

Really Useful Death and Dying Information for Everyone



Natural Death Care Centre
Celebrating Death & Life



Prepared by The Natural Death Care Centre & Tender Funerals, both in NSW, Australia.

Please use this document as a starting point to explore death and dying more deeply.

It has been created to help make your experience simpler, more informed and more meaningful.

Whatever approach you choose to take, we encourage you to prepare, have conversations and participate as much as you want to.

Know what your options are, consider your choices and make decisions that are right for you.

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Introduction

This document should inform and clarify, whilst demystifying some beliefs and misconceptions around dying, death, funerals & ceremony. It should empower individuals as well as communities, by providing practical information to help make better decisions and more considered choices in relation to end of life matters.

This information is not new. It describes the time-honoured traditional approach, where families and friends are involved at every stage or even do it all. Choices may be influenced by culture, beliefs, community, finances or sustainability issues.

This is not legal advice, but simple guidance based on the extensive experience of many people.

It may assist you to:

- better understand what is involved in the process of dying, death and loss
- participate more fully in any or all of the stages
- understand and complete the relevant and important legal paperwork
- talk to others about your or their wishes and needs
- clarify your or their instructions around dying and after death
- create a more meaningful ceremony to honour and celebrate a life
- have an easier and healthier bereavement

Death is the natural and sacred end to our lives. We all know we are going to die, although the time and place are often uncertain. Talking about death is something we all need to do.

Death can come suddenly or slowly, to the young or the old. Often, we will die as we lived; some will be very sudden, some deaths will be graceful, while others may be more difficult, most may be somewhere in between. Death and dying are sometimes referred to as the most significant journey or transition we will make. It is sensible and prudent to be prepared, just like we are in other aspects of our lives.

Although most of us want to get old and die in our own beds, this will not be the case for everyone. Sudden death can come to anyone at any time and it often brings shock, chaos and distress, especially if there is no preparation.

Your own cultural, scientific, religious or spiritual beliefs may help guide and support you, but sometimes questions may arise. The experience may be debilitating or distressing, healing or liberating, or all of these. It is a personal, and different experience for everyone each time.

Preparation and dialogue are two of the most useful tools in approaching end of life matters. They make dealing with death and dying more manageable for those left behind. If you are preparing for your own death you can state and discuss your wishes in advance, put things in writing, get your affairs in order, complete relevant documents, and tell your family where your documents are kept. It is one of the greatest gifts you can give to those you love.

Although you cannot change the circumstances of a death, you can create beautiful lasting and healing memories through the preparation and the experience of the ceremony. We encourage honesty throughout the dying, death and funeral process. This includes honesty with children, not leaving them out accidentally or on purpose, thinking it shelters or protects them.

For situations involving diverse cultural, religious or ceremonial practices and processes, we encourage contact with relevant people, organisations and communities.

We also acknowledge the term family is broad, not just by blood, but by marriage, love and choice.

Important Documents

Death is an anticipated event you can plan for.

Firstly, it is important to be familiar with, and understand legal documentation involved for your health care and end of life. They are of assistance to carers, the dying and those left behind. It can save your family and friends a lot of hassle to have the documents in place. Every person over 18 should consider these documents, and we recommend all adults complete them. You can download copies online. There are many versions available. These documents are discussed in more detail in the following pages and sometimes are State or Territory specific.

Legal documents valid while you are alive (until the time of your death):

- Advance Health Care Plan (AHCP)
- Enduring Guardianship (EG)
- Medical Enduring Power of Attorney (MEPOA)
- Power of Attorney (POA)

Legal documents valid when you have died (NOT while you are alive):

- Last Will

Non-legal documents:

- Legacy and love documents
- Death & After Death Care Plan
- Funeral Plan.

It is always practical and helpful to keep your documents in order, labelled and in an easy to find place.

Advance Health Care Plan (AHCP)

An AHCP setting out what quality of life would be acceptable to you and what treatments you would or would not agree to for your medical or health care. It can appoint a Substitute Decision Maker.

In some states there is a standard document, in others states there are many variations. Read through a few, get an understanding of the choices involved before you complete one. Your GP should be able to advise you and may also need to sign it.

An AHCP is completed when you have capacity, meaning you are of sound mind. It enables you to consent to medical treatment and to refuse medical treatment. It is made in preparation for a time when you may be confused, incapacitated or unable to communicate, due of illness or accident.

To be a legally binding document, it needs to demonstrate your capacity was present, be dated and witnessed, and be specific about medical and health choices.

An AHCP takes precedence over family wishes, only comes into effect if you lose your capacity to speak for yourself and is only legally valid while you are alive.

Your AHCP can:

- involve talking with your family, health care providers and other significant people to work out what is important to you and write it down.
- relieve your family or friends of making difficult decisions about your health care, because your wishes are known.
- guide health care providers in making critical decisions
- ensure your wishes are respected.

- greatly reduce your chance of having unwanted treatment.

Common treatment choices may include decisions regarding artificial feeding and hydration, resuscitation, assisted ventilation, antibiotics, dialysis and blood transfusions.

Your quality of life may inform these decisions, such as the ability to:

- get around by yourself
- recognise family
- be able to communicate
- wash yourself
- feed yourself
- have control of bladder or bowels
- remain in your own home

Enduring Guardianship (EG)

In NSW an EG is a standard and legally binding document, made while you have capacity. It follows the same principles as the AHCP, except you are appointing a guardian or guardians to act on your behalf after you lose capacity. It can be revoked before you lose capacity, but not after.

You may want to consider having both an AHCP and an EG.

Your EG can make decisions regarding:

- personal matters
- quality of life
- what medical and health care you do and do not receive
- where you live
- minor or major treatments, under provisions of part 5 of the Guardianship Act
- what support services you receive

Your EG cannot:

- be under 18 years of age
- override your objections to medical treatment
- consent to special medical treatments
- manage your finances
- make a will for you
- consent to marriage on your behalf
- break the law

If you complete an AHCP and/or an EG, inform your doctor and your family and tell them where it is. Give them a copy if you choose. You may want to keep a card in your wallet with some of this information. The AHCP informs the EG, who should follow your instructions.

Medical Enduring Power of Attorney (MEPOA)

Where it is permitted under State/Territory law, a Medical Enduring Power of Attorney is a legal document. By signing it, you authorise a person/s to make health care decisions for you.

This type of Power of Attorney is often used to plan for the future. There is always the possibility that you won't be able to make decisions because of age, illness or accident. They cannot make financial decisions.

If you have appointed a Power of Attorney, that person will have the authority to decide about your medical care in consultation with doctors and other relevant people, otherwise it will be next-of-kin.

Under the law, most life-saving procedures can be performed without consent. If you have not signed a Medical Enduring Power of Attorney, it may be necessary to apply to a local Court/Tribunal for the appointment of a Substitute Decision-Maker (often called a guardian).

Power of Attorney (POA)

A POA is a standard legal document appointing another person or persons to act on your behalf in your administrative or financial matters. A POA cannot make quality of life, health or medical decisions, such as placing you in a nursing home. A POA can be revoked at any time while you have capacity.

A general POA ceases when you lose your capacity. An Enduring POA has an extra clause and is witnessed by a lawyer and continues when you have lost capacity.

Last Will and Testament

A Will is a written legal document appointing an Executor/s to manage your affairs/estate after your death. It sets out your wishes and instructions. It needs to be signed, dated and witnessed by two people who do not stand to benefit from the Will. The executor has the legal right to the body after death.

Legacy and Love Documents

You may want to write letters to loved ones, your partner, children or parents while you can, for them to read and keep. This is often particularly important if you are leaving young children. You may want to write a series of cards for significant future events, such as a twenty-first birthday, a marriage, or the birth of a child.

You may also choose to leave a written legacy of your life, to share your beliefs, understandings or lessons from life. This can also be done by slideshow or video recording, which may be played at the funeral if you choose. It can be really helpful to those you leave behind to share your views and beliefs about what will happen to you after you die, and how you feel about it.

A Death Care & After-Death Care Plan

Available for purchase from the Natural death Care centre website for A\$15. This document allows you to consider and make directions to assist our family on what you want to happen.

Navigating the Health Care system

Most people want to live and will do all they can to stay alive. There may come a time, when your age, illness or condition deteriorates, and you move consciously into your dying process. This may begin a period of more intense emotions, and your care may become more demanding. The situation may need to be reconsidered and new decisions made, with advice and information from loved ones and health professionals. It is important to know what is available from the medical and health systems to ensure the care is the most appropriate for the person involved.

Moving into palliative care or a hospice is not a failure, just as death is not a failure. Palliative care provides appropriate services for a dying situation including great pain management.

Palliative Care Services

Palliative care is provided for people of all ages who are going to die, the primary treatment goal is a good quality of life. It is built on the values of **dignity, empowerment, compassion, equity** and **respect**, with specialist services with doctors, nurses and other staff.

Palliative care integrates psychological, emotional, social and spiritual aspects of care, and offers a support system to help people cope during the illness and in bereavement.

These services are generally consulted in the last months of life, or for a longer period to:

- provide relief from pain and other symptoms
- affirm life and regard death as a normal process
- neither hasten nor postpone death

If you have advanced disease and have pain and symptom control problems, or are planning for end of life care, it is worth contacting your local specialist palliative care service or ask your specialist or GP to refer you to one. Other health care workers, such as GPs and community nurses may not have specialist palliative care training. However, they are certainly able to provide good end of life care.

Keep in mind that over time your information requirements may change.

Some questions that may be useful are:

- How long do other people with this illness usually live?
- What will my quality of life be? What may happen in the future with pain and other symptoms?
- Are there treatments which will lead to recovery?
- Are there treatments that will extend life?
- What are the side effects of treatment or medication?
- I am worried that ... will happen. What can be done to prevent it or alleviate it?
- What is palliative care?
- Will anything be lost by opting for palliative care?
- Can you advise me on committing to a trip or event in the future?
- Is driving ok?
- What are good days going to be like?
- What are bad days going to be like?
- How can I explain what is happening to others?

Morphine

The use of Morphine and other strong painkillers called *opioids* is very common in end-of-life care. Morphine is a very safe and effective medication when used in end-of-life care. The aim is for good pain control without causing unnecessary drowsiness or confusion. When used appropriately, it does not cause sedation or death. Sometimes when the body gets used to morphine it becomes ineffective in the future, but if this happens other painkillers can be used very effectively instead. It is virtually unknown for patients nearing death to become addicted to morphine. However, people who have had addiction to morphine in the past may be more vulnerable.

Euthanasia/ Assisted dying

Euthanasia is the intentional hastening of a person's death in order to relieve that person's suffering. It can be voluntary or involuntary.

Voluntary euthanasia is when a person, with full knowledge, requests or consents to die. This may include refusing to eat or asking for help to die. Refusing medical treatment or withdrawing treatment at the end of life is not euthanasia. It is usually an appropriate decision in response to futile treatment.

Involuntary euthanasia is when a person cannot make a decision or cannot make their wishes known; for example, when a person is a baby, in a coma, is demented or severely cognitively impaired, severely brain damaged, or mentally unwell in such a way that they should be protected from themselves.

Physician assisted dying is when the doctor provides the knowledge and means, but the patient completes the act themselves.

Health care is changing to recognise that no doctor should prescribe a lingering death. Patients should be allowed to die of their disease; withholding or withdrawing treatment is appropriate in end of life care. This means we die a death by natural causes.

Start to open up discussion on these issues so that you are as well prepared and informed as you can be.

The Dying Process

Death is the natural end of our lives, an ordinary and sacred experience. Being aware of and able to talk about death, as a part of life, can help you live more fully. Talking about death does not make it happen, just as not talking about it cannot stop it happening. Being more informed and prepared may empower you to hold an attitude to death that creates a greater freedom.

Adjusting to the understanding and reality that you are nearing the end of your life, and your death is coming, is a unique experience for everyone. You may want to create some time in your life to think about what needs to be in place if you died tomorrow. Beginning the process of considering, recording and communicating these things can be an empowering, kind and life affirming act.

Preparing for Death

Death can be sudden or expected, coming in its own time and its own way. A dying process may take years, months, hours, minutes or be instantaneous. Being prepared covers, among other things, legal, practical, medical, emotional, social and spiritual matters. These areas are often intertwined.

An expected death can offer an opportunity to connect and talk about what matters to you, but in the event of your sudden death that opportunity is not there. Being prepared is good for everyone involved.

Whatever your circumstances, you may want to:

- Speak to the person(s) you want to be responsible for carrying out your wishes. Ensure what you are asking of them lines up with their values and beliefs, and they will action it for you. If they are unwilling or unable, this gives you the chance to talk about it and rethink who you need to appoint.
- Have as little unfinished business as possible for yourself, your relationships and your professional life.
- Convey what you want to happen to your body after you die. What sort of funeral and disposal method you want: burial, cremation or no preference?
- Bear in mind the Will is often only read after the funeral, so cannot be relied on to provide this information.

The dying process can begin long before death actually occurs. Dying happens to your whole being, not just your physical body. All parts of you may experience pain or suffering, and comfort or healing. Your quality of

life, medical treatment and pain control are all important matters in this.

Pain control is important, as there is no need to suffer unnecessarily. If you are physically comfortable you can do things like relax into your dying, complete unfinished business, both personal and professional, reflect on your life and your relationships with others, and even find new meaning in your life. It may be a time of growth, emotionally and spiritually for you and others. Your dying is uniquely yours, it is different for everyone, and you will probably die in a similar way to how you have lived your life.

You can be active and live your dying, and your responses may change as you move through your process. Talking about things can provide relief or comfort to you, and to all those involved.

You could discuss:

- Your care needs, as a support network may need to be created
- How you would like to be cared for, to assist your carers and allow for the death experience you want
- Appropriate pain relief, if your priority is to remain as conscious as possible
- Any preference to where you die, at home, in a hospice or a hospital.

You may want to consider your emotions and feelings:

Love – to express your love and to allow others to do the same

Gratitude – to express your gratitude and allow others to express theirs

Forgiveness – to forgive yourself and others, and ask others for forgiveness

Regrets – to express any regrets and allow others to do the same

Saying goodbye – to say goodbye to your loved ones, your possessions, the world and your life, and let others say their farewells to you

Acceptance – that things are as they are and may not be able to be resolved

Discuss with those who may be caring for you to clarify what is really important to you about the environment and atmosphere you will be in. Discuss your independence, friends, family, conversation, silence, access to nature, pets, art, photos, music, aromas, candles, and lighting, for example.

Your psychological, religious or spiritual needs may also be important, and you should communicate what is required to meet them if this is the case. Share these things with those around you to support them and you. Access social workers, counsellors, clergy, prayer, meditation, solitude, and friends and family, as needed.

Be as honest as you can with yourself and others about what you need to feel comfortable and supported. This may mean finding ways to express or release emotions as they arise. There are people who can help with this. So, if you need help, ask for help.

Considering and talking about personal things could be new or difficult. You may have no experience in speaking about your feelings and thoughts. If this is the case for you, it may be easier to write letters or notes, or you may choose to just make peace within yourself. What you consider and do can be a journey of incredible discovery. It's your life and your death, so it is entirely up to you.

Caring for the Dying Person

Being with someone while they are dying can be many different things: challenging, exhausting, heartbreaking, satisfying, expanding, joyful, or liberating. Any or all of these, and more. Every death is a unique and personal experience for everyone involved.

Most people want to live, and will do all they can to stay alive, but their illness or condition may deteriorate, and they progress into their dying process. This can begin a period of more intense emotions, and their care may become more demanding. The situation could need to be reconsidered and new decisions made, with

advice and information from loved ones and health professionals. Most people will die as they lived; someone who has always shared openly is likely to continue to do so, just as a person who has been stoic, private or independent through their life, is likely to continue to behave this way. This is a time when religious or spiritual beliefs, fears and myths, may help or hinder.

There are many places to die: at home, in hospital, in palliative care or hospice, or in an aged care facility, for example. A palliative care facility or a hospice is a place just for people who are dying. A hospital may have a specialist palliative care ward, or they may only have general wards.

Try to create an appropriate space and atmosphere. Check in with the person – their sensitivities and needs are paramount. Most hospitals will accommodate things like soft music, decoration, photos, and favourite or meaningful things in the room, as long as they are not obtrusive or in the way.

Hospital and Hospice visitors are generally permitted to stay around the clock, and they are often allowed to sleep in the room. The dying person may or may not be able to speak, so someone may have to gauge who, how many and for how long people may visit. Common sense and kindness will be needed as death can fascinate and repel at the same time. People often want to be there for as little or as much time as they can. This happens for a range of personal and complex reasons.

It is also kind to allow the dying person some quiet time, with no-one, or just one quiet person in the room. Silence and solitude can be a great gift to give. Imagine yourself ill – not even dying – with a room full of people, often talking to each other, being there all the time. It can be intrusive to your peace of mind. It is important to use your knowledge of the dying person to make these decisions. If you need to take time to sort anything, do try, but remember it is their journey; you cannot always make it happen as you want.

Some of the elements involved are:

Medical team – attending doctor/palliative care doctor, community nurses/palliative care nurses, health care providers, social workers etc.

Community team – primary carer, family, friends, neighbours, sport and social groups etc.

Documents – AHCP, EG, POA, Will, Plans etc.

Environment – a quiet space, suitable room, soft lighting, toilet and bath or shower access, and signs to inform or limit visitors

Equipment – bed, hospital bed and bar, pillows and light bedding, music machine, fans or air-conditioner, chair, walker, wheelchair, commode, toilet and shower seat, bowl and toiletries, gloves, pads, hot water bottle, internet access to research and receive bulletins that inform and to communicate, a bell, communication book, contact list, medication list, photos, altar, or other personal things. Chocolate, cigarettes, or alcohol may still be part of the person's life.

Some signs of the body shutting down are:

Less or no desire to eat, as the body does not need to be nourished; less or no desire to drink, as it becomes too difficult to swallow; therefore little or no faeces or urine.

Cool, moist or mottled skin, continuous sleeping, rhythmic periods of not breathing, and rattle-sounding breathing.

Did you know you can do any of these things ?

- Keep, care for and keep cold a body at home
- Wash, prepare and dress a body yourself
- Bury in a shroud without a coffin
- In some states be cremated in a shroud
- Build and decorate your own coffin, (it has to meet certain specifications so it can fit in the cremator or grave and be weight bearing)

- Cardboard coffins are legal
- A coffin can be lined with a soft absorbent liner, rather than plastic
- Drive a body in your own vehicle from a home or hospital, to the funeral and crematorium or cemetery

These things are all possible, and nothing new; rather, they are the way things were traditionally done.

If you want to care for someone so they can die at home, consider carefully your willingness, ability and support systems; the practical as well as the emotional. It can be a challenging time, as well as stepping up or becoming aware of new aspects of yourself. Sometimes the burden of physical care doesn't allow for emotional care. Consider honestly whether you want to do it, and whether you can do it.

These decisions are individual and must be made in the context of individual circumstances. There is no right or wrong choice, and even though the person may want to die at home, it may be too difficult or impractical. Do not take on caring for someone out of guilt; you can only do what you are capable of.

End of Life, the Moment of Death

If you have been caring for someone in their dying, then their end of life may be gradual and not as shocking as it could seem right now. Death can also come suddenly and catch you unaware; it is often when everyone has left the room, even for a moment.

The signs of approaching death may be a slowing down of the body's functions, a gradual or lesser interest in external things, like the world, politics, religion, community, friends, and even family. They may be with their own thoughts and feelings. Check in with them.

If it is true or appropriate, assure them of your love, presence, gratitude, and of your ongoing well-being. It may or may not be appropriate, or you may or may not want to: kiss, touch, hold hands, say goodbye, speak, be quiet, cry, go outside, leave, carry on as normal, and be with your own partner or family.

Those accompanying the dying bring their own lives into this moment. It can be anything and everything: a time out of time, many emotions, sad, fearful, anxious, excited, anticipatory, or relieved. These, and others, are all common feelings. Feel it all, and discuss them if appropriate, but remember you are there to accompany the other person.

Don't let your emotions overwhelm the situation.

Expected, Sudden or Unexpected Death

As we all know, death is certain, although the time and place are uncertain. **Sudden or unexpected death** can occur from illness, natural causes, accidents, or someone killing themselves. Sometimes the body does not appear until sometime later, or the circumstances may be unknown, or the body may never be located. **Sudden expected death** can also occur from illness, natural causes or an accident, where there is a delay involved. All call for a different understanding. You may believe or take comfort in the idea that *something* leaves the physical body at death: a soul, spirit, individual essence, energy or consciousness. You may not believe this. What often becomes clear for people when sitting with or viewing the body for a while, is that the person you knew is not there, the physical body is an empty shell.

We encourage age-appropriate honesty with children. Do not exclude them, thinking this will shelter or protect them. Be appropriate, be kind, and don't lie to them. Sometimes if they are not told the truth they can believe they are in some way responsible. They will know something is wrong or out of place. They will feel, process and behave within their own capacity, help them to do this well.

Once the person has died, the Will is now valid, and the executor of the Will has the legal right to make decisions regarding the body, funeral and disposal, though usually it is the next of kin who make these decisions.

With an expected death, it is not necessary for a doctor to be present. You will keep them informed but there is no set time that you must notify the attending doctor, usually within 12 hours. If someone dies in the evening or during the night, you may want to just spend extra calm time with their body and call the doctor in the morning, or a few hours later, when you are ready.

With a sudden or unexpected death there may be additional shock, distress or trauma for you. In some cases, you may be notified by the police. Prepare yourself by imagining this possibility.

If you discover the body, try to stay calm, take some deep breaths, take hold of something, sit or kneel down. If you feel the need or are able to, check for signs of life, such as a pulse, pupil response and temperature. If there is a possibility to resuscitate them, attempt CPR or call an ambulance, and try to stay as calm as you can. If they are clearly dead and unable to be resuscitated, you may just want to be still. This is a time and an experience you will only have once. Consider what needs to happen next. Take some time to be with your own feelings and the reality of the situation. This may be minutes or even hours. Continue to try to stay as present as you can.

Do not pick up the phone until you are ready. Depending on the circumstances you may choose to call loved ones, a doctor, an ambulance, the police or a funeral director. Once this course of action is taken, it can be difficult to stop it. In a short amount of time, you could find the place full of strangers asking questions, and the body whisked away. You may want to delay this until you have said your goodbyes, and you are ready to deal with this next stage.

If a person has not seen a doctor in the previous three months, or they have had an operation in the previous three months, an autopsy may be required. If the cause of death needs to be determined the body may be taken by ambulance or funeral director to a hospital morgue and undergo an autopsy. This may take days or weeks to occur. In some cases, the family may be given a choice, and can request no autopsy.

An autopsy is a procedure where the body is surgically opened by the Coroner. The organs are removed and examined to work out the cause of death and usually placed back in, and then the body is stitched back up. This can involve a cut to the hairline, and through the centre of the torso. The body can still be viewed, but we suggest you have someone explain the condition of the body beforehand so that you know what to expect. You could also have someone accompany you for your first viewing, allowing them to leave you as you get used to it and shock abates. You may want to ask for a chair so you can allow the shock to pass through and let your body be supported.

If there has been an autopsy it is still possible to:

- bring the body home
- wash and dress the body yourself
- sit, be with or hold a vigil with the body
- have an open coffin at the funeral

If a doctor has been visiting the person recently and knows the cause of death, they will issue a death certificate, so no need for an autopsy. In these cases, it is then possible to move the body from the home straight to the cremator or the grave, with the correct paperwork completed and due procedure followed. However, usually there is a ceremony before or after the disposal.

With an expected death the person is usually at home, an aged care facility, hospice or hospital. When life is extinct, especially if you have been caring for or attending on them, along with sadness, there may also be relief their physical or emotional suffering is over. Being with the body after-death can be a beneficial experience. Take time to just be with the body. Do not call anyone straight away, unless you want to. You may want family and friends to come and be there too.

When you are ready you must notify a doctor to come and a death certificate must be issued.

If you are using a funeral director, preferably chosen in advance, call them when you are ready, they can also organise the doctor. Do not rush; your time with the body can be precious and cannot be had again. The funeral director will take the body away to keep it in cold storage and await your further instructions.

Being with the body can be a very beneficial experience. If you want to keep it at home, it is legal in NSW and some other states to do so for up to 5 days. This is quite a long time. Often people will keep the body between twelve and forty-eight hours. It is **vital it be kept cold** (preferably at -5°C) as it will begin to deteriorate otherwise. This can be done with ice, dry ice, frozen containers, or a refrigerated cold plate. Cold plates are commonly used in some countries and are being used here more frequently now.

If you want to do this, find out more in advance so you know what is involved and where to obtain one.

You can also wash and dress the body yourself, before it is taken away. This may also include closing the eyes and mouth, and watching out for any body fluids, though there may not be any.

If you want to do this, find out more in advance so you know what is involved.

If a person is dying in hospital, tell the nursing staff if you intend to spend some quiet time with the body once death has occurred. You can also take the body home and care for it there. This time can be very precious. It can allow you to rest, appreciate what has happened, come to terms, and see clearly that life has gone. This time cannot be had again.

Practical Care of the Body

It was common in the past, and still is in many cultures, for loved ones to take care of and prepare the body. If you have been caring for someone during their dying, then caring for their body after death may be an easy and natural extension. Handling a dead body is something many people are not familiar with, but it can be a natural progression to caring for the sick and especially the elderly. It can be confronting, especially with the body of a child or young person, but also incredibly meaningful and beneficial in your loss. Many people find it useful, healing, intimate, sacred or vital to take care of the body. It may just be too difficult, or not possible. It is a personal choice.

If preparing the body seems challenging, it may be useful to ask for help from someone who is familiar with this experience, like a nurse, or someone who is willing and feels confident to help.

If the death is sudden, accidental or unexpected, taking care of the body may feel daunting because of your shock, emotional state, or the condition of the body. There may also have been an autopsy, but this does not prevent you from preparing the body. Discuss any worries or fears with the professionals around you, find out what is involved, consider what you want to do, prepare yourself, and then decide whether or not you want to do it. If it is too hard, let it go.

If you decide to go ahead, you should consider the appropriate and respectful way to do it.

Some will create a sense of ritual by using music and candles. Laughter and tears can both be elements in the process. It is useful to have the body on a board, or a tray, so that you can move the body easily if needed. This is easier than carrying the body or moving it with a sheet.

Rigor mortis is caused by natural chemical changes in the muscles after death. It causes the limbs to become stiff and difficult to move or manipulate. It begins anywhere between three and six hours after death and eases anywhere between twelve and seventy-two hours after death. However, after death the body remains somewhat taut, and never becomes really floppy again.

It is **NOT** a legal requirement to embalm a body, it is a choice. Most bodies in Australia are not embalmed. If a body is not embalmed, it is important to keep it cold to prevent further deterioration.

Often after death, the facial expression of the deceased relaxes. If the mouth is open, you can try to close it by:

- Placing a rolled-up towel or small pillow underneath the chin and tilting the head forward
- Closing the eyes, put a lightweight on them
- Placing a small pillow underneath the head
- Holding the chin in your hand, and closing the mouth for a few minutes at a time
- Looping a scarf or sash underneath the chin, tying it at the top of the head tightly, and removing it after a couple of hours
- Sealing the mouth with superglue (it needs to be applied to a dry surface). If the body is cold this will help the jaw to remain closed.

Ideally a **cold plate** can be used. This is a rectangular stainless-steel refrigerated plate, roughly shoulder to knee length. It has a motor to drive the refrigeration and is powered by electricity. Detailed instructions should be provided with a cold plate, but in short, it is placed under the body, with something between them, so the skin does not stick to it. You may want to also put a wet sheet over the body and have an air conditioner.

Dry ice is cold and evaporates, it changes from solid to gas and may leave condensation on surfaces it touches. It releases carbon dioxide, a gas which can cause light headedness, or worse. You must keep the room well ventilated to allow the gas to escape. The skin, living or dead, should be protected from dry ice. Handle it with thick gloves or a towel. Do not touch it with bare skin.

Preferably research your local supplier in advance, as they are not always open. You will need an Esky to collect and transport it and cover it with a towel.

The quantity needed is between seven and eleven kilograms per day, depending on the size of the body. Only purchase a two-day supply as the ice will constantly transforms to gas. Always store dry ice in an Esky and not in your freezer.

It may come in blocks or loose, similar to wet ice. Whatever form it takes, make a bed of dry ice to accommodate the whole torso. Using dry ice on a soft surface is sometimes easier than on a hard surface, as the ice will sink into the surface and the body will remain centred. Place a plastic shower curtain and large towel between the ice and the bed, to insulate and absorb the condensation. Ensure the organs are protected by the dry ice, as they decompose more quickly, so consider placing some on top of the abdomen. There must be a protective layer between the dry ice and the body.

Since the ice will elevate the body you may want to raise the feet and head to level the body. It is important to position the body, so it appears natural and comfortable, even though we know that no pain is being experienced, to avoid any distress to the living.

The body will become rigid and cold to touch.

If you want to remove the ice from the abdomen when people are visiting, you can replace it with a cold gel pack.

Sometimes wet ice or frozen containers are used to keep a body cold. Procedure is same as above, but be prepared for the water and change whenever needed.

All of these methods can be complemented by fans and an air conditioner and keeping the room as cold as you can.

If you have a **body tray**, you don't need to put the body in a coffin until you are ready. This makes it much more accessible to be with or view. You may use something like a door. If you have a coffin, you may want to put some dry ice in the base. If using dry ice in a cardboard coffin, be mindful and expect condensation so wrap it in plastic.

Health professionals may wear gloves. Be guided by them and the circumstances. You may choose to wear gloves, or not to.

Closing the eyes and mouth is optional, but usual. Gently close the eyelids and place a massage pillow or a Gladbag filled with rice or sand over them for a couple of hours. If the eyes are still not fully closed, you can place a cotton bud tip sized bit of cotton wool underneath the eye lid, or superglue them down (it needs to be applied to a dry surface).

Undressing and dressing the body is best done before rigor mortis sets in, or after it passes. The limbs of a body will become stiff when the body is kept cold. It can be difficult to remove clothing from the body and can be easier to cut it off.

Some people will have left specific instructions about what they want to wear, and these should be followed. If this is not the case, then you can simply dress the body in appropriate clothing or wrap it in fabric.

Dressing a body can be the same as dressing a bed bound person. The clothing is often cut at the back and slipped on from the front.

If it is a top garment, put both arms into sleeves and pull the fabric towards the head. Lift the head and pull the garment over. Roll the body from side to side pulling the clothing down a little at a time. Lifting the body and pulling the garment down is an option if you have enough help. You can also cut the clothing up the back and place the arms through the sleeves and cover the front of the body, tucking the clothing underneath.

If it is a bottom garment, put legs in each pant leg and pull toward the waist. If there are two or more people to assist with dressing, someone can lift the hips up while another pulls up the pants.

After dressing the body, place towels or plastic underneath to absorb any body fluids that may have collected in the body.

Body fluids need to be considered:

The bladder of the body may empty; or you may push down gently on the abdominal/pelvic area before bathing, to help empty the bowel or bladder.

Sometimes fluid collects in the lungs and drains out of the mouth when turning or moving the body. This can relate to the cause of death. Keep the head elevated during a vigil, or if you are moving the body. Be ready with a cloth at the mouth when turning for washing or dressing.

You do not need to place cotton in the nasal, throat and/or anal passages, unless it is a cultural requirement.

You may want to cover open wounds with a waterproof dressing.

The use of a cool plate or dry ice soon after death reduces or stops all drainage or odors.

Preparation of the body can also include washing, hair and make-up. You may need gloves (optional), a washing basin, several towels, soap, shampoo, hair dryer, creams, make up, oils or perfumes. A tray, massage table or hospital bed is an ideal location. Also, a sheet may need to be placed under the body to assist with moving and turning, though make sure you use good lifting techniques. You may want to cover the body with towels or a sheet.

It is best to have two or more people assist with washing the body, which is similar to giving a bed bound person a sponge bath. Use warm water and soap, add any oils to the water, and change the water as often as is needed. Begin by washing, rinsing and drying the face, ears and neck; then place a towel under the arms and shoulders, wash, rinse and dry. This should be followed by the chest, abdomen and pelvic area.

Next, turn the body from the back to the side, using the method outlined here, and wash, rinse and dry the back and bottom. Finally, wash the legs and feet.

Washing the hair is best done by two people. Use a draw sheet to move the body to the top of the table. One person should support the head over the edge (the head is often much heavier than you imagine). The other person should place a basin or bucket underneath the head to catch the water; then wet the hair using a jug of clean water, shampoo, condition, and rinse. When this is complete, use a dryer or comb the hair, and style it.

Make up is not essential; but can conceal skin discolorations and wounds. Be guided by whether the person wore makeup when alive. If it was part of who they were use the persons own make-up and apply appropriately.

Turning the body from the back to the side

- have two people stand on opposite sides of the bed.
- untuck the draw sheet – a regular sheet placed under the body, used to lift, turn or move the body – roll edges and grip tightly.
- together lift the sheet with the body to one side of the bed, making sure it isn't too close to the edge.
- the person further from the body should place far ankle over near ankle in the direction you want to turn, cross and tuck the arms over their chest in the direction you want to turn, move the pillow in the direction you want to turn, and place your hands on the shoulder and hips furthest away and roll them towards you.
- the person nearer the body should pull the draw sheet toward you.

Lifting, carrying and transporting

Discuss any plan for lifting, carrying and transporting the body with all helpers before going ahead. Confirm everyone is clear, have enough people, ensure everyone is able, and clear the route you are taking.

Use a draw sheet to lift the body into the casket, supporting and containing all limbs. Once the body is in the casket, remove the sheet or tuck it under the body. If moving a coffin through a house, do a trial walk through with the empty coffin, to make sure you can get it through doorways and around corners. Having people on the other side of doorways is helpful. Finally, measure the space in the vehicle you are using for transporting the casket, to make sure it will fit.

Funeral, Arrangements, Ceremony and Disposal

Depending on your circumstances, you may want to be prepared, assertive, and as empowered as you can be. It is most beneficial to understand what is involved before your need arises. Well considered choices may provide a more satisfying ceremony and experience, meaning no regrets, better memories and a healthier bereavement.

There are costs involved, so you may want to enquire or shop around for a funeral director (FD) before you need one, so the situation is easier to manage, and is not so emotionally charged. Don't be intimidated, make a list of questions. Discuss your plans with them, ask them what costs are likely to be involved. Take notes. Clarify anything you don't understand. Compare the quality of their service, their prices, and whether you like and trust them.

Although most people use a FD, in many states it is also legal and possible to do it all yourself.

You can complete all necessary legal paperwork, care for and transport the body, build a coffin and hold the

ceremony, and deliver the body for disposal.

There is a period of time, post-death and pre-ceremony, when funeral arrangements are usually discussed, ceremonies created, plans made, coffins decorated, eulogies and tributes written, photo boards assembled, slide shows compiled, and orders of service printed.

This time is precious and can only be experienced once, so don't rush. If in doubt, slow things down, so you can consider and create what is right for everyone. Most people assume that the funeral must happen immediately, say within three to four days, but legally there is no set time. It can take a week or two, or even up to a month, if personal or legal circumstances demand it. Speak to your FD.

During this in-between time, loved ones may also choose to wash, dress, view, sit, be with or hold a vigil with the body. The body can be taken home, which is often beneficial, especially in the case of sudden death. It is an opportunity to come to terms with the shock, to process some initial emotions and feelings, touch and sense the body, and sometimes to realise that the person is clearly gone, and their body is simply empty.

If a family member or friend has to travel far to attend the funeral, especially from overseas, it is often helpful to offer them the opportunity to be with the body when they arrive. They have likely been alone with the news, have had to make travel arrangements and been in long transit, so they may need time to catch up with other loved ones before the ceremony, to experience their loss and the feelings that go with it.

In the case of a sudden death there will often need to be an autopsy to discover or confirm the cause of death. This can take time – usually between two to five days – and you can inquire to the coroner, or your FD can keep you informed of the process.

In some circumstances when the body has not been found, or is not retrievable, this adds more distress to an already difficult situation. Sometimes in these cases it may be helpful to still hold a ceremony, so those affected can come together in their shock, to support and connect, and to honour and celebrate the person, and their next of kin.

Usually, if there is a Will, the executors has the legal right to the body and to organise a funeral, but usually the next of kin make funeral arrangements. The person who authorises the funeral is liable for the account. When someone dies, the bank usually freezes their accounts. The funeral account is the only expense paid from the bank account, until probate is granted. If there is no Will, then the next of kin or a 'person responsible' usually takes over. If there is no one, the arrangements fall to the State.

A local FD will have the tender for destitute burials. They will take care of the body and disposal, and there will be no input from anyone else.

Funeral Director (FD)

It is important to understand the role and purpose of a FD, to feel empowered in the consultation when making arrangements. They should assist, guide and empower you, not control or override your wishes, so you can be with your loss and your loved ones, and have the best possible experience. A good funeral helps you process the loss, at the ceremony itself and it can also mean a healthier bereavement. Remember, the FD are in a service industry, to serve you, and you are paying their account.

If you want, enquire with several FD's until you find the one that suits you. If possible, speak to them before the need is there, so you already have an existing relationship. Ask them to explain clearly the service they offer, what is involved in the process, what they handle, how much they will allow you to do and the costs involved. Take notes through the process, of questions and answers, as it can be difficult to concentrate or retain small details or conversations. Also tell them what you want. You may want to do all of this together with loved ones.

Some FD's are small independent or family businesses. Many, including well-known names, are owned by much larger corporations. They should all have a professional code of conduct. Most will come to your home to discuss the arrangements at your convenience. You may request being attended to by the same person, or you may be seen by many different people. In the case of large firms, the body may be taken from a small premise you attend, to a large cold storage depot holding many bodies, which may involve transport costs.

A FD usually collects the body, completes the legal paperwork required for burial or cremation, drafts optional death notices, cares for the body and keeps it in cold storage, prepares the body if required, places the body in the coffin, transports the body to and attends the ceremony and then transports the body to the burial or cremation. All of these services are legally possible without the aid of a FD.

A FD will charge a fee for their service. Remember they are a service industry, and are there to give assistance, good guidance, and the sort of service that you want. They must also give you a written quote of the costs involved. Don't feel pressured or intimidated to sign anything until you understand what you are signing, and you are ready.

Ceremony

Anyone can conduct a ceremony – a religious person, a celebrant, a friend or family member or even you. A ceremony can offer a rite of passage for the person's life, the body and for the people present. It is often the last time that the body is physically present. It is a time of transition, an opportunity to honour and celebrate the person and their life, to acknowledge the circumstances of the death, and to let the body go before cremation or burial. However, there is no legal requirement to have a funeral or a ceremony of any type. You may choose, on completion of the paperwork, to take the body from the bed or cold room straight to the cemetery or crematorium. This is called direct burial or direct cremation; and it is cheaper and a more useful option for some people. So, whether or not you have a funeral is an individual choice.

In some situations, you can:

- transport the body interstate yourself, or through a FD who organises a body transport service
- select and be charged for only certain parts of the FD's services
- supply or conduct any part of the process yourself, which should reduce cost
- help with washing and dressing the body
- hold a vigil, sit or be with the body for an extended period at the FD premises
- care for the body at home until the funeral. In NSW it is legal to keep the body at home for up to 5 days
- choose not to embalm – a toxic and invasive procedure – and still transport, take home, view and handle the body
- have a ceremony in a house, garden, park, hall, or sports venue
- provide your own transport to the ceremony for the body
- be a pallbearer and carry the coffin
- have a religious, spiritual or non-religious ceremony
- create and conduct a ceremony
- supply and use a hand built, eco, cardboard or wicker coffin
- wrap the body in a shroud for burial, with NSW Health Department's permission
- book two time slots at the crematorium or cemetery, so you have plenty of time
- lower the body into the grave or watch it go into the cremator
- use a natural burial ground
- have a direct delivery burial or cremation, with no fuss or ceremony

Consider the choice of venue: it can be outside, graveside, in a beautiful or familiar garden, a public park, beach, sporting arena, or natural bush setting. Alternatively, it can be held indoors, in a house, community hall, sports club, or chapel, for example.

The ceremony and disposal can occur in the same location, or there can be a walk or drive from the ceremony to the grave or cremator. If the venue is a public space, seek permission from the relevant authority, but remember it is legally possible.

If it is a religious ceremony, then the appropriate person will preside. The popular alternative is a funeral celebrant, who will work with you to create and conduct a ceremony appropriate to the person. Do not just take the first one offered or contacted. Talk to them to make sure you feel they are capable of giving what you want and require. Recommendations from others may be helpful.

The type of ceremony should be in keeping with any cultural traditions, religious, scientific or spiritual beliefs. The ceremony should attempt to address all the relevant aspects of the individual situation. It can be important for close people to have input and to be involved, in order to create the best possible and most beneficial experience.

Some of the inclusions for the ceremony may be a dress code, colourful or stylised, a eulogy, spoken tributes or memories (serious and humorous), poetry, readings and music. Choosing the music can be a great starting point as it can open up discussion, set the tone, and have a big impact on the emotions of the people attending.

A funeral should assist people in their acceptance of the loss and in saying goodbye to, and letting go of the physical body as it is buried or cremated. A good ceremony can contribute to the feelings of healing for the bereaved. A bad or unsatisfying one can compound sadness or grief and make the situation for the bereaved even more distressing.

Body Disposal

In NSW it is only possible to cremate at a crematorium. Burial can take place in a public or private cemetery, or a natural burial ground. It is also possible to bury on private land, and each local council should have a policy that sets out the conditions that must be met. If you are considering this option, check out the policy in advance.

A coffin will need to be made or selected before a funeral, especially if there is an intention to decorate it. It can be decorated inside and out in an appropriate way for the person. Gifts or significant items can be placed in with the body, though there are some restrictions on this with regard to pollution and safety. The coffin lid can be open or closed. Pallbearers can be loved ones, and women can carry just as well as men.

In some circumstances a shroud rather than a coffin can be used for burial, requested on religious or community grounds. Written permission needs to be given from the NSW Health Department.

IMPORTANT: While **advance payment funeral plans** often seem like a good option, and there is an enormous amount of marketing pressure to take one out, there are many pitfalls. Most consumer advocate group advise against them. Generally, you are much better off putting the money they cost into a savings account.

Bereavement and Loss

The response to loss and bereavement is a unique experience for everyone. Your response to each situation will depend on many factors, for example, your relationship to the person, the circumstances involved, familiarity with death, and the gender and the age of the person and the bereaved. Emotional responses may range anywhere from sadness or grief, to relief or joy.

Emotions and feelings often change. You can find yourselves shifting between tears and laughter, despair

and acceptance, and anger and gratitude. Emotion is an important part of the process for those left behind. Many people describe the sensations as coming in unexpected waves. Just try to be with what arises, and not expect to feel normal, or function as if nothing has happened. Those left behind need understanding, time to adjust, and support.

Sadness is the most common response to death. Some people will find the experience traumatic, while others may grow from it. A person's resilience also has an impact, as do religious, spiritual or scientific beliefs. Previously unresolved feelings around the person, family or death may also surface and complicate the response to death. Community, cultural or religious beliefs, gender and age, may all affect bereavement.

Men and women often deal with loss differently: many women want to talk and cry together, and many men want to be alone or get on with things or do something. Intimacy and sex can also be very different experiences at this time for men and women.

Children should be included in bereavement and treated with kindness and care. They will feel, process and behave within their own capacity. Telling children the truth is usually advised, as they will know that something is happening, and may be confused if they are deceived. Children will have their own individual response, they may continue to play and laugh, may be quiet at times, may be extra snuggly, or may be distant. Treat each child as the unique individual they are and seek professional help if you feel it is necessary.

Some of the physical reactions to death are lack of appetite, nausea, restlessness, agitation, disorientation, anxiety, and sleeplessness. Crying can be helpful and important as it is the body releasing distress. These are often initial responses that settle over time. Slow things down so that things have time to sink in and shock can subside; there is no hurry.

If you want to help someone, imagine yourself in their position. Listen with compassion, and be mindful of what you say, avoid hindering their process and responses. If you don't know what to say, sometimes it is best to just say 'I don't know what to say'. Actions are sometimes easier than words, and giving flowers and cakes, cooking meals, getting the shopping, and mowing the grass can all be helpful.

Don't expect or behave in a way that forces the bereaved person to have to make you feel better.

Usually, the intensity diminishes as time passes, but in some cases it doesn't. This may be understandable, but if, after a long period of time, you or someone else seems stuck, consult a health care professional.

Likewise, if you or someone else shows no response or emotion, and carries on like nothing has happened, this too may be a time to consult a health care professional.

Sometimes intense feelings may come back after three, six, twelve months or more, which may often be the time we expect to feel better. Response to loss is an individual and very personal process. Check in as often as you feel is appropriate, regularly, occasionally, but often on a big monthly, first- or second-year anniversary.