

5/ CARING FOR OR BEING WITH THE DYING

These information sheets have been created to demystify some beliefs and misconceptions around dying, death and funerals. They are designed to inform and 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 is not anything new, rather a return to a traditional approach, where families and friends are involved at every stage. Choices may be influenced by culture, beliefs, community, finances or sustainability issues.

These sheets may assist you to:

- better understand what is involved in the process of dying, death and bereavement
- participate more fully in any of the stages
- 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 funeral to honour and celebrate a life
- have an easier and healthier bereavement.

Being with someone while they are dying can be many different things: challenging, exhausting, heartbreaking, satisfying, expanding, joyful, or liberating. It can be 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 may 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.

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. 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, and not your own. 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.

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Some of the elements involved:

MEDICAL TEAM

attending doctor/palliative care doctor, community nurses/palliative care nurses, social worker (palliative care).

COMMUNITY TEAM

primary carer, family, friends, neighbours, church, sport and social groups.

DOCUMENTS

AHCP, EG, Last Will, Next of Kin, Person Responsible, Instructions on Death, and contact list, for example.

ENVIRONMENT

quiet house, 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, handles, 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.

Be guided by the health professionals, and tune into your own knowing.

Some signs of the body shutting down are:

- No desire to eat, as the body does not need to be nourished
- No desire to drink, as it becomes too difficult to swallow
- Little or no faeces or urine
- Cool, moist or mottled skin
- Continuous sleeping
- Rhythmic periods of not breathing, and rattle-sounding breathing.

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.

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END OF LIFE, THE MOMENT OF DEATH CONT.

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, and relieved. These, and others, are all common feelings. Feel it all, and discuss them if appropriate, but remember you are accompanying. **Don't let your emotions take over the situation.** The dying person is in the last and the biggest moment of their life.

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 time of fear and concern, 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 as they die out of guilt; you can only do what you are capable of.

THINGS TO CONSIDER IN BEING WITH THE DYING

- Be as prepared as possible. Death is certain, although the time of death is uncertain.
- Discuss where any documents are, what they contain + where they are kept (including the Advance Health Care Plan, Enduring Guardianship, Power of Attorney + the Last Will).
- Familiarise yourself with the community, welfare + medical service available.
- You may choose to be the primary carer or a support person. You may choose not to.
- It can be useful to have a support person for yourself.
- Decisions + circumstances can change.
- Stay flexible, consider yourself + regularly check in with the person, health professionals, + others.
- Consider plans for caring, death + the funeral. This may seem intimidating, but the person may want to have input. Environmental, psychological, emotional + spiritual needs all need to be considered, while they are still able to communicate.
- Consider what you are capable of + talk to other loved ones about their capabilities.
- There may be personal or emotional things they or you need to talk about.
- There is no certain timeframe, so you may need help with children, pets + other commitments you may have.
- Some personal issues may never be resolved.
- Some things may have to be put on hold.



The Natural Death Care Centre and Tender Funerals are both not-for-profit organisations based in NSW, committed to informing, educating and empowering individuals, communities, and medical and health professionals. We have a natural, holistic and respectful approach to dying, death, disposal, ceremony and bereavement.

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