides any alternative provision in a Will.)

Superannuation

Note also that your superannuation fund does not form part of your estate for purposes of the Will and that there are non-taxable and taxable elements according to who the benefit is paid to. Your superannuation fund manager should provide advice and a form on which you can specify how you want the fund to be treated on your death. The common form is a "Binding Death Benefit Nomination" which, in simple terms, allows payment of a continuing pension from the fund.

To Notify on my Death - Financial documents

It is important to keep a simple document with your end of life documents, stating the name and contact or location of your:

- bank(s)
- financial adviser/stock broker (or where your investments are held)
- superannuation provider
- pension details
- insurance policies (life, funeral, endowment etc)
- title to your house, and
- other details needed to ensure that your financial affairs can be dealt with efficiently.

Other important contact information is a list of who needs to be notified of your death (both business and personal, including for example your GP, your clubs and church as well as bodies such as the Tax Office.) Those who undertake a lot of business by computer also need to ensure that your Executors can access passwords and other key data (such as PayPal accounts). See **Attachment 1** for a simple form for listing these matters.

Expressing your wishes about financial matters - (Enduring) Power of Attorney

A Power of Attorney provides for someone to handle your financial and business affairs (whether temporarily or permanently) if for any reason you become unable to so. It is usually prepared for you by a lawyer or other professional with your agreement. It is safe (and wise) to complete one ahead of need. The powers are only activated when needed. It is important to distinguish between a temporary power – useful for example when travelling overseas or having an operation that will leave you unable to act for yourself for a period – from an Enduring Power of Attorney, which comes into effect when you are unable to act for yourself and 'endures' until the end of your life or until you recover and rescind it.

It is worth noting that there are arrangements that will reduce the need to prepare a Power of Attorney. The most important of these is if your financial affairs are in joint names, with either to sign. However, even then, it is necessary to remember that you may need back up arrangements, for example if travelling overseas, and that the situation may need review in the case of serious illness or disability of one of the joint signatories.

Power of Attorney is completely distinct from the Enduring Guardianship (below) and the person who holds your Power of Attorney can be but need not be the same person as your Enduring Guardian. It is critical that the person (or persons) you choose is one whom you completely trust to act as you would wish. This is usually a family member, but possibly a close friend or a lawyer or other professional you know well. It is wise that there should be a trusted legal or financial professional available in support if the holder of the power is not him/herself a professional. (As an example, the power may be held by a relative and the family solicitor jointly, with the solicitor instructed to act in accordance with the directions of the relative where the action depends on an understanding of your wishes - such as a move from one care home to another - subject to legal considerations.)

There are forms for different purposes (e.g. temporary or permanent) of which one, the General Enduring Power of Attorney (Form 4), is most commonly used. For those most commonly needed see **Attachment 2**.

Website: http://dpipwe.tas.gov.au/Documents/Form-4-General-Enduring-Power-of-Attorney.pdf

This is probably the best page for an overview of the different forms of power of attorney and how (and in what circumstances) to complete them.

Expressing your wishes about health and lifestyle issues

Introductory Note

This section is concerned with the treatment that you will receive in case of illness or accident. By their nature, these matters can be unpredictable, so it is extremely important to have thought about your treatment wishes in advance and to ensure that the documents described below, when completed, are lodged with your GP and also with any hospital at which you have a file. If you change your wishes at any time, replacement copies need to be sent. You should also keep a number of copies in your own files. Particularly if you have an on-going medical condition or are travelling, you should include copies in an emergency kit that you can carry with you.

The key documents designed for completion by you concerning medical and lifestyle matters are the Enduring Guardianship (EG) and Advance Care Directives (ACD). EG is provided for in Tasmanian State legislation, the *Guardianship and Administration Act 1995.* ACD forms are used by many health care organisations (a few still use the term Statement of Wishes rather than ACD). Although a standard ACD form is increasingly being adopted, a variety of ACD forms continue to be used by different organisations.

When you enter a hospital, the doctor or admissions officer may also complete other forms needed to guide treatment. One that is increasingly being used is a "Medical Goals of Care" form. This is designed to ensure that the doctor is clear whether the treatment is intended to cure a condition or is limited or palliative. As the patient, you have the right to refuse particular forms of treatment but within those limits you have to recognise that the treatment undertaken is the responsibility of the doctor's professional judgement of the situation that s/he finds when treating.

Enduring Guardianship and Advance Care Directive

The EG and ACD are two ways of setting out your treatment wishes in different circumstances so that medical and other staff can better plan and respond to your needs in a way that you would prefer. Both methods enable you to express your treatment wishes. Both approaches allow you to specify a person (Enduring Guardian in the case of an EG, Person Responsible in the case of an ACD) who will have the power to determine what treatments would or would not be acceptable if you are unable to express these for yourself. Note that the Guardian or Person Responsible may only make decisions that are consistent with the written wishes stated in your EG or ACD. You may also specify in either form if there is any person who you specifically wish to be excluded from decision-making about your treatment (for example a relative with religious or ethical views that are seriously contrary to your own). **Both come into effect only when you are unable to speak for yourself.**

The two essential differences between the two approaches are:

1. The EG requires appointing a person or persons who have the legal power to make decisions consistent with your expressed wishes if you are unable to express those wishes yourself. No such person need be appointed for an ACD, but you may specify one or more. If you have an ACD but no Enduring Guardian or Person Responsible nominated (or if you have not completed any written direction) and are unable to speak for yourself, the people who have the right to specify what treatment you would or would not accept are – in order of legal priority:

    - a guardian who has the power to consent to health care, which includes the power to refuse or withdraw consent to treatment
    - a spouse - including a de-facto spouse
    - an unpaid carer who is now providing domestic services or support to the patient, or who provided these services and support before the patient entered a residential facility, or
    - a relative of friend who has both a close personal relationship and a personal interest in the patient's welfare.

2. The EG, being prepared under specific legislation, is statutory law, whereas all forms of ACD are what is known as common law documents. This means that the EG is a legal document only within Tasmania (but is likely to be accepted elsewhere as a clear guide to patient wishes) whereas the ACD applies anywhere in Australia and probably in most other countries. Any problems of interpreting or applying an EG are dealt with by the Guardianship and Administration Board, while any issues of interpreting or applying an ACD must be dealt with by a Court.

The fact that the two processes are different and that it is not entirely clear which would have precedence in case of a clash simply **highlights the importance of ensuring that the two documents (if you have both) are entirely consistent with each other**. If you have previously completed an EG it is very important that any institution requiring that you also complete an ACD is aware of your EG and that the new ACD is completed in accordance with any wishes expressed in your EG (or that you specifically direct that it is the new ACD must be followed, not the EG which requires that you formally revoke your EG and lodge the revocation with the Board). Staff should be able to assist you with this.

Both the EG and the ACD are ways of expressing your legal right to specify any medical support or intervention you will not accept in particular circumstances of illness or accident. The EG does not *require* that you complete the section in which you express these wishes, **but we very strongly recommend that you do so.** ACD forms are designed specifically to record your wishes in regard to medical support or intervention.

Deciding your wishes requires careful thought and discussion, with your Enduring Guardian if you appoint one and, where possible, with your family or close friends.

It is not necessary to go into a lot of medical detail about specific treatments you will or will not accept as long as your statement makes your wishes clear. In fact it is far better to describe what sort of life situations you would find unacceptable (e.g. incurable dementia, or intractable pain) than the medical condition itself (e.g. Altzheimer's or prostate cancer). This is because medical practice advances continuously and conditions that are now incurable may well become treatable within a few years.

Examples A and C in **Attachment 6** are examples of 'plain language' statements, while Example B contains a number of specific statements about medical treatments. Example D is a listing of

possible conditions from a book

Enduring Guardian

Under present circumstances, **our strong recommendation is that you appoint an Enduring Guardian and include a statement of your wishes regarding treatment within the document that appoints your Enduring Guardian**. This of course depends on there being a suitable person who you are willing to appoint and who will accept the appointment and whether you are willing to accept the associated cost – see Attachment 3. Where a person to act as Enduring Guardian cannot be found, it is necessary to rely on a very carefully worded ACD. This should provide good protection, particularly if you specify by name any person who might otherwise have a say in your treatment but who you wish to have specifically excluded from this role.

The process and form for appointing an Enduring Guardian is completely distinct from the Power of Attorney above and the Enduring Guardianship form **must be lodged with the Guardianship and Administration Board for it to be valid.** You need to also make copies for your patient file with your GP and any treating specialist, for your Enduring Guardian and also one that you can take with you if you go into hospital or an aged care facility. If you decide to change it, you must complete the new form and send it to the Board with a letter revoking the old one. The Board will file the original and send you a copy.

Attachment 3 has a copy of the form and accompanying information sheet. More details including copies of forms and a Handbook are available from the website, http://www.guardianship.tas.gov.au/about_us#aboutusEG

Your Enduring Guardian is "a person you appoint to make your personal or medical decisions if you should lose the ability to decide for yourself because of a disability". It is therefore very important that you are sure that the person you appoint is in sympathy with your own wishes for your care, particularly in the final stages of your life. **Once you have worked out and made a note of your wishes, it is very important to allow plenty of time for detailed discussion with the person you intend to appoint to ensure that you both share the same understanding of your wishes and the appointee is comfortable with them.** It is also important that the person you appoint understands the responsibility that they have accepted, which may involve making difficult decisions, and is also prepared, if necessary, to be calmly assertive in dealing with professionals. It is an unfortunate fact that there are still a very few professionals who regard their own views as more compelling than those of their patient. In situations of conflict it is possible to go to the Public Guardian for resolution. It is also possible to go to the Medical Council if a doctor refuses to follow directions in the EG form.

You can appoint both a primary and one or more alternative Enduring Guardians. If you are becoming elderly, it would be desirable for at least an alternative guardian to be of a younger generation. For example many people appoint their spouse as primary Guardian and a child or younger close friend as alternative Guardian. If you have nominated only one guardian and that person pre-deceases you or leaves the State, it will be necessary to complete and lodge a replacement EG form.

The role of Enduring Guardian is a substantial responsibility and the process of deciding your wishes, selecting your Enduring Guardian and your Enduring Guardian understanding the issues that may arise should be undertaken thoroughly and carefully. **Attachment 5** contains detailed advice on the process and the issues that may be encountered in acting as Enduring Guardian or Person Responsible.

Advance Care Directive

An increasing number of hospitals, retirement homes, palliative care centres and similar institutions are making use of a form of Advance Care Directive, essentially a form that sets out your treatment wishes in case you are unable to make decisions for yourself at the time when treatment is needed. An ACD form has been developed by a working party of the Tasmanian Palliative Care Clinical Network, and the Clinical Ethics Committee of the Southern Tasmania Area Health Service. It is understood that this is intended to become the standard form in Tasmania. A copy of this form is included in this Guide (se Attachment 4) and copies may also be downloaded at:

http://www.dhhs.tas.gov.au/__data/assets/pdf_file/0008/129455/2482_ACD_Form_Online_Version_4_page.pdf

If you completed an ACD before this form was issued any form is entirely valid provided that it is properly signed, witnessed and dated and expresses your wishes clearly) .

A person accessing these services or institutions may be asked to complete such a form with the assistance of staff. To reiterate, the forms may differ between services but all cover the same broad set of issues.

We stress again that, if you have stated your wishes in the form of an EG, it is very important that anyone wishing you to complete an ACD is aware of this and any wishes expressed in the ACD be fully consistent with those in the EG (or a new EG prepared if the ACD is a more accurate statement of your wishes). The new ACD referred to above includes a section for you to include information about your Enduring Guardian. Make sure that a copy of the EG is filed with the new ACD.

An important point is that completion of an ACD, unlike the EG, does not *require* that you appoint a person who is authorised to make decisions on your behalf when you cannot do so, although the ACD form included in this booklet has provision for you to do so if you wish. Appointment of such a person increases your assurance that your wishes will be followed, particularly in situations where there is some doubt about the best course of action.

If you are unable to complete an ACD, the form can be completed on your behalf, but the risk is that they may not accurately reflect your wishes if this is done.

It is also worth noting that a hospital to which you may need to be admitted at some time is prepared to create a record with your ACD or EG even if you have never had an admission.

Medical Goals of Care

As mentioned in the introduction, this (MGOC) form is progressively being introduced. It is for use by medical staff to record which of four alternative goals of care (ranging from curative to comfort for the dying) is appropriate for the treatment. If you are living independently the doctor will normally complete it during the pre-admission or admission process. This is a medical document, but have the right to satisfy yourself that it fully takes account of your directions in an ADC or EG as to what forms of treatment should not be undertaken or the medical circumstances in which treatment should be limited. As the form makes clear, the patient does **not** have the right to demand forms of treatment that the doctor assesses to be futile or counter-productive.

A body called the Better Access to Palliative Care Program (BAPC) has put out an extremely useful

table comparing these three types of document. While the publishing body's main focus is palliative care, the comparison is a useful guide in all forms of treatment, as it shows how the MGOC, the ACD and the EG complement each other. A copy of the table is attached as Attachment 7.

Organ Donor

It is increasingly common for people to enrol as organ donors. However, under current practice, it is open to relations after your death to countermand your wish to make your organs available. You may want to include your wishes in your Enduring Guardian form or Advance Care Directive, which would strengthen the hand of your Enduring Guardian or Person Responsible to see that your wishes are carried out.

An organ donor form is included on all Medicare claim forms. It only needs to be completed once and will be held on your file by Medicare.

Note that, if you wish your organs to be available after your death, it may be medically necessary for short-term life support to be provided while arrangements are made. You may wish to give permission for life support for this purpose, even if you reject continuing life support as part of the care you receive.

In addition, the University of Tasmania Faculty of Health Science runs a Body Bequest Program through which people can "donate their body to sciences". Details and forms are available at http://www.utas.edu.au/medicine/quick-links/body-bequest-program

The Advance Care Directive form contains a space to record if you have taken up either of these options

Funeral arrangements and What to do following the death of another

If you have strong views about funeral arrangements, it may be wise to record them with your other documents.

Funeral insurance has been strongly promoted by some companies. An article in Choice Magazine questions the value of funeral insurance. It suggests that either paying a lump sum for a pre-paid funeral or paying premiums similar to those you would otherwise pay for funeral insurance into life insurance are both likely to be a better choice for most people. In Tasmania, provision for pre-paid funerals is regulated under an Act administered by the Department of Consumer Affairs and Fair Trading. If no other arrangements are made funeral costs are normally a charge on your estate.

The Department of Human Services has a very valuable guide to required action and forms of support available following death of another. The website is quoted on the next page.

Useful websites

Dying with Dignity Tasmania (Inc) http://www.dwdtas.org.au/
The site includes advice on completion of an Enduring Guardian form and a wealth of material relating to the organisation and issues concerning end of life. It lists related organisations in other States

YourLastRight.com http://www.yourlastright.com

The body is the peak organisation for State and Territory dying-with-dignity and voluntary euthanasia societies.
The site includes a listing of where Australian politicians stand on voluntary euthanasia. It also gives guidance on how to find the end of life planning requirements and choices in other States.

Power of Attorney http://dpipwe.tas.gov.au/Documents/Form-4-General-Enduring-Power-of-Attorney.pdf
This is probably the best page for an overview of the different forms of power of attorney and how (and in what circumstances) to complete them.

See also http://www.publictrustee.tas.gov.au/enduring-power-of-attorney/ for information about when the power begins to operate.

Enduring Guardianship http://www.guardianship.tas.gov.au/about_us#aboutusEG
The body administering this legislation is part of the Guardianship and Administration Board. The site listed gives a brief description and links to the appointment form and related documents.

This page contains valuable references to a wide variety of issues concerned with guardianship, including coverage of emergency situations, linkage to powers of attorney and fuller description of the powers of the Guardianship and Administration Board (GAB) to provide support at need.

In particular, while the focus in this booklet is on providing information for those who are currently legally competent to express their wishes in relation to end-of-life issues, the GAB Handbook provides valuable advice for situations where legal competence is an issue.

The Victorian office of the Public Advocate has an extremely detailed guide to power of attorney and guardianship in Victoria at http://www.publicadvocate.vic.gov.au/publications/121/

Clinical Care and Palliative Care
The Tasmanian Dept of Health and Human Services has a site relating to palliative care at
http://www.dhhs.tas.gov.au/palliative_care/welcome
And the Tasmanian Association for Hospice and Palliative Care has a site at
http://www.tas.palliativecare.org.au/Default.aspx?tabid=1915

Advance Care Directives
The Tasmanian Dept of Health and Human Services offers a form for an Advance Care Directive at http://www.dhhs.tas.gov.au/__data/assets/pdf_file/0007/104794/Web_ACD_large_print_form_only_style_compatible_barcode_binding_first_2012-10-29.pdf

The Australian College of General Practitioners has a useful page with an explanation of advance care planning and links to useful documents in each Australian State and Territory
http://www.racgp.org.au/guidelines/advancecareplans

What to do following the death of another
See https://www.humanservices.gov.au/customer/subjects/what-to-do-following-death

Attachment 1

SIMPLE FORM FOR LISTING OF KEY

END-OF-LIFE DOCUMENTS

The forms that follow may be useful for listing the data that will need to be available to your Guardian or Responsible Person if you are unable to act for yourself.

They need to be kept securely in a place that is accessible to yourself or Responsible Person but not to others. As access codes may change over time, it is also important to remember to update the forms at need.

TO NOTIFY ON MY DEATH

Name **Contact**

Lawyer (or holder of original of Will)

Bank

Bank

Bank

Financial Adviser (or where shares etc listed and held)

Superannuation/pension provider
(and other pension details and contacts)

Insurance policies (property, life, endowment, funeral etc)

Location of House Title (and other key ownership documents)

Other people to notify (e.g. relations/friends, GP, Centrelink, clubs, church, Tax Office)

Health Directives (Enduring Guardian, Advanced Health Care) and where copies are kept.

Other comments (e.g. preferred funeral arrangements)

Computer/internet Many people have internet based accounts, so it is important to maintain information on computer and protective passwords.

Note re Internet Assets.

In the computer age, many people have a lot of on-line activities and assets.

For communication there may be email addresses, blogs, Facebook and similar and so on, as well as photo sharing, genealogy and similar accounts.

You may have Ebay, PayPal, or any of a range of other on-line accounts, possibly with attached credits or debits.

It is important to remember and deal with these when making end-of-life arrangements, recognising that each of the major carriers (e.g. Gmail, Facebook, YouTube, Linkedin, eBay, Amazon) have their own requirements when it comes to closing accounts and recovering any assets.

Many of us have trouble keeping track of our own passwords and so on at the best of times. It is therefore important to have an *up-to-date* record of all accounts accessed with a username and password combination kept somewhere secure from access by others but where your heirs can find it (it may also be useful to you when you forget a password!). One way of keeping passwords relatively simple but secure is to use several variants of one basic password for all business and financial accounts and a quite different but relatively simple password for social and similar accounts.

The record should include:

- a list of any websites that you operate, with password and operating details;
- a list of any on-line accounts, with password details;
- a list of usernames, passwords and other necessary log-in data to any other sites that you use;
- instructions on how each account should be dealt with – for example you may wish to close down email, PayPal and similar accounts, but to hand over ownership of photo sharing or genealogy sites to a nominated person.

Increasingly, people are keeping their records and often their professional life work on computer or in digital storage, and these people should give serious thought, as part of their end-of-life planning, to how to ensure that this material is passed on to the appropriate people or institutions (or destroyed).

A form for listing these items is included with the loose leaf forms at the back of this folder.

Pins and related data at _____

CARDS

Card name	Number	Pin	Comments

BANK ACCOUNTS

Bank A/c	Number	Pin	Comments

PENSIONER OR OTHER CONCESSION CARD AND HEALTH CARDS

Card type A/c	Number	Pin	Comments

OTHER PINS

Organisation A/c	Number	Pin	Comments

OTHER DATA E.g. Enduring Guardian Registration, Organ donor, Prosthesis identification

Attachment 2

ENDURING POWER OF ATTORNEY

An extract of key explanations and forms from the website http://dpipwe.tas.gov.au/Documents/Form-4-General-Enduring-Power-of-Attorney.pdf is included on the following pages.

NOTE

Enduring Power of Attorney is concerned with your business and financial affairs, not with your health care wishes. The holder of your Enduring Power of Attorney need not be the same person as your Enduring Guardian – see Attachment 3.

Attachment 3

ENDURING GUARDIAN

A copy of the form and examples of conditions included are set out on the following pages.

Note that if there is no Enduring Guardian and no Advance Care Directive, medical professionals will consult (where possible) with your spouse, unpaid carer or relatives and will follow the course of treatment they believe to be best suited to your condition and known wishes.

DOCUMENTS FOLLOW

1. Enduring Guardianship infosheet
2. Instrument Appointing Enduring Guardian(s)

NOTE: Our current recommendation is that you complete an Enduring Guardianship, with a full statement of your end-of-life health care wishes, whether or not you also complete an Advance Care Directive (see Attachment 4). The examples shown in Attachment 5 may help you in framing your wishes.

Some services and facilities require completion of an Advance Care Directive when you access them. If so, you need to make sure that:

- **they receive a copy of your Enduring Guardianship form,**
- **the Advance Care Directive is completely consistent with the Enduring Guardianship provisions, and**
- **that the institution has the name and contact details for your Enduring Guardian.**

Guardianship and Administration Board Fees

The Board recently introduced fees for registering or revoking an Enduring Guardianship – currently at $64.80 for registration, $46.00 for revocation and $28.00 for a search for an existing Enduring Guardianship.

This is extremely unsatisfactory, as the Enduring Guardianship is the best legal form to use to set out your end of life wishes and nominate your carer/guardian.

An Advance Care Directive can be developed and registered without charge, but in our view does not offer as good protections.

Attachment 4

ADVANCE CARE DIRECTIVE

An example of an Advance Care Directive follows. Note that a number of organisations use somewhat different forms and collect them/ have them completed in different ways.

The form and accompanying notes are useful as a guide to thinking about what you might want in different circumstances.

DOCUMENT FOLLOWS

1. Advance Care Planning Fact Sheet and Form

NOTE: Under current circumstances we strongly recommend that you rely primarily on an Enduring Guardianship to record your end-of-life health care wishes if a suitable Enduring Guardian is available. If you are also asked to complete an Advance Care Directive by an institution, it should be completely consistent with the wishes stated in your Enduring Guardianship.

The examples in Attachment 6 may be useful in deciding your own wishes.

Attachment 5

Suggested Process in Establishing Enduring Guardianship

and

Issues and Responsibilities in acting as an Enduring Guardian.

1. **Step by Step Guide to writing an Advance Care Directive (ACD) or appointing an Enduring Guardian (EG).**

2. **Guide to the Role of (Enduring) Guardian (or Person Responsible).**

3. **Some Common Questions and Answers**

Step by Step Guide to writing an Advance Care Directive (ACD) or appointing an Enduring Guardian (EG).

1. **By yourself**, think through your beliefs, values and the things that are most important in your life, making notes for yourself as you go along. It is important to think about outcomes and situations rather than specific medical interventions at this stage. And it is important to think independently about your own wishes before opening yourself to influence from others.

You may want to think about the things that make day-to-day life enjoyable:

for example -

seeing my family

keeping up with my social group

interests or activities such as gardening or bushwalking

the ability to arrange my own life in my own way, without having to depend unduly on others.

If 'independence' is important to you, think about what level of necessary support would result in you feeling that you had lost independence.

You may also want to think about deeper things related to the end of your life:

for example -

I believe that my life is properly in God's hands

I, and only I, have the right to choose whether I want to go on living

I would not want to carry on if there is no hope of recovery to independence

I have seen the load on other families through the last stages of a long dying process and I don't want that to happen to my family

I don't think it is ethical to take up a lot of scarce skilled resources simply to keep me alive when there is no hope of recovery.

Think about what kinds of outcomes you would or wouldn't want from future medical care:

Examples

I wouldn't want to go to intensive care and be hooked up to machines unless there was a good chance of making a good recovery.

If I can't hold a normal conversation with people any more, I would see little point in living.

I wouldn't mind being physically immobile, but I would hate to not be able to communicate with my friends.

I am frightened of dying in pain and without dignity, so I would want to be kept comfortable.

2. Writing these things down in brief points is useful at this stage.

3. Talk to your family, and other people important to you about these things, and let them know what you would want if the time came when you were unable to express your wishes.

4. Think about who you would want to speak on your behalf if you couldn't understand or communicate your wishes for yourself. Talk to that person about whether they are prepared to speak for you. Before committing yourself to ask that person to act for you, you need to be very sure that they understand what you wish and its implications and that they are prepared to support you fully. If they do not agree and are not prepared to support you, find someone else to act for you. You can also specify in your EG or ACD any person you specifically want to have no say in your treatment or care. It is essential to ensure that the person you plan to appoint understands the role and duties of an Enduring Guardian or other Person Responsible. There are notes for guidance of an Enduring Guardian or Person Responsible in the next section of this Attachment.

5. If there is no-one who is prepared to become your Enduring Guardian or Person Responsible (or who you are prepared to ask), a very carefully worded ACD provides almost as much certainty that your wishes will be followed.

6. Write an ACD or an EG (there are a number of alternative forms of wording that may help in this set out in **Attachment 6**). When writing the document, you should focus as much as possible on outcomes rather than medical processes. Example C of Attachment 6 contains examples of this sort of wording.

7. Ensure that the statement is properly witnessed by two independent people and, in the case of the EG, lodge it with the Guardianship and Administration Board.

8. Tell your doctor, your family and other people who you think should know that you have made an ACD or EG. Give them copies. Tell them where you keep your copy at home.

Attachment 5-2

Guide to the Role of (Enduring) Guardian (or Person Responsible).

Terminology and abbreviations

- An ***Enduring Guardian*** is one appointed through an Enduring Guardianship (EG) which has been registered with the Guardianship and Administration Board.
- An ***Advance Care Directive*** (ACD) is a written set of instructions or wishes about future health care and treatment. It may be simple or detailed and may or may not be on a form.
- ***Person Concerned*** (PC) is the most common term used in health care institutions for the person who has prepared the Enduring Guardianship form or Advance Care Directive (ACD) or who needs someone to speak on their behalf.
- ***Person Responsible*** **(PR)** is the most common term for the Enduring Guardian or other person acting for the Person Concerned when he or she is incapacitated.

Who has the legal right to speak on behalf of the Person Concerned?

If the patient is an adult and the PC has not made a specific nomination which has been accepted, the PR in priority order is either:

- a guardian (including an Enduring Guardian) who has the power to consent to health care, which includes the power to refuse or withdraw consent to treatment
- a spouse - including a de-facto spouse
- an unpaid carer who is now providing domestic services or support to the patient, or who provided these services and support before the patient entered a residential facility, or
- a relative or friend who has both a close personal relationship and a personal interest in the patient's welfare.
- Unless someone is specified as the PR or specifically excluded by the PC in the EG or ACD form.

In most cases the duties of the EG or PR are fairly straightforward, but they can be substantial. The active part of their job begins when the PC asks for support or loses decision-making capacity and is no longer able to act for him or herself and serious decisions affecting their care or accommodation need to be made. This loss is not itself always clear (a patient may move in and out of clarity and may be clear about some things but not others). The key is whether there are 'reasonable grounds to doubt capacity' - and there is a risk that the capacity of, for example, a dementia patient for these sorts of decision may be under-estimated. In these marginal situations the PR's presence and sympathetic understanding of the PC's wishes and beliefs may be critical to achieving the right outcome.

Powers of the Guardian/Person Responsible

The power of the PR is to:

- ensure that those wishes set out in the EG or ACD are observed in the most appropriate way to the situation. and
- to make decisions on any matters on which the EG or ACD gives no guidance.

The PR may not do, or allow to be done, anything that is directly inconsistent with the PC's wishes as stated in the EG or ACD document.

In requiring that the PC's expressed wishes are followed, in particular in relation to withholding of

specific forms of treatment, the PR is supported by Australian case law to the effect that any clear and legal direction, whether or not it appears reasonable to the caring institution or professional, must be followed. Medical practice is based round an ethic of respect for autonomy, doing no harm, doing good and being fair. Some doctors believe that failing to prolong life does harm or may fear they may not be seen to have done enough, and may wish to persuade for continuation of treatment. But consent is central to autonomy, so the PR may have to deal with attempts to persuade to a course of action that the PC would not in fact want and, in a complex medical case, may also have difficulty in identifying which professional is in charge. The situation is further affected by the fact that the legal underlying view is that a person's 'best interest' is to maintain life – which underlies normal emergency practice of paramedics such as ambulance officers.

In order to be effective, the PR needs to really understand what is important to the PC, as the precise nature of the outcome from some illness or event **in relation to those things most critical to the PC's enjoyment of life** may make the difference between a decision to proceed or not to proceed with an intervention. An outcome acceptable to Stephen Hawking (a clear mind and a means, however arduous, of communicating with his peers and the outside world), would be wholly unacceptable to another person, say, Jacqueline du Pre as she would be quite unable to play the 'cello which was the centre of her life.

Medical science deals with probabilities, not certainties. Apparently 'miraculous' recovery from an apparently hopeless situation does occur and normally safe procedures can result in catastrophic complications, but both these situations are rare. The professional can give you a prognosis (a fairly accurate idea of the odds or probabilities), but the PR has to advise on whether those odds would be acceptable to the PC. This is why it is so important to know whether the PC is generally of a mind to fight on or would prefer not to prolong the dying process. These discussions can be difficult where the professional strongly believes that a particular course of action should be taken and you are sure that the PC would not want it. In these situations it is necessary to be calmly assertive and to rely on the written content of the EG or ACD as well as your own knowledge of the PC.

Medical advances are being made all the time. The PR may need to make judgements around acceptability of treatment for a condition for which it has been specifically rejected, because of the dramatically different prognosis for treatment from the time that the EG or ACD was completed. In that case it may be desirable or necessary to go to the Guardianship and Administration Board or the Court as appropriate. This possibility also highlights the value of the EG or ACD focussing on outcomes (e.g. the ability to live a reasonably independent life) rather than the specific condition (e.g. Alzheimer's disease).

Third, there may be on-going calls on the PR, not just a single 'yes or no' involvement. What should be done if the PC has expressed a very strong wish not to be moved from home, but further care at home is no longer practical? Does a particular form of treatment or relief fall within the range that the PC would agree to? Should the doctor proceed where an adequate dosage for pain relief carries a significant risk of death? These are questions on which the doctor will give a professional opinion and recommendation, but it is finally up to the PR to decide whether or not to proceed in accordance with that advice.

Finally, in a 'worst case scenario' of family dissension, the PR may have to make clear to family members that the doctor needs to follow the directions of the PC and that their objections have no weight in the decision-making. In these worst case scenarios there is always access to the Guardianship and Administration Board or to the Court (as appropriate), but that, in itself can be arduous - and the onus of taking any such action would normally be on the family rather than the PR.

SOME NOTES ON THE COMMON LAW AND ISSUES FOR DOCTORS
IN THE CONTEXT OF PATIENT AUTONOMY AND CONSENT.

TO BE READ IN CONJUNCTION WITH ATTACHMENT 5-2

Note that this is general advice only and is not an authoritative statement of the (fairly complex) law in this area.

There can be potential for difficulty between the patient (or the Enduring Guardian or Person Responsible) and the doctor(s) because of the ethical principles to which doctors work and the presumptions of common law.

The legal underlying view is that, all other things being equal a person's 'best interest' is to maintain life (hence the normal practice of ambulance personnel and other paramedics). The law also assumes that a person has capacity to make decisions unless there is good evidence to believe the contrary. However, exactly what is 'good evidence' is not entirely clear and there is a problem that capacity of certain patients (e.g. some with intermittent dementia) is routinely underestimated.

Doctors work to four underlying ethical principles (stated in the simplest terms):

- Respect for autonomy
- Do no harm (and some doctors may think that not prolonging life does harm)
- Do good
- Be fair

The core to autonomy is the concept of consent and the right to refuse, so the medical profession is deeply concerned with gaining consent to whatever treatment (or non-treatment) is proposed. There may in some circumstances be conflict between consent and the doctor's urge to persuade to a course of action, sometimes possibly driven by a doctor's fear of being seen not to have done enough. In complex cases there may also be a problem of disagreement between professionals as to the best course of action (or non-action).

Doctors have the right to withdraw or withhold treatment on the grounds of net negative impact or futility. Both decisions have an element of judgement and, in general it is easier to withhold treatment than to withdraw treatment already in place.

Consent depends on capacity. This can vary from time to time and can be specific to the decision domain (I may be capable of some decisions but not others). So the doctors must do everything in their power to assess capacity and, if capacity is absent, to determine wishes – hence the importance of carefully stated written wishes and/or an Enduring Guardian or Person Responsible who is knowledgeable about the patient's wishes. Hence also the importance of proper witnessing of written statements to ensure there is no coercion.

Some Common Questions And Answers

Q: What if I don't have someone I can appoint to be my Enduring Guardian, and there isn't anyone as my Person Responsible?

A: If there is no-one who is prepared to become your Enduring Guardian (or who you are prepared to ask), a very carefully worded ACD provides almost as much certainty that your wishes will be followed. In these circumstances you do need to be sure that your instructions that you give in your Advance Care Directive are clear and unambiguous, using clear 'if ….(such and such an event/circumstances)…. then (I would/not want…) as suggested in some of the examples shown in Attachment 6.

Q: What if medical science has advanced in the years since I wrote my Advance Care Directive, and my condition can now be cured or treated effectively?

A: In case this happens, it is wise to include a phrase such as "If there is little or no hope of me recovering to a degree which would enable me to enjoy a reasonable quality of life, either because of mental or physical disability" in any statement of how you want a particular condition (such as Alzheimer's disease) to be treated. In any case, your Enduring Guardian or Person Responsible would be able to discuss the issue with your physician and to approach the Guardianship and Administration Board or the Court if he or she believes that the situation is such that your written directions should be departed from.

Q: What happens if the doctor disagrees with my Advance Care Directive and/or the decisions of my Enduring Guardian/Person Responsible?

A: There is now a body of case law that makes it clear that, if your directions are clear and specific, providing treatment that you have stated that you do not want would constitute an assault.

Q: What happens if my family disagree among themselves, or with my Enduring Guardian/Person Responsible?

A: If an Enduring Guardian or Person Responsible has been appointed, their decision over-rides the family's opinion. Under the Guardianship Administration Act, if no Enduring Guardian has been appointed, there is a clear hierarchy (the same as with an Advance Care Directive) of who is an appropriate Person Responsible who may take on the role of substitute decision maker. Disputes can be taken to the Guardianship Administration Board, or to the Courts, (as appropriate), and the onus of taking any such action would normally be on the family rather than the Person Responsible.

Q: Do I need to see a lawyer to complete an Advance Care Directive or Enduring Guardianship nomination form?

A: No, you don't. It is important that whichever document you complete, it must be properly witnessed, signed and dated. An Enduring Guardianship form becomes legally binding only once it is lodged with the Guardianship and Administration Board. If you want advice or assistance with making directions for end of life decisions, you can talk to your GP, or see a community health social worker. Information is also available from the websites included on pages 8-9 of the text of this document.

Attachment 6

EXAMPLES OF HEALTH CARE DIRECTIONS TO CONSIDER FOR INCLUSION IN ENDURING GUARDIANSHIP OR ADVANCE CARE DIRECTIVE

This requires careful thought and discussion, particularly with any person you plan to choose as your Enduring Guardian or Alternate Guardian. You are trying to think forward to what you would want in a situation where you may no longer be able to decide for yourself or express your wishes effectively. These directions can be used for either EG or ACDs.

As long as you are clear about what you want and do not want, it is not necessary to go into a lot of detail about medical conditions or types of treatment. In fact, it is better to focus on outcomes (e.g. retention of independence) than on specific conditions (e.g. Alzheimer's disease) because treatments and abilities to cure continue to progress rapidly. Examples A and C are examples of a request that avoids this detail.

In the absence of any expressed wishes, medical professionals would normally arrange for you to be moved to the most suitable facility for treating your condition, and would undertake whatever forms of medical treatment are most likely to contribute to your recovery or, if recovery is very unlikely, to maintain life and freedom from pain to the best of their ability.

In the simplest terms you need to consider:

- where you would like to be treated (e.g. at home or in a hospital or care centre), recognising that some situations can only be treated in a hospital;
- whether you want treatments that are designed to maintain and prolong life in situations in which recovery is unlikely; and
- whether there are any forms of treatment that you reject under all circumstances (as an example, the Jehovah's Witnesses reject anything involving blood transfusion under any circumstances).

You may also wish to specify any situations in which you would like assistance in ending your life **if such action is legal at the time**. In this connection note that you cannot request action that is currently illegal, but you can make such a request if it is preceded by the words "if it is legal at the time".

Example A is perhaps the briefest statement that all the same gives a very clear indication of wishes. If this example truly reflects your own wishes, we strongly recommend that you use it as a basis to which you add any further conditions you wish, for example conditions taken from Examples B or C.

Example B is a slightly longer statement with additional detail. Because of its length, detail and somewhat legal language, **it is not recommended for use – certainly not in full** – but it does contain a useful list of situations and wishes that may help you to think through your own issues and concerns.

Example C is not very specific as to types of illness or disability, but includes a fairly comprehensive statement of wishes for assistance with dying if that becomes a legal option.

Example D is a listing taken from a book.

Note that any service or facility that you access may have a form different from any of these. The examples are to illustrate what you may consider and possible wording in your EG or ACD form.

Example A

ENDURING GUARDIAN OR ADVANCE DIRECTIVE WISHES

If there is little or no hope of me recovering to a degree which would enable me to enjoy a reasonable quality of life, either because of mental or physical disability, I want no measures taken to prolong my life, but want maximum effort concentrated on keeping me comfortable and free from both mental and physical distress, even if this shortens my life. For me this defines the conditions that allow me to die in a dignified state.

Specifically, in these circumstances:

- In the event of a cardio-respiratory collapse I do not want to be resuscitated.
- If I get an life threatening infection, do not treat it. Use no antibiotics. Just make me comfortable.
- If I cannot feed myself, do not feed me, nor give me intravenous fluids. I do not want tube feeding of any kind.
- I want no blood transfusions, no renal dialysis and no invasive tests or procedures.
- I want no regular vital signs taken.

If you choose to use this example as the basis for your own statement, here are some wishes from the examples below that you may wish to consider adding:

- I do not want to be treated in a hospital, but wish to be made comfortable where I reside.
- Situations such as those set out in Example C in which assistance in ending life may be desired if it is legally available at the time
- A statement of your ethical position on acceptance of health care (such as that included in Example C)

Example B*

ENDURING GUARDIAN OR ADVANCE DIRECTIVE WISHES

I authorise my guardian, in the event that I become unable by reason of a disability to make reasonable judgments in respect of matters relating to my circumstances, to exercise the powers of a guardian under section 25 of the *Guardianship and Administration Act 1995.*

I require my guardian to observe the following conditions in exercising or in relation to the exercise of the powers conferred by this instrument:

I declare that if:

1. I am unable to take part in decisions concerning my medical care due to physical or mental incapacity,
2. I develop one or more of the medical conditions listed under medical conditions below: and
3. Two independent physicians conclude that there is no prospect of my recovery, then

my wishes are as follows:

- I want no measures taken to prolong my life.
- I wish to be kept comfortable, free of pain, and maintained in a dignified state.
- I wish any medication that is used to keep me comfortable and free of pain or other distress to be in sufficient dosage that distress, physical or psychological, is relieved, even if such medication hastens my death.
- If I get an infection, do not treat it - just make me comfortable. Use no antibiotics.
- If I cannot feed myself; just leave the food for me. Do not spoon feed me or encourage me in any way to eat or drink, Do not treat dehydration with anything other than fluids offered orally, and do not try to encourage drinking beyond what I clearly desire.
- Give me no artificial feeding or hydration of any sort I do not want a tube inserted to administer food or hydration (no intravenous fluids).
- If I cannot breathe for myself, I do not wish to be put on a ventilator. Oxygen is not to be administered other than possibly for the relief of air hunger. Low oxygen levels in the blood are not a sufficient indication for the use of oxygen.
- If my kidneys fail, I do not want dialysis.
- If I stop breathing or my heart stops beating, I do not want cardiopulmonary resuscitation.
- I want no blood transfusions.
- If I have a heart attack or stroke, do nothing to extend my life, but do provide comfort measures.
- I want no surgery unless it is absolutely necessary to control pain.

- I want no x-rays, blood tests, other laboratory tests, or invasive diagnostic procedures.
- I do not want regular vital signs to be taken, including blood pressure and temperature measurements.
- I do not want to be treated in a hospital, but wish to be made comfortable where I reside.

The medical conditions are:

1. Severe and lasting brain damage sustained as a result of an accident or injury.
2. Advanced disseminated malignant disease.
3. Advanced degenerative disease of the nervous and/or muscular systems with severe limitations of independent mobility, and no satisfactory response to treatment.
4. Stroke with extensive persisting paralysis.
5. Alzheimer, multi-infarct or any other type of dementia.
6. Any other medical condition which leaves me totally incapacitated such that I require 24 hour nursing care.
7. Any other condition of comparative gravity.

I absolve my medical attendants of all legal liability arising from action taken in response to and in terms of this declaration.

This is an appointment of an enduring guardian made under Part 5 of the Guardianship and Administration Act 1995.

_____ _____

(Signature of appointer) (Date)

_____

(Signature of Witness)

* see introductory note to this attachment.

"Because of its length, detail and somewhat legal language, **it is not recommended for use – certainly not in full** – but it does contain a useful list of situations and wishes that may help you to think through your own issues and concerns."

The example is included for its listing of wishes and conditions that you may wish to consider. As stated in the introductory note, we recommend some combination of variation or A or C which focus on outcomes, and if possible that your statement is no longer than those 2 examples.

Example C

ENDURING GUARDIAN OR ADVANCE DIRECTIVE WISH LIST

In any circumstances in which injury or illness makes recovery to full mental or physical independence unlikely, I do not want any medical intervention other than to relieve pain.

My views on suicide and voluntary euthanasia are well known to you. I have been a member of Dying with Dignity Tasmania and of Exit International for some years. I am currently in good physical and mental health and hope to be able to look forward to continuing in this state for many years. However, in order to ensure that there is a record of my intentions in case of serious disease or accident, this document sets out the circumstances in which I would expect to end my own life and, if it becomes legally available*, would seek assistance in obtaining materials to self-administer for a peaceful end or assistance in terminating my life if I am no longer capable of taking the necessary action myself.

Broadly, these circumstances include any incurable mental or physical condition which would result in loss of my capacity for independent living, cause continuing intractable pain, or require extensive continuing professional support to maintain even marginal independence. Examples of situations that would trigger a desire to end my life include:

the onset of Alzheimer's disease or any other dementia;

stroke or any of the progressive degenerative diseases of the nervous system resulting in serious and probably permanent loss of function;

cancers that result in severe progressive disability and where the prognosis is statistically poor;

skeletal disorders, auto-immune conditions or other conditions resulting in continuing severe pain requiring medical management;

Trauma from which recovery of the ability to function independently is unlikely.

This view is based partly on concern for my own quality of life and partly on a view that it is wrong to take up scarce professionally skilled resources in these situations, when they can be used more productively in care of people who can expect to return to full health and function.

When I die

I have registered as an organ donor. Any organs that can be used for others or for purposes of potential medical benefit to others should be available.

I would like my remains to be disposed of in the most economic and ecologically sound way legally available at the time of my death.

*** NOTE: This phrase recognises that under current law this request could not be acted on.**

Example D

ENDURING GUARDIAN OR ADVANCE DIRECTIVE WISHES

The book "To Die Well" by Sidney Wanzer MD gives the following list of 'Wishes' that may be considered.

- I want no measures taken to prolong my life.
- I wish to be kept comfortable, free of pain, and maintained in a dignified state.
- I wish any medication that is used to keep me comfortable and free of pain or other distress to be in sufficient dosage that distress, physical or psychological, is relieved, even if such medication hastens my death.
- If I get an infection, do not treat it – just make me comfortable. Use no antibiotics.
- If I cannot feed myself, just leave the food for me. Do not spoon feed me or encourage me in any way to eat or drink. Do not treat dehydration with anything other than fluids offered orally, and do not try to encourage drinking beyond what I clearly desire.
- Give me no artificial feeding or hydration of any sort. I do not want a tube inserted to administer food or hydration (no intravenous fluids).
- If I cannot breathe for myself, I do not wish to be put on a ventilator. Oxygen is not to be administered other than possibly for the relief of air hunger. Low oxygen levels in the blood are not a sufficient indication for the use of oxygen.
- If my kidneys fail, I do not want dialysis.
- If I stop breathing or my heart stops beating, I do not want cardiopulmonary resuscitation.
- I want no blood transfusions.
- If I have a heart attack or stroke, do nothing to extend my life, but do provide comfort measures.
- I want no surgery unless it is absolutely necessary to control pain.
- I want no x-rays, blood tests, other laboratory tests, or invasive diagnostic procedures.
- I do not want regular vital signs to be taken, including blood press and temperature measurements.
- I do not want to be treated in a hospital, but wish to be made comfortable where I reside.

Attachment 7.

TABLE EXPLAINING DIFFERENCES BETWEEN THE

Medical Goals of Care Plan (MCOG)

Advance Care Directive (ACD) and

Enduring Guardianship (EG)

This table is reproduced by kind permission of The Better Access to Palliative Care Program

Attachment 8.

WHAT TO DO FOLLOWING A DEATH.

This article is reproduced from the site of the Department of Human Services. It contains information which is valuable to those responsible for dealing with the death of another.

The Department is available to provide payments, counselling and financial services to help people adjust to life after someone close to them has died.

What to do following a Death

What happens first

When someone dies, a doctor must sign a certificate that confirms the death. Funeral arrangements cannot be completed until the doctor has signed and issued this certificate. It is generally called a Doctor's Certificate of Cause of Death. The funeral company can then take the deceased into their care.

The funeral director in charge of the funeral arrangements will collect all the information needed for registering the death and send it to the relevant state or territory government office. The funeral director may also help with things such as newspaper notices, flowers and religious services.

Read more about who to contact on the Australian Funeral Directors Association website.

If a funeral director is not involved with the funeral arrangements, the person who manages the final arrangements for the deceased is responsible for registering the death.

Insurance policies, funeral plans and Wills

Sometimes private health, sickness, accident or life insurance policies may help to pay funeral and other expenses. If you find that the person who died had insurance, call the company and ask if assistance is available.

Some people pay for their funerals in advance. Funeral plans involve paying in advance for an agreed funeral service. Funeral bonds represent money the person has put aside to cover their funeral costs.

If you think there may be a prepaid funeral or a funeral bond but cannot find the paper work, it may have been left with someone such as a solicitor or the Executor of the Will.

A Will is a legal document that states how the deceased person's belongings are to be distributed after their death. The Executor of the Will is responsible for distributing the person's assets to the people named in the Will. This happens after any debts are paid.

If the person has not left a Will, the estate is shared under a formula set by law. If there are no close relatives there is a chance the estate could be paid to a state or territory government.

Who to notify

It’s important that you tell us when someone has died so we can update their Centrelink and Medicare records.

To tell Centrelink:

- call the Bereavement line
- visit us, or
- complete the Advice of death form and fax or post it to us

To tell Medicare:

- call the Medicare general enquiries line
- complete the Notification of deceased person form and post it to us

There are other people and organisations that you may also need to tell. Use the following checklist to help you identify the people and organisations you may need to contact:

- Who to notify checklist
- Who to notify checklist

Removing someone's name from mailing lists

Register the details on the Association for data-driven marketing and advertising website or write to them at:

ADMA
GPO Box 3895
Sydney NSW 2001

Social media accounts

Social media networks usually have procedures in place to deal with the accounts of deceased members. As these procedures can differ between networks the best thing to do is to search the 'help' section of the network in question if you wish to close an account.

Assistance from us

Read about eligibility and how to start the claiming process for the following payments and services:

- Bereavement Allowance - a short term income support payment for recently widowed people to help them adjust after the death of their partner
- Bereavement Payment - helps ease your adjustment to changed financial circumstances after the death of your partner, child or person you were caring for
- Double Orphan Pension - provides help with the costs of caring for children who are orphans or who are unable to be cared for by their parents in certain circumstances - there is no income or assets test required
- Pension Bonus Bereavement Payment - a payment to the surviving partner of a deceased member of the Pension Bonus Scheme, who did not make a successful claim for the bonus before their death
- Widow Allowance - ensures women have an adequate income if they have become widowed, divorced or separated later in life, were born on or before 1 July 1955 and have no recent workforce experience
- Social work services - our social workers can help you during difficult times by providing counselling, support, and information
- Financial Information Service - a free, confidential service available to all Australians to help you make informed decisions about investment and financial issues for your current and future needs
- Someone else to deal with us on your behalf - if you would prefer to have someone else deal with us on your behalf about our payments and services, you can authorise a person or organisation to be your nominee or make enquiries only

You may also be eligible for Parental Leave Pay, Stillborn Baby Payment or Dad and Partner Pay in the case of a stillbirth or infant death.

Read more about Bereavement Payment or call **136 150**

Financial matters

After the death of a loved one, you may need to understand more about the investments you own. When a member of a couple dies the survivor usually inherits assets previously held in joint names. You should advise us of any changes to your income and assets as they may impact any payment you receive or become eligible for.

If your partner had superannuation you may also be entitled to a superannuation payment. You need to contact the relevant superannuation organisation and find out if you could be eligible for any payments.
You should also carefully consider the implications of passing on assets to children or other family members and friends and bypassing yourself, as this can affect your asset position and may result in changed payment rates.
Relatives and friends do not have to pay the debts of the person who has died unless the debts are in joint names. Debts can be paid from the estate.

Financial assistance

If you would like assistance to work out a budget, manage your financial affairs or help if you are in financial trouble, you can speak to a financial counsellor by contacting any of the following:

- your local Community Information and Referral Service
- a Welfare Rights Centre
- Rural Financial Counselling services
- Financial Counselling Australia
- Financial Information Service

Early superannuation release

Superannuation cannot generally be accessed before you reach your preservation age. However, in some specific circumstances, the law does allow you to access your superannuation early. These limited circumstances include specified compassionate grounds and severe financial hardship.
Read more about the early release of superannuation on compassionate grounds, call **1300 131 060**, or contact your superannuation fund.
For more information about early release of superannuation for severe financial hardship, contact your superannuation fund.

Support for you after someone has died

Grieving

Grieving is a natural part of losing someone close to you, so adjusting to your new circumstances may take time. Counsellors can often assist people who are grieving. Our social workers can refer you to grief counselling. Counsellors can also be contacted through organisations such as community health centres, the National Association for Loss and Grief or Lifeline.

Loneliness

It may seem difficult at first to take part in social groups and activities. You may or may not want people around you. With time, the company of others may help you develop new interests. Your local council, community health centre or our social workers can put you in touch with organisations such as Rotary or Apex that would value your assistance as a volunteer. You can also join in their activities and outings.

Health

Taking care of your diet and regular exercise can assist you to re-establish a routine. We can arrange for visits by a community nurse if necessary. Community groups or local councils may arrange services to help care for your house or garden. Some of these services are free and some may be provided only after your needs have been assessed.

Housing

You may want to stay in your family home. However, if this is difficult, think about all the options carefully before you decide on a change. Moving too quickly may not be the best solution.

You can talk to a Financial Information Services officer who can give you information about how any decisions you make could affect the payment you receive from us.

Other government and community support services

There are a range of other organisations that provide support services and useful information you may find helpful. You can use Service Finder to locate assistance in your local area.

MoneySmart has information to help you make the most of your money. Read the Losing your partner section on the MoneySmart website.

Financial Counselling Australia is the peak body for financial counsellors in Australia and provides information about how financial counsellors can support and advocate for people experiencing financial difficulty.

Headspace is the national youth mental health foundation and can help young people who are going through a tough time.

If you are experiencing depression, anxiety or stress, you may find it helpful to talk to somebody about your mental health.

Lifeline is a national charity providing all Australians experiencing a personal crisis with access to 24 hour crisis support and suicide prevention services.

Solace Australia provides support for people who have lost their partner.

Related services

- Bereavement Allowance
- Bereavement Payment
- Dad and Partner Pay
- Double Orphan Pension
- Early release of superannuation
- Family Tax Benefit
- Financial Information Service
- Parental Leave Pay
- Pension Bonus Bereavement Payment
- Social work services
- Stillborn Baby Payment
- Widow Allowance

Related subjects

- Concession and health care cards
- Crisis and special help