Health
Hunter New England
Local Health District

Advance Care Planning

Advance Care Planning is a process of thinking about, planning and recording what is important to you and discussing and/or documenting this, with your family, significant others and your medical team.

An Information Package

April 2017

Contact Phone Numbers

Armidale Hospital	Other
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Aboriginal Liaison Officer Tel 02 6776 9670 Mob: 0434 604 475	**NSW Trustee & Guardian** Tel: 1300 364 103 www.tag.nsw.gov.au
Renal Social Work Tel: 02 6776 9896 Mob: 0428 540 975	**NSW Office of the Public Guardian** Tel: 1800 451 510 www.publicguardian.justice.nsw.gov.au

All information contained in this booklet has been sourced from NSW Health, NSW Trustee and Guardian, NSW Office of the Public Guardian and the NSW Ambulance Service

The example of an Advance Care Directive located at the back of this booklet has been developed with legal assistance. There are many examples of Advance Care Directives and these resources are available from a number of sources. If you would like more information on Advance Care Directives please contact the Social Work Department on one of the numbers listed above.

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Definitions

Advance Care Planning (ACP) – ACP is a process of thinking about what is important to you and your lifestyle then discussing these things with your family, friends, doctor, spiritual advisor and/or legal representative. ACP should become part of your regular discussions with those closest to you. It may result in a written record of your preferences in either an Advance Care Plan or an Advance Care Directive (sourced from Medicare Local Central Coast NSW)

Advance Care Directive (ACD) – sometimes called a 'living will', is a document that describes one's future preferences for medical treatment in anticipation of a time when one is unable to express those preferences because of illness or injury. Completion of an ACD ideally should be one component of the broader advance care planning process.

End of Life (terminal) Care – a form of palliative care that is appropriate when the individual is in the final days or weeks of life and care decisions may need to be reviewed more frequently. Goals are more sharply focused on the individual's physical, emotional and spiritual comfort needs and support for the family.

Enduring Guardian – is a substitute decision maker that an individual appoints under the Guardianship Act 1987 (NSW) to make lifestyle and/or other health care decisions should the individual lose the capacity to make their own decisions at some time in the future. The terms of all enduring guardianship appointments must be carefully checked to ensure that the enduring guardian has the authority (called 'functions') to make the particular decision at hand.

Power of Attorney – is a legal document which appoints a person (the attorney) to make decisions about a person's financial affairs, such as accessing bank accounts or selling land. A Power of Attorney can only be used to make financial decisions; it cannot be used to make medical or lifestyle decisions.

Enduring Power of Attorney - an Enduring Power of Attorney is a Power of Attorney that continues to be effective even if the person loses mental capacity. The decision to appoint Enduring Power of Attorney or Power of Attorney requires careful conversation with family or others who may be involved as they can act on your behalf at any time. An application can be made to the Guardianship Tribunal to review the appointment if it is no longer in the best interests of the person. The Tribunal has the power to vary or revoke such arrangements.

Capacity

Capacity is the ability to make decisions for oneself.

A person has capacity when they can go through the process of making their own decisions by:

- understanding the information and choices presented
- weighing up the information to determine what the decision will mean for them
- communicating that decision.

If a person is unable to follow this process and make their own decisions, that person is said to lack capacity.

Family – can be considered as any person who is part of the central core in the support network of an individual, including carers. A definition of family is 'those closest to the patient in knowledge, care, and affection'. This includes the biological family, the family of acquisition (related by marriage/contract), and the family of choice and friends (not related biologically, by marriage/contract). Based on this definition, family could include carers, friends, and neighbors and extends the boundaries beyond biological and legal relationships.

Carers – usually family members and sometimes friends. Their work is based on a pre-existing relationship and is unpaid and often unrecognised. The primary carer is the person who has provided the most informal assistance to the person in relation to self-care, mobility and communication. When the word 'family' is used, it also includes carers.

Person Responsible – the role of the 'person responsible' is to make substitute decisions that consent to, or refuse consent to medical treatment for someone who lacks capacity to consent/refuse. This person is required to have regard to the views of the patient but they are not bound to follow them. The 'person responsible' replaces the old term 'next of kin' as the person from whom consent for active treatment in the incompetent patient must be sought. The 'person responsible' is determined according to the hierarchy within the Guardianship Act 1987 (NSW). Health professionals are obliged to seek consent from the 'person responsible' and can give them the same information they would have given the patient if they had been able to consent themselves (See over for flow chart).

Informed Consent – the voluntary and informed agreement by an individual required before the commencement of a medical procedure, test, or medication.

Residential Aged Care Facility (RACF) – residential aged care is for older* people who can no longer live at home. Reasons include illness, disability, bereavement, an emergency, the needs of the carer, family or friends, or because it is no longer possible to live at home without help. RACFs can provide either permanent or short-term care. Short-term is referred to as 'respite care'. There are two broad types of aged care – low level and high level care:

- Low level of care homes (formally known as hostels) generally provide accommodation and personal care, such as help with dressing and showering, together with occasional nursing care.
- High level care homes (previously known as nursing homes) care for people with a greater degree of frailty, who often need continuous nursing care.

**There are instances where younger people with disabilities receive care in aged care homes*

‘Person Responsible’ Hierarchy (Guardianship Act 1987)

The ‘person responsible’ is determined according to the hierarchy within the Guardianship Act 1987 (NSW) and in the following order:

- An appointed guardian (enduring guardian) with the function of consenting to medical and dental treatment.

If there is no-one in this category:

- A spouse or de facto spouse who has a close and continuing relationship with the person.

If there is no-one in this category:

- The carer or person who arranges care on a regular basis and is unpaid (the carer pension does not count as payment).

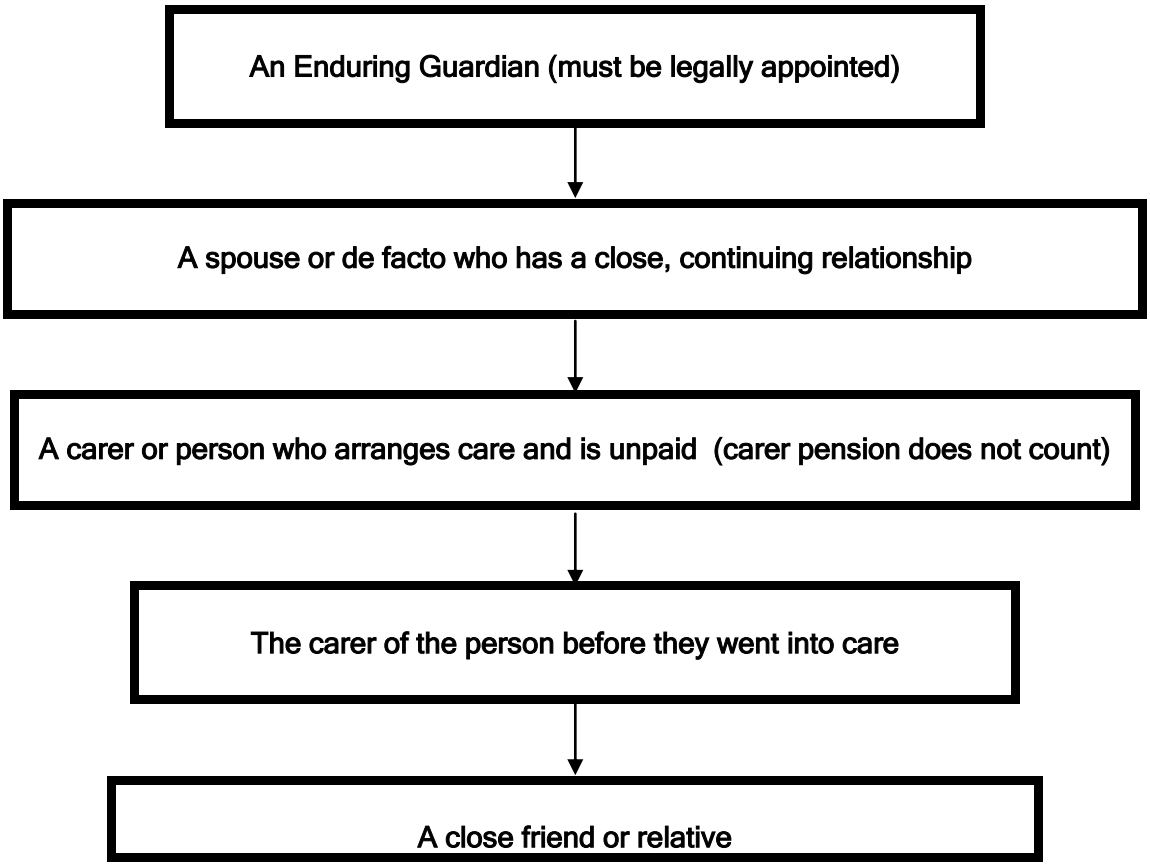
If there is no-one in this category:

- The carer of the person before they went into residential care.

If there is no-one in this category:

- A close friend or relative.

Hierarchy Flowchart



Information Sheet Advance Care Planning	*Information for patients and their families about Advance Care Planning at Armidale Rural Referral Hospital*

The goal at Armidale Hospital is to ensure that patients receive the best care possible. We aim to do this by supporting patients and their families in talking about their medical care and treatment. Some people may want to be very involved in having these discussions. Some people may not want to discuss this at all. It is your choice as to how involved you wish to be.

What does this mean?

Staff at Armidale Hospital would like to talk with you and your loved ones about your understanding of:

- Your health problems and which one/s you think affect your life the most
- The things you need to do to manage your health problems on an everyday basis
- Any questions or care preferences you might have about your health problems and how they might affect you in the future.

This is called Advance Care Planning

Why would I want to talk about this?

No one plans on getting sick. We never know exactly if or when we are going to be ill, or how it will affect us.

Sometimes people are too ill to be able to talk with their doctors about their health problems or to discuss the treatment that is needed to manage their illness when they come into hospital.

If you cannot talk yourself, or cannot understand the treatment you need, then your doctor has to talk about your treatment with someone close to you. This is called substitute decision making.

What happens if I can't make my own decisions?

Your substitute decision maker is the person who can say 'yes' or 'no' to offered treatment on your behalf and is decided by the NSW Guardianship Act.

Your 'next of kin' might not be the same person as your legal substitute decision maker. The legal term for a substitute decision maker is **person responsible** and there is a special order (hierarchy) that identifies who is your 'person responsible'.

You might want to know more about who your 'person responsible' is. Please ask staff caring for you for a free information factsheet to learn more about the 'person responsible' role.

Can I choose who I want to make medical decisions for me?

Yes, you can choose to legally appoint one or more 'enduring guardian/s' to make medical decisions on your behalf when needed. This legal process needs a lawyer or Registrar of Local Court to witness the paperwork. Please ask staff caring for you for a free 'Enduring Guardian' factsheet to learn more.

Please ask for a 'Guide for Substitute Decision Making' factsheet if you would like to know more about being a substitute decision maker.

Understanding Advance Care Planning

How will talking about these things help me?

You are the best person to make decisions about yourself. Many people who live with health problems everyday have some firm ideas about what they would and would not want to happen with their care.

Talking with your family and others about what life is like for you everyday and the things that are important to you will help them to understand how you make your own decisions.

Many people feel that if they got sick their loved ones would 'know what I want'. Studies show that families make choices that are often different to what you would choose for yourself. Talking about your 'care wishes' if you become ill, helps your family to make choices that are in line with the choices you would make for yourself. If you would like more information about the types of things you can talk about with your family, please ask staff for a 'values worksheet'.

How will others know what I want?

You can talk about:

- who you want to be your decision-maker
- what goals, values and beliefs are important to you when making decisions for yourself
- your experiences of and wishes for healthcare treatments.

Talking is really important, and generally people will remember some of what you have said. You can also write your care wishes down in an Advance Care Directive.

What is an Advance Care Directive?

An advance care directive is a written record of your wishes for future care and medical treatments.

It may include statements about your values, beliefs and goals of medical treatment, and often specifically records end of life care preferences.

An advance care directive does not get used UNLESS you are unable to make medical decisions for yourself. It is used to guide substitute decision making if you are unable to speak for yourself.

An advance care directive can be changed or withdrawn (revoked) at any time, while you are able to make and understand your own medical decisions.

The medical team will discuss your care with your loved ones before making any decisions. They will confirm that these decisions are consistent with what you have discussed with your substitute decision maker.

An advance care directive can be written however you like. There is no one form that you must use. Hunter New England Local Health District staff are required to record advance care planning discussions they have with you or your loved ones in your medical record. You are able to ask for a copy of documented discussions if you wish.

Please ask staff caring for you if you would like some advance care directive samples.

Do I have to do advance care planning?

No. All people in Armidale Hospital are given this information and asked if they would like further discussion. It is your choice whether you wish to discuss advance care planning during your stay.

Families/carers are welcome to ask for further information if they would like to know more.

Notes and To Do List

Understanding Levels of Care

As medical technology has enabled an increased ability to keep people alive by mechanical or artificial means, our ageing and frail elders may be sustained longer than they wish to be.

Coupled with capacity loss (via ageing, illness, accident or stroke) health care decisions fall to families, friends and physicians who may not be aware of the patient's wishes if advance care planning has not occurred in the context of the resident's care.

The 'default' level of care (where families are unsure of what to do) is invariably hospitalisation in an acute facility. Defaults may also involve artificial life support, such as ventilation, PEG feeding, CPR or other invasive treatments.

Dr D William Molloy (Canadian Geriatric Specialist) promotes the following model as a means in which discussion around the stages of care can be readily explained to patients and/or their substitute decision-makers.

Molloy Level of Care	What generally occurs at this level
Palliative Care (comfort Care)	• Keep me warm, dry and pain free • Do not transfer me to hospital unless absolutely necessary • Only give measures that enhance comfort or minimise pain • Start an intravenous line only if it improves comfort • No x-rays, blood tests or antibiotics unless they are given to improve comfort
Limited Care (includes comfort/palliative care)	• May or may not transfer to hospital • Intravenous therapy may be appropriate • Antibiotic use should be limited • A trial of appropriate drugs may be used • No invasive procedures • Do not transfer to intensive care unit
Active/Surgical Care (includes limited care)	• Transfer to acute care hospital (where evaluation may occur) • Emergency surgery if necessary • Do not admit to intensive care unit • Do not ventilate (except during and after surgery)
Intensive Care (includes active care)	• Transfer to an acute hospital without hesitation • Admit to intensive care unit if necessary • Insert central line • Provide surgery, biopsies, all life-support systems and transplant surgery • Do everything possible to maintain life
Artificial Feeding and Hydration	Provision of fluid and or liquidised nutrients by artificial means. If the patient is unable to swallow, eat or drink. Feeding occurs via tubes inserted: • Via the nose • Via direct insertion of a tube into the stomach • Via a tube inserted into a vein (If the patient does not have artificial feeding or fluids, they will still have mouth care by which the mouth is kept moist)
Dialysis	Treatment aimed at replacing the function of kidneys, that being removal of toxic waste products from the body via urine.

Advance Care Planning

Assisting families with understanding levels of care

"It is important to reinforce with patients and their families, during the advance care planning process, that the patients will never be abandoned in care".

The foundation of good 'discussion' revolves around a mutual understanding of the terminology and phrases. Here are some helpful terms that may feature in advance care planning discussions.

Term	Explanation
Terminal	A condition that will result in death; the patient can reasonably be expected to die from the disease. This prognosis is generally confirmed by a second medical practitioner.
Irreversible	A condition that is unable to be turned around; there is no possibility that the patient will recover. For example, motor neurone disease
Incurable	A condition by which there is no known cure
Permanent unconsciousness (Coma)	A condition whereby brain damage is so severe that there is little or no possibility that the patient will regain consciousness
Post coma unresponsive (PCU of PVS)	An irreversible condition by where wakefulness and sleep cycles are present, as well as other bodily functions, but the person is totally unconscious, unaware of surroundings and unable to experience pain

Clarifying for discussion what 'life-sustaining' measures are:

Life sustaining measure	What occurs at this level
CPR (Cardio-Pulmonary resuscitation)	Treatment aimed at providing artificial ventilation (air flow) via mouth, mask to mouth or tube down throat to maintain breathing. Cardiac (heart) compression is by pumping compressions to chest or electrical stimulation. (Statistics regarding survival rates may be useful to explain as well)
Assisted ventilation	Use of a machine (ventilator) to assist the patient to breathe, if they cannot breathe spontaneously

Molloy D.W: 2004: "Let Me Decide-The Health and Personal Care Directive that speaks for you when you can't." British Columbia Edition. Vancouver Island Health Authority

Information Sheet Power of Attorney	*Understanding the roles and responsibilities of a 'Power of Attorney' to manage your financial affairs*

What is a Power of Attorney?

A Power of Attorney is as important for life planning as making a Will. Many people prepare a Will but do not give the same consideration to appointing an attorney until it is too late. Appointing an attorney gives your attorney the legal authority to look after your financial affairs on your behalf.

You can appoint an attorney to act for you in a variety of circumstances such as an extended interstate or overseas trip, or for a time when you are no longer able to manage your affairs. NSW Trustee and Guardian is able to act as your attorney and can help you identify the type of attorney service that suits your needs.

NSW Trustee and Guardian provides Power of Attorney so you can appoint an independent, impartial and skilled asset manager to manage your financial affairs.
NSW Trustee and Guardian offers:

- **Future Assist** : A Power of Attorney designed to provide you with a safety net should unforseen events occur;
- **Active Assist**: A Power of Attorney where you are able to choose the level of assistance you require.

There are many reasons to consider using a Power of Attorney:

- you may wish to be free of the day to day demands of financial paperwork and record keeping;
- you may want to place funds in a secure account with interest calculated daily and flexible access;
- you may be going overseas or around Australia and don't want to deal with these affairs while you're away;
- you may not wish to burden a family member or friend with the responsibility of looking after your financial affairs;
- or you may simply find the demands of financial management have become too much for you to handle on your own.

What is an Enduring Power of Attorney?

An ordinary Power of Attorney cannot continue to be used by your attorney after you have lost capacity to deal with your financial affairs. An Enduring Power of Attorney continues after you have lost capacity. This is important for everyone, but particularly for elderly people. In NSW, a Power of Attorney can only apply to financial or legal matters. Matters your attorney is able to handle include receiving income, paying bills, taxation and contractual issues, investment or property management.

Should you require someone to make decisions relating to where you live, who you live with, what health care you receive, and daily issues like diet and dress, you will need to appoint an Enduring Guardian. A separate document is required to do this. The person you appoint will be able to make decisions about your lifestyle and general welfare when you no longer have the ability to do this for yourself.

Who can Witness a Power of Attorney?

Recent changes to the Power of Attorney legislation have resulted in new, more specific requirements for witnesses of an Enduring Power of Attorney. At the end of all Enduring Power of Attorney forms there is a prescribed witness certificate. This certificate can only be completed by:

- Solicitor or barrister
- Registrar of a NSW Local Court
- A licensed conveyancer who has completed an approved course under the Powers of Attorney Act, or
- An employee of NSW Trustee and Guardian or a Private Trustee company who has completed an approved course under the Powers of Attorney Act.

The certificate states that the witness:

- explained the effect of the Power of Attorney directly to you before it was signed;
- was satisfied that you appeared to understand the effect of the Power of Attorney.

If the Witness has any doubts about your ability to understand what you are signing, they are required to take reasonable steps to confirm your mental capacity.

The witness who signs the certificate cannot be the attorney but a solicitor or other accredited employee at NSW Trustee and Guardian may be a witness. NSW Trustee and Guardian can only assist you when we are appointed attorney or substitute attorney. Every branch of NSW Trustee and Guardian has staff who are qualified to act as witnesses, ensuring that using NSW Trustee and Guardian's Power of Attorney is simple and professional.

Where Do I Start?

NSW Trustee and Guardian has 18 branches and also the Registrars of the Local Court who act as our agents throughout NSW. Should you have any further questions relating to Powers of Attorney or wish to make an appointment to take out a Power of Attorney with the NSW Trustee and Guardian you can contact your nearest branch of the **NSW Trustee and Guardian by calling 1300 364 103.**

Information Sheet Person Responsible	*Understanding the roles and responsibilities of a 'person responsible' for substitute decision making in healthcare*

Medical and dental practitioners have a legal and professional responsibility to get informed consent to treatments before treating any patient.

Usually, you (the patient) will be able to consent or decline the treatment that is being offered to you. If you are too sick, or injured, and you lack the capacity to make your own medical treatment decisions, then your doctor will need to seek consent from a substitute decision-maker. This person is called a 'person responsible'.

What does 'person responsible' mean?

Before 1987, substitute consent was sought from a person's 'next of kin'. When the NSW Guardianship Act was accepted in 1987, the legal term 'person responsible' replaced the more commonly used term 'next of kin'.

A 'person responsible' is determined on the basis of the relationship that they have with the person who is incapable of giving consent. This means that your 'persons responsible' may be someone who is not a member of your biological (blood) family.

Who is a 'person responsible'?

The Guardianship Act sets out a legal order/ hierarchy that guide doctors and dentists of who could be considered a 'person responsible'. If you lack the capacity to make your own medical decisions then your doctor uses this legal order to decide who would be a 'person responsible' for you.

Your doctor will determine a 'person responsible' for you, and will ask this person to accept or not accept the medical treatment the doctor is recommending.

Unless you have legally appointed someone to be your ***'enduring guardian'***, you cannot choose who your 'person responsible' is, and someone cannot volunteer to be your 'person responsible'. *(Please refer to fact sheet on Enduring Guardianship for more information.)*

How do you determine a 'person responsible'?

Your doctor will determine your 'person responsible' using the following legal order.

They will ask for a substitute consent from:

Firstly, a person who has been appointed as your guardian (including enduring guardian) who has permission to give consent for your medical treatment.

If there is no one at this level, then:

Secondly, your most recent spouse, de facto or same sex partner that you have a close and continuing relationship with.

If there is no one at this level, then:

Thirdly, the person who arranges care for you on a regular basis (called a carer), who does not receive payment from you to provide this care. Note: The Carer's Allowance does not count as payment.

If you go into residential care, it would be the person who provided regular care for you **before** you went to live in residential care.

If there is no one at this level, then:

Finally, if there is no one in any of the above levels, it is a close friend or relative that you have a continuing relationship with.

Can anyone be a 'person responsible'?

A 'person responsible' must be over 18 years of age, have capacity to make decisions and cannot be under guardianship orders themselves. *Enduring guardian appointments are not guardianship orders.*

What is capacity?

To have decisional capacity (a legal term), a person needs to be able to clearly demonstrate (explain in their own words) that they understand:

- that they need medical treatment
- the general nature and effect of the treatment that is being offered to them
- the likely consequences of having and not having the treatment offered.

If a person cannot understand the nature or effect of the offered treatment or is unable to communicate their understanding, then they are 'incompetent' under the NSW Guardianship Act (1987).

Can someone refuse to be a 'person responsible'?

If someone is identified as a 'person responsible' and they do not want to act as a substitute decision-maker, they can decline the role and the next person in the legal order is identified. If the 'person responsible' lacks capacity to make medical treatment decisions, then the doctor will document this in writing, and identify the next person in the hierarchy.

What is the role of a 'person responsible'?

A 'person responsible' can give or withhold consent to offered medical or dental treatment of procedures on behalf of the patient who does not have the *capacity* to consent for themselves.

The 'person responsible' role is **only** active when a substitute medical/dental consent decision needs to be made and is **only** about substitute medical treatment decision-making.

The ‘person responsible’ has a responsibility to make decisions that will promote or maintain your health and wellbeing.

A ‘person responsible’ cannot consent to treatment that you are refusing. This decision needs to go to the Guardianship Tribunal.

What should a ‘person responsible’ think about when making a substitute medical decision?

A ‘person responsible’ has a right and a responsibility to know and understand:

- what the proposed treatment is
- what the risks and alternatives are
- that they can say ‘yes’ or ‘no’ to the proposed treatment
- that a second opinion can be asked for.

A ‘person responsible’ is making a substitute decision for the incompetent person. This requires them to consider:

- the wishes of the patient, and any previously expressed wishes that may be relevant to this situation
- the wishes of the patient’s family
- the consequences for the patient if the treatment does not proceed
- significant risks for the patient should be identified and considered
- alternative treatments should be considered.

A ‘person responsible’ should always understand **why** the treatment is being proposed before making any decisions.

Are there any medical decisions a ‘person responsible’ cannot make?

There are different categories of medical and dental treatment that a ‘person responsible’ may be asked to consent to (see Office of Public Guardian Person Responsible fact sheet)

A ‘person responsible’ cannot consent to:

- ‘special’ medical treatment such as reproductive therapy treatments
- treatment where the patient is objecting to receiving this treatment (unless the treatment is classed as ‘urgent’)
- treatment that does not promote and maintain your health and wellbeing.

What if I don’t have a ‘person responsible’?

If you do not have someone to act in a ‘person responsible’ role, then an application to the Guardianship Tribunal will be made on your behalf to have a public guardian make substitute decisions for you.

Information Sheet ENDURING GUARDIAN	*How to legally appoint the person who would make medical and lifestyle decisions for you, if you were unable to speak for yourself*

Planning ahead for future medical treatment decisions

In NSW, you can legally appoint the person/s that you would want to be your substitute decision-maker to make health care and/or lifestyle decisions on your behalf, should you lose the capacity (ability) to make your own decisions at some time in the future.

How does it work?

- You complete, sign and have witnessed an Enduring Guardianship appointment form. The person/s that you are appointing also need to have their signature/s witnessed on the appointment form.
- Your Enduring Guardian makes health care and/or lifestyle decisions on your behalf if you lose the capacity to make your own decisions
- Your Enduring Guardian can provide or withhold consent to a range of medical or dental treatments on your behalf, if you lose capacity.

Why would I give someone this authority?

Appointing your enduring guardian is the only way you can have control over who will make health care and/or lifestyle decisions on your behalf, if you are ever unable to do so yourself. By appointing an enduring guardian, you decide who will be included in making significant decisions on your behalf. This ensures that your views, values and experiences are put forward and considered when substitute decisions need to be made.

What types of decisions can your Enduring Guardian make?

You must choose the decision-making areas you give to your enduring guardian. These decision-making areas are called 'functions' and can include:

- Decide where you live
- Decide what health care you receive
- Decide what personal services you should have to support and assist you
- Accept or withhold consent to medical or dental treatment on you behalf.

Your enduring guardian does not have the authority to make financial decisions for you.

Are there medical decisions your Enduring Guardian cannot agree to?

Your enduring guardian can only consent to medical and dental treatment that will promote or maintain your health and wellbeing.

Your enduring guardian cannot consent to medical or dental treatment on your behalf where you are objecting to that treatment.

Your enduring guardian cannot consent to treatment that is defined as special medical treatment (see Office of Public Guardian 'Person Responsible' fact sheet).

Who can appoint an Enduring Guardian?

You can appoint an enduring guardian if you are over 18 years of age and have the capacity to make the appointment.

What is capacity?

To have capacity (a legal term) is to know what you are doing, to understand the consequences of your actions and to make choices based on your knowledge and understanding.

To have 'capacity' to appoint enduring guardian, you must understand:

- That you are appointing someone to make decisions on your behalf, should you lose capacity (ability) to make lifestyle and medical decisions for yourself
- Your enduring guardian will continue to make medical/lifestyle decisions for you as long as you lack capacity to make these decisions
- You can revoke (cancel) your enduring guardian appointment at any time, as long as you have the capacity.

Choosing your Enduring Guardian

You can appoint a person who is 18 years or over and has the capacity to make decisions.
You can appoint one or more person/s and they may each work in a different function.

The person/s that you appoint cannot be in a position where they receive payment from you for their professional services (for example your GP, Community nurse or nursing home staff).

A person who receives a Carer's Allowance as a result of caring for you is able to be appointed as your enduring guardian (refer to 'Enduring Guardianship – your way to plan ahead' booklet, available from NSW Office of the Public Guardian).

Some other things that you may want to consider in deciding who to appoint as your enduring guardian include:

- The willingness of the person to take on the role
- The person's availability
- The person's age and health.

It is important to choose someone who:

- You trust and who knows you well
- Is willing to respect your views and values (even if they don't agree with the decisions that you have made)
- Is able to make decisions under circumstances that may be difficult or stressful.

How do I appoint an Enduring Guardian?

To make an enduring guardian/s appointment, you must sign a form of appointment of enduring guardian. These forms are available from:

- The Office of the Public Guardian 1800 451 510
- Online forms are available from www.lawlink.nsw.gov.au/opg
- Advance care planning office on 4921 4776
- Lawyer, solicitor or registrar of the local court offices

You and the person/s you are appointing as your enduring guardian/s must sign the form of appointment of enduring guardian. An eligible witness must witness all signatures.

Eligible witnesses at this time are:

- A NSW barrister of solicitor
- Registrar of a Local Court
- Interstate legal practitioner

The form of appointment can be signed by different people at different times (to allow for people who are not living locally to be appointed) and each signature must be witnessed by an eligible witness each time. If you are unable to sign the form for yourself, you can instruct an eligible signer to sign the form for you. This signature also must be witnessed. The Office of the Public Guardian has a booklet available, free of charge, which explains the process of appointing an Enduring Guardian in detail. The booklet is called **Enduring Guardianship (NSW) – your way to plan ahead.** Call 4921 4776 or 1800 451 510 to have a copy sent to you.

Safeguards

You do not have to register or send the completed and witnessed form of appointment anywhere. It is a private arrangement between you and the person/s that you appoint. You should keep the original copy of the document in a safe place, and ask for certified copies of the completed document to be made, so that you can give copies to the relevant people in your life, such as the person/s you have appointed, your doctor/s family members and friends.

If an enduring guardian is not acting in your best interest, then anyone who has a genuine interest in your welfare can request the Guardianship Tribunal to review the appointment of your enduring guardian (provided that you do not have the capacity to revoke the appointment yourself). If you change your mind about your enduring guardian appointment, you can withdraw or cancel the appointment as long as you still have the capacity (ability) to do so. This revocation must be made in writing and on a *Form of revocation of appointment of enduring guardian*.

To help your enduring guardian/s understand your views about possible medical treatments, it is recommended that you talk to them about your health care preferences and you may wish to write an advance care directive or advance plan to provide written guidance of your choices to your enduring guardian and doctors.

This fact sheet has been developed in consultation with NSW Office of the Public Guardian

Information Sheet Guide for Substitute Decisions-Makers	*Information for patients and their families about Advance Care Planning at Armidale Rural Referral Hospital*

What does substitute decision-making mean?

- If you are required to act as a substitute decision-maker for someone else, it means that a loved one or friend can no longer make decisions or speak for themselves.
- As a substitute decision-maker you may be known as the 'person responsible'. This means under NSW Guardianship Law you are in a position to make medical or dental treatment decisions on behalf of someone else, but only if you agree to do so.
- As a substitute decision-maker, your role is to make decisions that you think the person would have made for themselves.
- Your decision will be based on your knowledge of the person and discussions that you may have had with them regarding the things that are important to them.
- Remember - acting as a substitute decision-maker only occurs if your loved one loses the ability to make or communicate health-care decisions on his/her own.

In general, you will have authority to make any and all decisions a patient would make for him/herself, if able. This includes:

- Receiving the same medical information the individual would receive
- Asking questions and receiving explanations about proposed tests or treatments
- Discussing diagnostic tests and their results
- Discussing treatment options and their possible outcomes
- Requesting consultations and second opinions
- Weighing up the benefits and burdens of treatment for the person you are making decisions for
- Considering all the medical tests or invasive treatments, including life-prolonging medical treatments, as part of the care plan for the person
- Authorising transfers to other doctors or treatment facilities (such as hospitals) or a residential care facility (this can only occur if you are appointed as an enduring guardian, with the authority to make lifestyle decisions)

Key points to help you as a substitute decision maker:

1. **Prepare in advance with the individual:**

   - Learn what is important to your loved one in making healthcare decisions.
   - Talk with them before he/she loses the ability to make choices.
   - Talk about values, beliefs regarding living and dying.
   - Talk about their spiritual beliefs and preferences.

2. **Make yourself and your role known to medical/healthcare staff:**

   - Make sure if the person has had an advance care plan or advance directive (if written) that it is in the person's medical chart and the healthcare team are aware of its contents.
   - Keep a copy yourself, to show people involved in your loved one's care.

3. **Stay informed about the person's condition:**

   - Medical conditions can change
   - Healthcare staff can change, daily, monthly
   - Stay involved and be flexible.

4. **Insist that someone is responsible for overall care:**

   - Identify the person who can best keep you informed of the individual's condition

5. **Keep the family informed (if appropriate):**

   - You may have the legal authority to make medical decisions even where families disagree. Most substitute decision-makers feel more comfortable if there is agreement regarding treatment amongst loved ones. Good communication fosters greater consensus.

Adapted from: ABA Commission on Law and Aging.

Further Information & Resources

Enclosed in this booklet is information for you and your family about Advance Care Planning and an example of an Advance Care Directive. You may access other Advance Care Planning information, directives and documents from the following websites:

For further information regarding Advance Care Planning and Directives click on the link to NSW Health.

Further Information can also be found at:

- http://www.hnehealth.nsw.gov.au/acp
- http://www.planningwhatiwant.com.au/Documents/userguide.pdf
- http://intranet.hne.health.nsw.gov.au/acp
- http://www.respectingpatientchoices.org.au
- www.advancecaredirectives.org.au
- http://aslarc.scu.edu.au/downloads.html

For further information regarding appointing an Enduring Guardian
Public Guardian
http://www.publicguardian.lawlink.nsw.gov.au/publicguardian/pg_index.html

NSW Trustee and Guardian
http://www.tag.nsw.gov.au/about-us.html OR
http://www.lawlink.nsw.gov.au/opg

For further information regarding appointing an Enduring Power of Attorney click on the link to
NSW Trustee and Guardian.
http://www.tag.nsw.gov.au/about-us.html

Taking Control of your Health Care Decisions *at*

www.lawsociety.com.au

Other Resources
My Health, My Future, My Choice / An Advance Care Directive for NSW. To order the book contact the Advance Care Directives Association (18/113 Johnston Street, Annandale NSW 2038 or Ph: 0423 157 003)

Guidelines for End of Life Care and Decision Making.
NSW Health. www.health.gov.au/pubs/2005/endlifecare.html

Using Advance Care Directives.
NSW Health. www.health.nsw.gov.au/pubs/2004/pdf/adcare directive.pdf

ADVANCE CARE DIRECTIVE

This directive should never be used if I have the capacity to speak competently for myself or if there is evidence that it has been revoked.

1. My Details

I, _____*(print your full name)*, of

_____ *(print your address)* freely and voluntarily make the following directives concerning my future medical and personal needs.

2. My Acknowledgements

I acknowledge:

- this is an important document;
- this document is an advance care directive which deals with my future care;
- I have read it carefully and understand it fully.

3. My Future Intentions

When the time comes that I am not able to make decisions for myself then it is my clear and stated intention that my wishes and intentions as set out in this Advance Directive are followed.

From my perspective, the most important aspect of this document is that the wishes and intentions that I have set out are followed and respected by my family, my friends and the health professionals who may from time to time treat me, even if this has the effect of shortening my life.

I want my dying and the process associated with it to be dignified and to be respected so that I die in the manner which I have decided and not what others (including health professionals) may think is in my best interests.

4. My Current Diagnosis

I have been told by my general practitioner and other treating doctors that I have

_____ *(Print your diagnosis here)*

As a result of this diagnosis I have been informed by my doctors that my life expectancy has been significantly reduced. It is because of this diagnosis that I have made this advance care directive.

5. My Future Care

In treating me for my current diagnosis I direct that any doctor or health professional follow and respect my wishes in relation to the following whether I am conscious or unconscious:

A. Please complete the details below by circling the option you **do want**, as appropriate

- I **do/do not** want to be resuscitated by emergency means or artificial measures;
- I **do/do not** want my breathing to be assisted by any artificial means;
- I **do/do not** want to be fed by an artificial means including tubes;
- I **do/do not** want to receive fluids including water by any artificial means including tubes;
- I **do/do not** want food or drink to be "forced" on me.

B. Please write out below any other direction regarding your future care in the space below:

Other directions

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

6. My end of life/palliative care

There will come a time when my current diagnosis will bring my life to an end. In the time prior to my death:

Here insert specific wishes relating to end of life and palliative care

_____

_____

_____

_____

_____

_____

_____

7. My Treating Doctor

I have asked one of my treating doctors to complete the details below:

I, _____ *(name of my doctor)*

of _____ (my doctor's address)

declare the following:

- I am registered to practice medicine in New South Wales;
- I have read this document and discussed it with

  _____ *(doctor to print my name here)*

- In my opinion _____ _____ *(doctor to print my name here)* has the necessary capacity to understand the nature and effect of the document and its implications in terms of his/her future health care.
- I am not related to _____*(doctor to print my name here)* nor am I his/her Enduring Guardian, nor am I related to his/her Enduring Guardian, nor am I a beneficiary under his/her will.

_____

(Signature of medical practitioner)

Date:_____

8. My Signature

I understand:

- the nature and likely effects of the directives set out in this document;
- that I may change or revoke any or all of this document at any time.

_____
(Your signature)

This is the signature of _____ *(print my name here)*

Date:_____

9. My Witness

The signing of this document was witnessed by:

I, _____ *(print name of witness)*

of _____ *print address of witness)*

declare the following:

I was present when _____ *(print my name here)* signed and dated this document which they appeared to do voluntarily and freely.

_____
Signature of witness

Date:_____

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INSTRUCTION SHEET

Authorised Adult Palliative Care Plan

NSW Ambulance Authorised Care Plans encompass Adult Palliative Care Plans, Paediatric Palliative Care Plans and Authorised Care Plans. It is the responsibility of the treating clinician to ensure all fields are completed prior to submission

SUBMISSION OF AN AUTHORISED CARE PLAN

- The document may be completed electronically and saved utilising a PDF viewer e.g. ADOBE reader.
- Completed forms may be submitted electronically via email: protocolp1@ambulance.nsw.gov.au or fax: (02) 9320 7380
- All fields are to be completed. If handwritten, all fields must be clear and legible.
- Address fields must be complete including post codes.
- Patients with an existing NSW Authorised Care Plan must have 'Existing Patient' checked in the patient details section of the plan.

ENDORSEMENT OF AUTHORISED CARE PLANS

- The treating clinician must approve all authorised care plans by signing the 'Clinician Details' section on page one.
- Adult Palliative Care Plans require authorisation from the patient, where appropriate, in the relevant section on page two
- Adult Palliative Care Plans require endorsement from the patient's family and/or enduring guardian.

ENDORSEMENT BY NSW AMBULANCE

- NSW Ambulance will review and endorse each completed application upon receipt.
- Patients will receive via post a copy of the completed endorsed plan and a covering letter. Please allow up to five business days for receipt. Adult Palliative Care Plans may be sent to either the patient or the family/enduring guardian as nominated in the relevant section of page two. Where no selection is made, the plan will be sent directly to the patient.
- A copy of the completed endorsed plan will be forwarded to the treating clinician via fax or emailed in PDF format where a valid email address has been supplied.
- Incomplete forms may result in processing delays.

MEDICATION ADMINISTRATION

- NSW Ambulance paramedics may administer medications within their specific clinical scope of practice without additional authorisation. Note: not all clinical levels can administer the entire suite of pharmacology.
- Medications outside of the NSW Ambulance clinical pharmacological scope of practice must be available with the patient at all times to enable administration by NSW Ambulance paramedics in accordance with the instructions detailed on the patient's plan.
- The current list of medications available under the NSW Ambulance Clinical Pharmacology (as of July 2015) include: Adrenaline, Amiodarone*, Aspirin, Atropine*, Benzyl Penicillin, Calcium Gluconate*, Clopidogrel, Compound Sodium Lactate, Droperidol, Enoxaparin Sodium, Fentanyl, Fexofenadine, Frusemide, Glucagon, Glucose 10%, Glucose Gel, Glyceryl Trinitrate, Ibuprofen, Ipratropium Bromide, Ketamine*, Lignocaine*, Methoxyflurane, Metoclopramide, Midazolam, Morphine, Naloxone, Ondansetron, Oxygen, Paracetamol, Salbutamol, Sodium Bicarbonate*, Tenecteplase (*intensive care paramedics only).
- Unless specified otherwise, paramedics will administer medications in accordance with NSW Ambulance pharmacology.

ENDORSED CARE PLAN EXPIRATION

- All endorsed Authorised Care Plans will remain in effect for a period of 12 months from the date of endorsement unless a reduced review date is requested by the treating clinician.
- It is the responsibility of the treating clinician to review the plan and submit a new plan prior to the 12 month review date.
- In the event the endorsed plan is no longer required, a cancellation notification including the reason for the cancellation should be forwarded to NSW Ambulance via email: protocolP1@ambulance.nsw.gov.au.

Date of Application:		Review Date:	
Trim number:		Document number:	

Patient Name:		New patient ☐	Existing patient ☐
Surname:		Date of Birth:	
Given Names:		Male ☐	Female ☐
Address:			
Interpreter Required: No ☐ Yes ☐ Language		Contact Number	

CARDIAC ARREST TREATMENT DECISION

If the patient is in cardiac arrest (select one) ☐ PERFORM CPR ☐ WITHOLD CPR

Please check the statements which are applicable (may be more than one):

- ☐ If withholding CPR, the patient, family and/or enduring guardian and I, as treating clinician, have considered the care options and a decision to withhold resuscitation has been made based on the discussion between the patient, family and/or enduring guardian.
- ☐ The patient's current medical diagnosis and prognosis is such that if CPR is successful it is likely to be followed by a length and quality of life which is not in the wishes of the patient.
- ☐ Initiation of CPR is not in accordance with the orally expressed and/or documented wishes of the patient who is/was mentally competent at the time of making the decision.
- ☐ If initiation of CPR is not in conjunction with an Authorised Care Directive (ACD).

Note: If concerns arise about the validity of the documents or the safety of the environment, NSW Ambulance protocol will be followed.

TREATMENT AND MEDICATION OPTIONS

In cases where the patient is not in cardiac arrest, the following treatment and medication options have been considered appropriate through consultation with the patient and/or family and/or enduring guardian:

Airway Management	Administer ☐	Withhold ☐
Oxygen	Administer ☐	Withhold ☐
Nasopharyngeal suctioning	Administer ☐	Withhold ☐
IV access	Administer ☐	Withhold ☐

The following medications are to be administered by NSW Ambulance paramedics as directed. Please note: medications outside of the NSW Ambulance clinical scope of practice are required to be with the patient at all times.

Medication	Dose/Route	Repeat times and intervals

CLINICIAN DETAILS (PLEASE PRINT CLEARLY)

Name:	Contact number:
Provider number:	Fax:
Organisation/Practice Name and Address:	
Email:	

As the treating clinician, I authorise this Care Plan and by signing this form I authorise NSW Ambulance paramedics to implement the treatment options specified which have been discussed with the patient and consistent with their treatment requirements.

Signature:	Date:

Trim number: Document number:

Patient Name:	Date of Birth:

PATIENT CLINICAL HISTORY (PLEASE PRINT CLEARLY)	
Diagnosis:	
History:	
Co-morbidities:	
Current Medications:	
Allergies:	

FAMILY/ENDURING GUARDIAN (PLEASE PRINT CLEARLY)			
Surname:			
Given Names:			
Relationship	Family Member ☐	Enduring Guardian ☐	Other:
Address:			
Contact Number:		Interpreter Required: ☐ Yes ☐ No (If yes, language):	
All correspondence will be sent to the person identified in this section			

PATIENT/FAMILY/ENDURING GUARDIAN AUTHORISATION	
Patient's Signature:	Date:
Family/Enduring Guardian Signature:	Date:

Trim number: Document number:

Patient Name: Date of Birth:

LOCATION OF CARE

While every effort will be made to accommodate the patient's wishes, NSW Ambulance will review the location of care at the time of attending the patient, distances and travelling times will be factored into the destination decision.

In the event that care at home becomes too difficult, the choice for end of life care is at:

Should death occur during transport, treatment will be in accordance with the patient's wishes detailed on page 2 of this plan.
In the event of death during transport the patient should be transported to:

POST DEATH MANAGEMENT PLAN:

If the patient dies, the management of the patient is the responsibility of the clinician/palliative care team. Paramedics should contact the patient's:

General Practitioner (GP): Name: Phone:

or Palliative Care Team: Name:

Phone (BH): (AH):

CONTACT LISTS

Team	Name	Contact Number (BH)	Contact Number (BH)
General Practitioner			
Palliative Care Team			
Primary Care Team			
Community Nurse			
Other Health Services			
Spiritual/Religious Supports			

NSW AMBULANCE USE ONLY

Endorsed by:	:
Signature	Date

NSW Ambulance

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INSTRUCTION SHEET

Authorised Paediatric Palliative Care Plan

SUBMISSION OF AN AUTHORISED CARE PLAN

The document can be completed electronically and saved utilising a PDF viewer e.g. ADOBE reader.

All documentation must be completed using the attached form and may be submitted electronically, via email or facsimile. All applications are to be endorsed by the treating clinician.

Email contact: protocolp1@ambulance.nsw.gov.au
Facsimile: (02) 9320 7380

DATE OF APPLICATION & REVIEW DATE

The date of application is today's date. The review date may be any period of time up to 12 months from the date of applica-tion. It is the responsibility of the treating clinician to review the existing plan and submit changes to NSW Ambulance prior to the review date.

PATIENT DETAILS

All fields are to be completed. Any handwritten details are to be clear and legible. The patient's full address (including street number) is complete (as the Ambulance response alert is linked to the individual's address).

Patients with existing NSW Ambulance Authorised Palliative Care Forms must have the 'Existing Patient' box checked.

CARDIAC ARREST TREATMENT DECISION

Ensure 'Perform CPR' or 'Withhold CPR' is selected (not both). All relevant statements must be checked in the box at the start of each statement.

All clinical treatment options must be checked as either 'administer' or 'withhold' (not both).

The treating clinician may authorised paramedics to administer medications outside their current scope of practice and/or as a variation to current pharmacology. Please note that medications outside of NSW Ambulance current clinical scope of practice must be with the patient at all times.

NSW Ambulance Clinical Pharmacology Scope of Practice as of July 2015: Adrenaline, Amiodarone*, Aspirin, Atropine*, Benzyl Penicillin, Calcium Gluconate*, Clopidogrel, Compound Sodium Lactate, Droperidol, Enoxaparin Sodium, Fentanyl, Fexofenadine, Frusemide, Glucagon, Glucose 10%, Glucose Gel, Glyceryl Trinitrate, Ibuprofen, Ipratropium Bromide, Ketamine*, Lignocaine*, Methoxyflurane, Metoclopramide, Midazolam, Morphine, Naloxone, Ondansetron, Oxygen, Paracetamol, Salbutamol, Sodium Bicarbonate*, Tenecteplase (* Intensive Care Paramedic only)

CLINICIAN DETAILS

All relevant details must be completed by the treating clinician. A completed plan with NSW Ambulance Authorisation will be sent to the treating clinician for their records. A valid email and/or facsimile number is required.

PATIENT CLINICAL HISTORY

All relevant fields must be completed.

FAMILY/ENDURING GUARDIAN DETAILS AND AUTHORISATION

The contact details for the appropriate family member/ enduring guardian must be entered. For adult palliative care plans you may opt for the completed plan to be sent to the patient or the family/enduring guardian in this section. (Note for paediatric patients the plans will be sent to the person nominated in this section only).

Where required the patient and/or family member/enduring guardian should sign the form on page 2.

LOCATION OF CARE, POST DEATH MANAGEMENT PLAN AND CONTACT LISTS

All relevant fields must be completed.

DEPARTMENT OF FAMILY AND COMMUNITY SERVICES (PAEDIATRIC PALLIATIVE CARE PLANS ONLY)

All relevant fields must be completed.

Please note: The Authorised Adult Palliative Care Plans will remain valid for a 12 month period from date of endorsement by NSW Ambulance. Adult Palliative Care Plans will need to be reviewed and renewed prior to expiry by the treating clinician.

Approval of Authorised Adult Palliative Care Plans

Please note: A NSW Ambulance Delegate will review each Authorised Adult Palliative Care application. Once the plan has been endorsed by NSW Ambulance, a letter will be sent to both the patient and the referring Treating Clinician

Date of Application:		Review Date:	
Trim number:		Document number:	

Patient Name:		New patient ☐	Existing patient ☐
Surname:		Date of Birth:	
Given Names:		Male ☐	Female ☐
Address:			
Interpreter Required: No ☐ Yes ☐ Language		Patient Weight	

CARDIAC ARREST TREATMENT DECISION

If the patient is in cardiac arrest (select one) PERFORM CPR WITHOLD CPR

Please check the statements which are applicable (may be more than one):

- ☐ If withholding CPR, the patient, family and/or enduring guardian and I, as treating clinician, have considered the care options and a decision to withhold resuscitation has been made based on the discussion between the patient, family and/or enduring guardian.
- ☐ The patient's current medical diagnosis and prognosis is such that if CPR is successful it is likely to be followed by a length and quality of life which is not in the wishes of the patient.
- ☐ Initiation of CPR is not in accordance with the orally expressed and/or documented wishes of the patient who is/was mentally competent at the time of making the decision.
- ☐ If initiation of CPR is not in conjunction with an Authorised Care Directive (ACD).

Note: If concerns arise about the validity of the documents or the safety of the environment, NSW Ambulance protocol will be followed.

TREATMENT AND MEDICATION OPTIONS

In cases where the patient is not in cardiac arrest, the following treatment and medication options have been considered appropriate through consultation with the patient and/or family and/or enduring guardian:

Airway Management	Administer ☐	Withhold ☐
Oxygen	Administer ☐	Withhold ☐
Nasopharyngeal suctioning	Administer ☐	Withhold ☐
IV access	Administer ☐	Withhold ☐

The following medications are to be administered by NSW Ambulance paramedics as directed. Please note: medications outside of the NSW Ambulance clinical scope of practice are required to be with the patient at all times.

Medication	Dose/Route	Repeat times and intervals

CLINICIAN DETAILS (PLEASE PRINT CLEARLY)

Name:	Contact number:
Provider number:	Fax:
Organisation/Practice Name and Address:	
Email:	

As the treating clinician, I authorise this Care Plan and by signing this form I authorise NSW Ambulance paramedics to implement the treatment options specified which have been discussed with the patient and consistent with their treatment requirements.

Signature:	Date:

Please fax completed form to: (02) 9320 7380 or scan/email to: protocolp1@ambulance.nsw.gov.au

Trim number: Document number:

Patient Name:	Date of Birth:

PATIENT CLINICAL HISTORY (PLEASE PRINT CLEARLY)	
Diagnosis:	
History:	
Co-morbidities:	
Current Medications:	
Allergies:	

PARENT/FAMILY/ENDURING GUARDIAN (PLEASE PRINT CLEARLY)			
Surname:			
Given Names:			
Relationship	Family Member	Enduring Guardian	Other:
Address:			
Contact Number:		Interpreter Required: Yes No (If yes, language):	
All correspondence will be sent to the person identified in this section			

PATIENT/FAMILY/ENDURING GUARDIAN AUTHORISATION	
Patient's Signature:	Date:
Family/Enduring Guardian Signature:	

Trim number: Document number:

Patient Name:	Date of Birth:

LOCATION OF CARE

In the event that care at home becomes too difficult, the choice for end of life care is at:

While every effort will be made to accommodate the patient's wishes, NSW Ambulance will review the location of care at the time of attending the patient, distances and travelling times will be factored into the destination decision.

Should death occur during transport, treatment will be in accordance with the patient's wishes detailed on page 2 of this plan. In the event of death during transport the patient should be transported to:

POST DEATH MANAGEMENT PLAN:

If the patient dies, the management of the patient is the responsibility of the clinician/palliative care team. Paramedics should contact the patient's:

General Practitioner (GP): Name: Phone:

or Palliative Care Team: Name:

Phone (BH): (AH):

DEPARTMENT OF FAMILY AND COMMUNITY SERVICES

Is the patient known to the Department of Family and Community Services (Formally DOCS)? No Yes

If yes (tick as appropriate):

- Family and Community Services are aware of the patient's condition and treatment decisions
- In the event of the patient's death Family and Community Services should be notified

CONTACT LISTS

Team	Name	Contact Number (BH)	Contact Number (BH)
General Practitioner			
Palliative Care Team			
Primary Care Team			
Community Nurse			
Other Health Services			
Spiritual/Religious Supports			

NSW AMBULANCE USE ONLY

Endorsed by:	Date:
Signature:	