

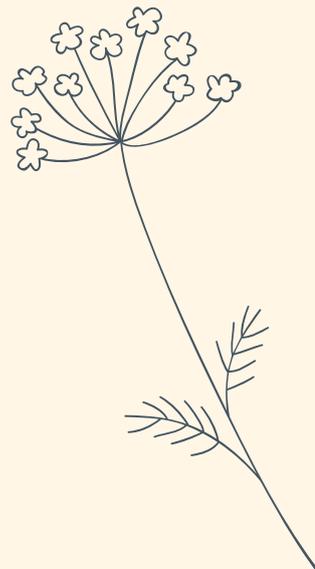


End-of-Life Planning

A guide to documenting
your wishes in legal form

SECOND EDITION
BILL GODFREY & COTA TASMANIA

COTA 
TASMANIA
for older Australians



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COTA Tasmania acknowledges the work of Bill Godfrey and Dying with Dignity Tasmania in developing the first edition of this *End of Life Planning* document published in 2019.

This second edition has been updated by Bill Godfrey and COTA Tasmania to reflect current conditions and legislation. Our aim is to update the document as required with up-to-date versions available on COTA Tasmania's website or on request from COTA Tasmania.

End-of-life Planning was published by COTA Tasmania, with the assistance of the Tasmanian Government.

Note

The principles underlying end-of-life planning have wide application. However, the law and support structures available differ between countries and, within Australia, from State to State or Territory. This booklet discusses Tasmanian law and institutions. If you live elsewhere, you should refer to the laws and institutions of your own jurisdiction.

The booklet can be read on its own but is designed primarily to support an interactive end-of-life planning seminar available through COTA Tasmania. A range of supporting documentation is available on the COTA Tasmania website or on request from COTA Tasmania.

While this booklet has been prepared using the best advice available, it is written as a general guide only. COTA Tasmania believes it to be applicable in most normal situations for people living in Tasmania. However, you should seek professional legal, medical or financial advice before you take any action.

Table of contents

Foreword	4
Summary	5
Key points	5
The need	6
Document storage and accessibility	8
Your Will	9
Joint ownership of assets.....	9
Superannuation	10
“To notify on my death” – financial documents	11
Expressing your wishes about financial matters	12
Expressing your wishes about health and lifestyle matters	14
Introductory note	14
Overview	14
Enduring Guardianship.....	16
Advance Care Directive.....	17
Medical Goals of Care	18
Organ donor.....	18
Funeral arrangements and what to do following the death of another	19
Attachments	20

Foreword

COTA Tasmania is indebted to Bill Godfrey for his excellent work developing this document and the associated workshops.

I am confident that this body of work will help many people to better understand and navigate the end-of-life planning process.

The clear messages that flow through the document are to start early with the process, seek legal advice, think about what you want and have conversations with your family, friends and supporters about your wishes.

It is our aim to reach as many people as possible with this information about the four key documents that together are used to capture our end of life plans and give them legal standing in Tasmania.

Thanks also to those people who have contributed their time to review and provide feedback on the document and the workshop in the development phase.

COTA Tasmania has been able to publish this document and develop the workshops with the support of the Tasmanian Government through the End of Life Care Small Grants Program.

Sue Leitch

Chief Executive Officer
COTA Tasmania



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.

Key points

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 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 as long as you are still deemed to have the capacity to understand your decisions. All the formal documents should be reviewed every 5 years or when your circumstances 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.
- » There are advantages in *documenting* your wishes. This is particularly important if 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 important to store your copies 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.



Please remember that much of the legislation referred to in this booklet is State based and differs from State to State or Territory. 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.

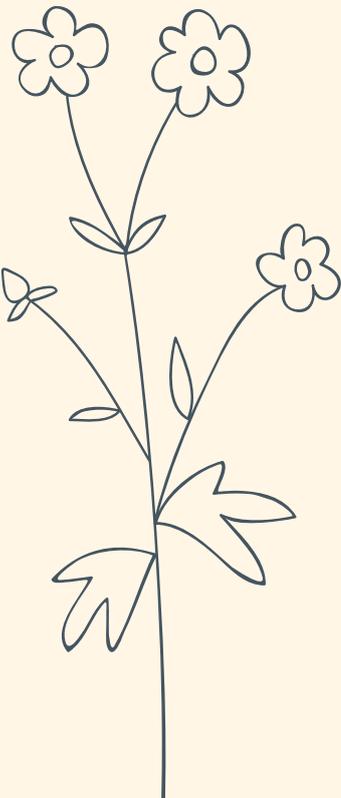
It is important to have sensible plans in place to minimise the trauma, inconvenience and plain muddle that can occur, and to ensure that your wishes are known and will be followed if you are not yourself able to state what you want – for example, as a result of trauma or dementia.

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 a range of health and other end-of-life circumstances.
- » If there is any risk of “family politics” getting in the way of outcomes that accord with your wishes, take extreme care 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.

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, and any changes made remain 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.

A serious risk of delaying end-of-life discussions in an age when we are tending to live longer is that dementia could overtake us before we get our planning sorted out. Dementia is by no means inevitable, but our risk of dementia increases with age. All the legal documents discussed in this booklet have to be completed while "of sound mind". The precise stage at which we may be deemed to be not of sound mind is not entirely clear, but 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.

Another reason to discuss your end-of-life wishes with your loved ones while you are "of sound mind" is so your loved ones know in as much detail as necessary what you would wish to be done, should you lose your capacity to make decisions for yourself. Even though you will outline your wishes in the documents you prepare and sign, face-to-face discussions enable you to talk at length with your loved ones and those you nominate to make decisions for you at the end of your life. It also helps ensure none of your wishes, whatever they may be, will come as a shock to your loved ones at a time when they may be distressed. If you talk about what you want well in advance, you can take the opportunity to ask them if they have any questions or need clarification.



If you find it hard to discuss your wishes with family members for any reason, consider Relationships Australia Tasmania's Elder Relationship Service (<https://tas.relationships.org.au/elder-relationships-services>). This free service supports older people and their families to discuss important life decisions such as end-of life planning or have other difficult discussions.

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.

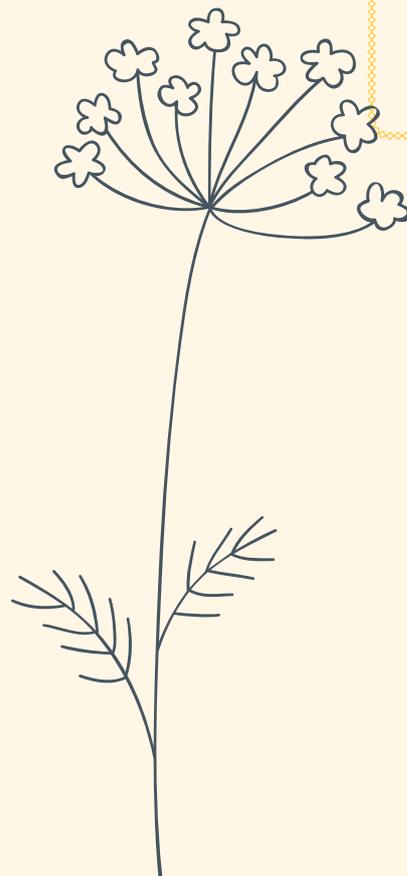
It is sensible to carry a reference card with key details (including the contact of a family member/friend *not* travelling with you) with or in your passport/wallet/purse.

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!

If you have an Advance Care Directive (a document we discuss in detail later in this booklet), consider having a copy on your fridge, where emergency service officers can see it. You should also give a copy of your Advance Care Directive to your loved ones, enduring guardian (see later in this booklet), GP and hospital.

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If you have an Advance Care Directive (a document we discuss in detail later in this booklet), consider having a copy on your fridge, where emergency service officers can see it. You should also give a copy of your Advance Care Directive to your loved ones, enduring guardian (see later in this booklet), GP and hospital.



Your 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 have a copy.

Your copy should be marked to show where the original is. However, use of a lawyer or the Public Trustee to make a Will is not cheap. As at February 2021, the Public Trustee charged \$140 for one person or \$210 for a couple to prepare a fairly standard Will, and more for complex Wills. If you hold a Seniors Card or Australian Government Pensioner Concession Card, the Public Trustee will prepare your Will for free, but only if you appoint the Public Trustee as your executor rather than another trusted person (or people). However, the Public Trustee will charge a commission based on the value of your assets when the time comes for it to carry out its duties as the executor of your Will.

You can prepare your Will yourself as long as it is properly worded, signed and witnessed. However, as mentioned above, we recommend you seek legal advice if at all possible. If a Will is prepared incorrectly, it can be invalid.

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 simplify things and save potential disagreements, it is important to recognise that such a list is not a legal statement.



Tasmania Legal Aid has a useful fact sheet (<http://www.legalaid.tas.gov.au/factsheets/Wills.html>) that explains why Wills are important, when Wills made before marriage become invalid, why you should make a new Will if you get divorced, and why it is prudent to seek legal advice.

In law these things would go to your residuary beneficiary (the person who gets everything not specifically left to someone else) unless that person chose to distribute them according to your request. It is sensible to hold the list with your copy of the Will.

The Public Trustee recommends you update your Will every three to five years, or when your circumstances change significantly, such as if you marry, divorce or have children.

Joint ownership of assets

Property and assets jointly owned, such as houses, bank accounts or shares, automatically transfer to the surviving partner without becoming part of the Estate covered by the Will of the person who has died. This also means they are not subject to probate. (Note also that joint ownership overrides any alternative provision in a Will.) However, if a property is held as tenants in common probate will be required as it is considered an asset of the estate.

Superannuation

Your superannuation assets do not form part of your estate for purposes of your Will unless you have previously arranged for your superannuation fund manager to deposit them in your estate on your death.

Moreover, the amount of tax, if any, to be paid on various components of your superannuation after you die depends on how they are distributed and to whom. Your superannuation fund manager should provide advice and a form on which you can specify how you want the assets and/or pension to be treated on your death.

The common form is a “Binding Death Benefit Nomination” which allows you to specify which of your dependents you want to receive a lump sum or – if you choose a “reversionary” option – your pension. If your superannuation is paid through a company or government fund, it will have rules on what happens on your death, but if you have a private fund you will need professional advice to ensure that the rules are in accordance with your wishes.

It is important that you understand the difference between a binding and non-binding Death Benefit Nomination as this may impact on who can make a claim against your superannuation and who ultimately receives it in what proportions.



“To notify on my death” — financial documents

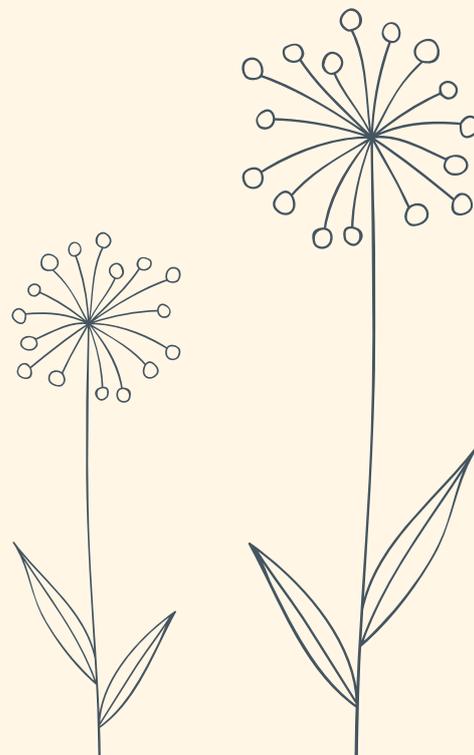
It is important to keep a simple document with your end of life documents, stating the name and contact or location of your:

- » 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
- » 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.)

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If you undertake a lot of business by computer, you 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 them. You might also consider lodging a copy of this document with your lawyer along with your Will. It does not form part of the Will, rather is a helpful additional source of information.



Expressing your wishes about financial matters

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, under your instructions.

It is safe (and wise) to complete one ahead of need. Whether the powers are activated when you register the document with the Tasmanian Land Titles Office depends on the wording of the document. This is discussed further on the next page.

It is important to distinguish between a General Power of Attorney – useful, for example, if you are 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 continues (“endures”) if you lose cognitive capacity, unless you revoke it before that happens.

If your financial affairs are in joint names, with either to sign, the other party can generally act without a Power of Attorney from you. 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.

In Tasmania, an Enduring Power of Attorney is completely distinct from 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. When making a General or Enduring Power of Attorney, you are referred to as the donor and the person (or people) you appoint as your attorney. It is critical that the person or people you choose is someone you completely trust to act as you would wish. It may be a family member, a close friend, a lawyer or another professional you know well.

It is wise to have a trusted legal or financial professional available to support your attorney if that person is not expert in financial management. You can appoint multiple attorneys to act “jointly”, in which case they must act together, or “jointly and severally”, in which case they can act independently of one another.



We recommend you prepare an Enduring Power of Attorney as part of your end-of-life planning, so that a person you trust can make decisions on your behalf if you are no longer able to do so. You can download one of these forms yourself from the Land Titles Office website (<https://dpiwwe.tas.gov.au/land-tasmania/land-titles-office/power-of-attorney-forms>) and then follow the instructions about how to register and activate the signed document.

However, the Land Titles Office, Tasmania Legal Aid and COTA Tasmania **strongly advise you to get legal advice first**. This is because the online forms make Enduring Powers of Attorney look simple but they are actually very powerful. It is possible to add clauses to ensure they more accurately reflect your wishes, and a lawyer is the best person to advise you about how to do this. A lawyer can also ensure you understand the documents and the powers you are assigning.

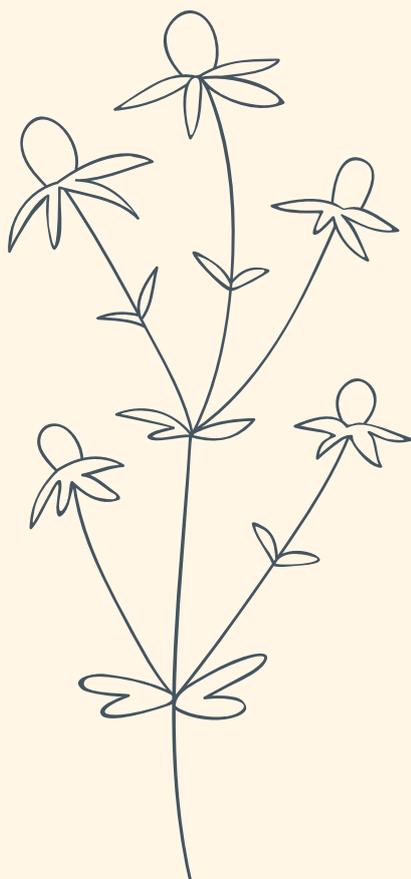
If you don't have a lawyer, the Public Trustee can prepare an Enduring Power of Attorney for you. As at February 2021, the Public Trustee charged \$140 for one person or \$210 for a couple to prepare fairly standard documents, and more for complex ones. If you have a Seniors Card or Australian Government Pensioner Concession Card, the Public Trustee will prepare your Enduring Power of Attorney for free but only if you appoint the Public Trustee as your attorney rather than another trusted person (or people). If you appoint the Public Trustee, it will charge fees if and when the time comes for it to manage your financial affairs.

Remember, a Power of Attorney and Enduring Power of Attorney must be registered with the Land Titles Office to be activated. As at July 2021, the cost of registering a Power of Attorney or Enduring Power of Attorney at the Land Titles Office was \$149.32. Revocation cost was \$116.32

It is important to remember that the *general* powers an Enduring Power of Attorney assigns are activated as soon as it is registered unless, for example, you have stipulated in your document that they do not take effect until you lose cognitive capacity (enter the "enduring" phase). If you prepare an Enduring Power of Attorney when you are "of sound mind" but do not register it, the person (or people) you have nominated as your attorney(s) can register it for you if you lose cognitive capacity.

You can revoke a Power of Attorney but for the revocation to take effect it, too, must be registered at the Land Titles Office.

Finally, we strongly advise that you ensure the person (or people) you nominate as your attorney not only understand your wishes but understand that their appointment does not allow them to treat your financial assets as their own.

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At the time of writing this document, Tasmania Legal Aid's Senior Assist service was preparing an information sheet for people appointed as attorneys. If you would like a copy, please contact Legal Aid (<https://www.legalaid.tas.gov.au/>).

Expressing your wishes about health and lifestyle matters

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 to complete concerning medical and lifestyle matters are the Enduring Guardianship and Advance Care Directives. Enduring Guardianship is provided for in Tasmanian State legislation, the *Guardianship and Administration Act 1995*. Advance Care Directives are used by many health care organisations, a few of which might still refer to them as Statements of Wishes. Although a standard Advance Care Directive form is increasingly being adopted, a variety of Advance Care Directive 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 he or she finds when treating.

Overview

The Enduring Guardianship and Advance Care Directive are two ways of setting out your treatment wishes in a range of 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 Enduring Guardianship, person responsible in the case of an Advance Care Directive) who will have the power to make decisions about your treatment if you are unable to express these for yourself. Note that the guardian or person responsible cannot make decisions that are inconsistent with the written wishes stated in your Enduring Guardianship or Advance Care Directive. However, if you do not include any conditions in your Enduring Guardianship, your guardian will have full power as set out in Section 25 of the Act. (https://www.guardianship.tas.gov.au/_data/assets/pdf_file/0007/207619/11_Infosheet_Enduring_Guardians_Jan_2014.pdf)

You may also specify in either document 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 documents come into effect only when you are unable to speak for yourself.**

There are two essential differences between Enduring Guardianship and an Advance Care Directive:

- 1 Enduring Guardianship enables you to give a trusted person (or people) the legal power to make lifestyle decisions for you (such as accepting or refusing particular medical treatments, accommodation or visitors) consistent with your expressed wishes if you are unable to express those wishes yourself. An Advance Care Directive is a set of instructions from you about your future health care and treatment. (https://www.health.tas.gov.au/palliativecare/advance_care_planning_for_healthy_dying/advanced_care_directive_information_sheet). It does not require you to nominate a person responsible, but you may specify one or more if you wish. If you have an Advance Care Directive 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 or friend who has both a close personal relationship and a personal interest in the patient's welfare.

- 2 Enduring Guardianship, being prepared under specific legislation, is statutory law, whereas all forms of Advance Care Directive are what is known as common law documents. In April 2021 legislation was introduced to the Tasmanian Parliament that will give Advance Care Directives legal status when it is enacted. Enduring Guardianship is a legal document only within Tasmania (but is likely to be accepted elsewhere as a clear guide to patient wishes) whereas an Advance Care Directive applies anywhere in Australia and probably in most other countries. Any problems of interpreting or applying an Enduring Guardianship are dealt with by the Guardianship and Administration Board, while any issues of interpreting or applying an Advance Care Directive must currently be dealt with by a court. This will change when legislation is passed.

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 Enduring Guardianship it is very important that any institution requiring that you also complete an Advance Care Directive is aware of your Enduring Guardianship and that the new Advance Care Directive is completed in accordance with any wishes expressed in your Enduring Guardianship. If you make an Advance Care Directive that is different from your existing Enduring Guardianship, you must explicitly state that the Advance Care Directive must be followed, not the Enduring Guardianship. In addition, you must formally revoke your Enduring Guardianship and lodge the revocation with the Guardianship and Administration Board via Service Tasmania.

Both Enduring Guardianship and Advance Care Directives 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. Enduring Guardianship does not *require* that you complete the section in which you express these wishes, **but we very strongly recommend that you do so**. Advance Care Directive 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 and/or person responsible, 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., late-stage dementia or severe intractable pain) than the medical condition itself (e.g., Alzheimer'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.

Attachment 7 contains an extremely useful table comparing Enduring Guardianship, Advance Care Directives and Medical Goals of Care that was originally released through the Better Access to Palliative Care Program (BAPC). While the main focus is palliative care, the comparison is a useful guide in all forms of treatment, as it shows how the three documents complement each other.

Enduring Guardianship

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 them. 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 Advance Care Directive. 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 document for appointing an enduring guardian is completely distinct from the Power of Attorney above and the Enduring Guardianship document must be lodged with the Guardianship and Administration Board (via Service Tasmania) for it to be valid. You need to also make copies for your patient file with your GP and any treating specialist and your enduring guardian, and also a copy 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 document, clearly stating it revokes the existing document, and register it at Service Tasmania. The original will be filed and you will receive a copy.

A registration fee applies when you make an Enduring Guardianship and any time you change or revoke one. As at July 2021, the fee for registering an Enduring Guardianship was \$74.25. You can apply to the Guardianship and Administration Board to waive these fees.

Attachment 3 has a copy of a standard Enduring Guardianship form and accompanying information sheet. More details, including copies of forms (<https://www.guardianship.tas.gov.au/forms2>) and fact sheets (https://www.guardianship.tas.gov.au/publications_/factsheets), are available from the Guardianship and Administration Board website.

COTA Tasmania strongly encourages you to seek legal advice when preparing an Enduring Guardianship. Alternatively, you can seek assistance from the Guardianship and Administration Board or the Public Trustee.

The Public Trustee can prepare Enduring Guardianship documents for you for a fee. As at April 2021, it charged \$140 per person or \$210 for a couple.

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 Guardianship and Administration Board for resolution. It is also possible to go to the Medical Council if a doctor refuses to follow directions in an Enduring Guardianship document.

You can appoint both a primary and one or more alternative enduring guardians. If you are of advanced age, it would be desirable for you to appoint at least an alternative guardian of a younger generation. For example, many people appoint their spouse as primary enduring guardian and a child or younger close friend as alternative enduring 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 Enduring Guardianship document.

The role of enduring guardian is a substantial responsibility. The process of deciding your wishes, selecting your enduring guardian and ensuring your enduring guardian understands the issues that may arise should be undertaken thoroughly and carefully. **Attachment 5.1** 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 Advance Care Directives. These set out your treatment wishes in case you are unable to make decisions for yourself at the time when treatment is needed. A standard form is included in this booklet (see **Attachment 4**) and copies may also be downloaded at: https://www.dhhs.tas.gov.au/_data/assets/pdf_file/0008/129455/FT021550_Advance_Care_Directive_public_20200512.pdf

If you completed an Advance Care Directive before the current 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 the services or institutions mentioned above may be asked to complete an Advance Care Directive 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 Enduring Guardianship, it is very important that anyone wishing you to complete an Advance Care Directive is aware of this and any wishes expressed in the Advance Care Directive be fully consistent with those in the Enduring Guardianship (or a new Enduring Guardianship prepared if the Advance Care Directive is a more accurate statement of your wishes). The standard Advance Care Directive form referred to above does not include a section for you to include information about your enduring guardian, but you may wish to include a nominated responsible person on the form.

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. Make sure that a copy of the Enduring Guardianship is filed with the new Advance Care Directive.

If you are unable to complete an Advance Care Directive, the form can be completed on your behalf, but the risk is that it 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 in the future may be prepared to create a record for you with your Advance Care Directive or Enduring Guardianship on file, even if you have not been admitted there in the past.

Medical Goals of Care

As mentioned in the introduction, Medical Goals of Care forms are progressively being introduced. Medical staff use them to record which of four alternative goals of care (ranging from curative to comfort for the dying) are appropriate for your 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 you have the right to satisfy yourself that it fully takes account of your directions in an Advance Care

directive or Enduring Guardianship 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 counterproductive.

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 Guardianship or Advance Care Directive, which would strengthen the hand of your enduring guardian or person responsible to see that your wishes were 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.

You can also register with the organ donation registry which gives you the option to select the organs you wish (or do not wish) to donate. To do this go to <https://www.donatelife.gov.au/join-register>

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 College of Health and Medicine runs a Body Bequest Program through which people can “donate their body to sciences”. Details and forms are available at <https://www.utas.edu.au/health/community-programs/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. <https://www.choice.com.au/money/insurance/life/articles/funeral-insurance>

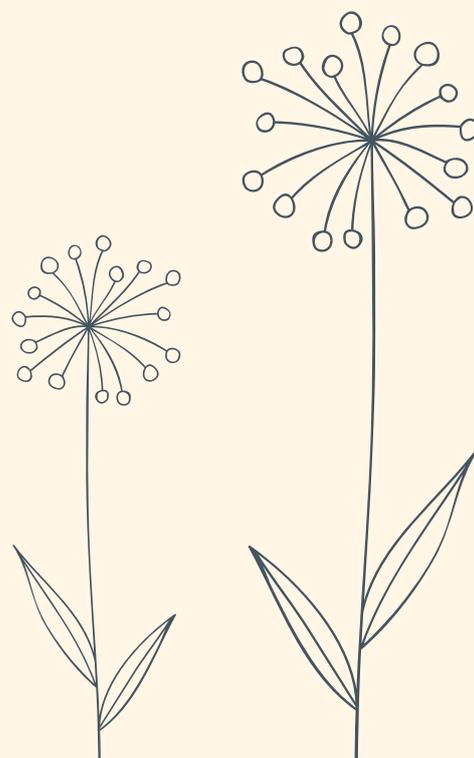
It suggests that either paying a lump sum for a pre-paid funeral or paying premiums similar to those you would otherwise pay for funeral insurance into life insurance are both likely to be a better choice for most people. In Tasmania, provision for pre-paid funerals is regulated under an Act administered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

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Services Australia has a very valuable guide to required action and forms of support available following death of another (<https://www.servicesaustralia.gov.au/individuals/subjects/death-and-bereavement/what-do-when-someone-dies>)

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COTA Victoria has produced a document called *Death of a Partner, A Practical Guide for Partners and Family*, which is available on their website <https://www.cotavic.org.au/wp-content/uploads/sites/2/2019/04/Death-of-a-Partner-V3pdf.pdf>



Attachments

ATTACHMENT 1

Simple form for listing of key end-of-life documents..... 21

ATTACHMENT 2

Enduring Power of Attorney 27

ATTACHMENT 3

Enduring Guardian 28

ATTACHMENT 4

Advance Care Directive 29

ATTACHMENT 5

5.1 Step by Step Guide to writing an Advance Care Directive (ACD)
or appointing an Enduring Guardian (EG)..... 30

5.2 Guide to the Role of (Enduring) Guardian (or Person Responsible) 32

5.3 Some notes on the common law and issues for doctors in the
context of patient autonomy and consent 34

5.4 Some common questions and answers 35

ATTACHMENT 6

Examples of health care directions to consider for inclusion in
Enduring Guardianship or Advance Care Directive 36

EXAMPLE A Enduring Guardian or Advance Directive wishes..... 37

EXAMPLE B Enduring Guardian or Advance Directive wishes..... 38

EXAMPLE C Enduring Guardian or Advance Directive wish list 39

SECTION D Examples of wishes you may consider for your
Enduring Guardianship or Advance Care Directive 40

ATTACHMENT 7

Advance Care Directive 41

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.

Organisation	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)		

Organisation	Name	Contact
Insurance policies (property, life, endowment, funeral etc)		
Location of House Title (and other key ownership documents)		
Health Directives (Enduring Guardian, Advanced Health Care) and where copies are kept.		
Shares and shareholder reference number		
Other people to notify (e.g. relations/friends, GP, Centrelink, clubs, church, Tax Office)		

Computer/internet accounts

Many people have a range of internet accounts for communicating, shopping online, photo sharing, genealogy and many other purposes.

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

The rules outline whether family or executors can access or close accounts and remove online information, as well as any evidence that may be required.

- » Some services simply terminate the account upon death.
- » Others may allow you to access, backup or remove your late partner's content.
- » Facebook allows relatives of a deceased person to "memorialise" an account so people can still see it, but it can't be logged into.

It is best to check the policies or terms or conditions of the relevant services. **Everplans** offers instructions on how to cancel accounts with more than 230 different online services: <https://www.everplans.com/articles/how-to-close-online-accounts-and-services-when-someone-dies>

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). It is wise to keep a copy with your Will and/or with your Attorney.

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 found on the following page.

Service	Login details	Instructions/comments
	Username: Password:	

Pensioner or other concession card and health cards

Card type	Card number	PIN	Comments

Other accounts

Account type	Card number	PIN	Comments

Other data

E.g. enduring guardian registration, organ donor, prosthesis identification

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ATTACHMENT 2

Enduring Power of Attorney



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**.

For further information on Enduring Powers of Attorney

- » <https://www.legalaid.tas.gov.au/factsheets/enduring-power-of-attorney/>
- » <https://www.publictrustee.tas.gov.au/enduring-power-of-attorney/>

Links to the relevant Enduring Power of Attorney forms

- » General Enduring Power of Attorney (Form 4)
- » Registration Application (Form 5)
- » Lodgement Form
- » Your Guide to Enduring Powers of Attorney (Forms 3 & 4)

<https://dipwe.tas.gov.au/Documents/Form-4-General-Enduring-Power-of-Attorney.pdf>

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.

For further information on Enduring Guardianship

Legal Aid for Tasmania

<https://www.legalaid.tas.gov.au/factsheets/enduring-guardianship/>

Guardianship and Administration Board

<https://www.legalaid.tas.gov.au/factsheets/enduring-guardianship/>

Public Trustee

<https://www.publictrustee.tas.gov.au/enduring-guardianship.html>

Links to the relevant Enduring Guardianship forms

Cover Sheet for Service Tasmania

https://www.guardianship.tas.gov.au/__data/assets/pdf_file/0016/246103/F19-Enduring-Guardianship-Coversheet.pdf

Enduring Guardian Instrument

https://www.guardianship.tas.gov.au/__data/assets/pdf_file/0003/336666/Instrument_Appointing_Enduring_Guardian_Oct_2014.pdf



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 5.1** may help you in framing your wishes.

Some services and facilities require completion of an Advance Care Directive when you access them. If so and you do not already have an Advance Care Directive, 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 has fees for registering or revoking an Enduring Guardianship – at July 2021 \$74.25 for registration and \$52.80 for revocation of an Enduring Guardianship. Please note that these fees are subject to change and are a guide only.

An Advance Care Directive can be developed and registered without charge at June 2021. This may change when legislation to formalize Advance Care Directives is passed in Parliament and becomes law.

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.

For further information about Advance Care Directives

Advance Care Directive Information sheet

https://www.health.tas.gov.au/palliativecare/advance_care_planning_for_healthy_dying/advanced_care_directive_information_sheet

Advance Care Planning Australia

<https://www.advancecareplanning.org.au/>

Link to an Advance Care Directive forms

Tasmanian Advance Care Directive:

https://www.dhhs.tas.gov.au/__data/assets/pdf_file/0008/129455/FT021550_Advance_Care_Directive_public_20200512.pdf

People who are important to me

https://www.health.tas.gov.au/__data/assets/pdf_file/0020/411842/People_who_are_important_to_me_-_ACD_resource_21052020.pdf



Note

Under current circumstances we 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, or wish to complete an Advance Care Directive, it should be completely consistent with the wishes stated in your Enduring Guardianship.

ATTACHMENT 5.1

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

Step one

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.

Step two

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

Step three

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.

Step four

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 Enduring Guardian or Advance Care Directive 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.

Step five

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 Advance Care Directive provides almost as much certainty that your wishes will be followed.

Step six

Write an Advance Care Directive or an Enduring Guardian (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.

Step seven

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

Step eight

Tell your doctor, your family and other people who you think should know that you have made an Advance Care Directive or Enduring Guardian. 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.

ATTACHMENT 5.3

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**

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Note

This is general information only and is not an authoritative statement of the fairly complex law in this area. Legal advice should be sought when dealing with specific issues of this nature.

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 judgment 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.

ATTACHMENT 5.4

Some common questions and answers

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

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](#).

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?

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.

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

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.

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

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.

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

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 Enduring Guardianship or Advance Care Directive.

If 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.

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), recognizing 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 Witness 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".

The examples are to illustrate what you may consider and possible wording in your Enduring Guardianship or Advance Care Directive.

- » **Example A** is perhaps the briefest statement that all the same gives a very clear indication of wishes. You can add your own personal wishes using the examples provided in section D that are designed to help you think through your own issues and concerns.
- » **Example B** is a slightly longer statement with additional detail and again you can add your own wishes to this example.
- » **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.
- » **Section D** provides a list of example wishes for your consideration.

Note that any service or facility that you access may have a form different from any of these.

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:

- » *Insert wish*
- » *Insert wish*



Insert your own wishes here.
The list of example wishes in Section D is designed to assist you in considering what you would like to include, but is not intended to be definitive.

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:

Specifically, in these circumstances:

- » *Insert wish*
- » *Insert wish*

The medical conditions are:

- » *Insert medical conditions here*

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

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, 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.**

SECTION D

Examples of wishes you may consider for your Enduring Guardianship or Advance Care Directive

The book "To Die Well" by Sidney Wanzer MD gives the following list of 'Wishes' that may be considered. Please note that these are examples only to act as thought starters in determining your own personal wishes.

- » 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.
- » 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.

List of possible medical conditions that you may wish to consider for inclusion:

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

ATTACHMENT 7

What to do following a death

After the death of a someone close, getting through the red tape can be challenging — so it's important to look after yourself. We have provided some information and links below that provide helpful, practical information.

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.

It is also important to contact the legal firm where the Will is held as they may have instructions regarding burial wishes.

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.

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.

You might want to have a look at COTA Victoria's document called Death of a Partner for some additional information:

» <https://www.cotavic.org.au/wp-content/uploads/sites/2/2019/04/Death-of-a-Partner-V3pdf.pdf>

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 Services Australia when someone has died so their records can be updated.

Services Australia has valuable information on Death and Bereavement online to assist those who are responsible for dealing with the death of another. You can find this information here:

- » <https://www.servicesaustralia.gov.au/individuals/subjects/death-and-bereavement>
- » <https://www.servicesaustralia.gov.au/sites/default/files/who-to-notify-checklist.pdf>

The Australian Tax Office also has a Deceased Estate Checklist that may be of assistance:

- » <https://www.ato.gov.au/individuals/deceased-estates/deceased-estate-checklist/>

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. 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.

For a full list of statewide services in Tasmania the following link is helpful:

- » <https://bcntasmania.org.au/index.php/directory-of-services/statewide-services>

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.

For information about community activities and events in your areas see COTA Tasmania's Community Activity online information:

- » <https://www.cotatas.org.au/information/activities/> or call us on **03 6231 3265**.

Health and Support at Home

Taking care of your diet and regular exercise can assist you to re-establish a routine. 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. For information about Government supported aged care call My Aged Care on 1800 200 422. For assistance navigating the aged care system please contact COTA Tasmania on 03 6231 3265.

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 Services Australia Financial Information Services Officer who can give you information about how any decisions you make could affect the payment you receive from Government. Call the Older Australians line on 132 300.



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