3. Navigating the Medical and Health Care System

Death and Dying Matters

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

Most of us want to live, and will do all we can to stay alive. For some of us, there may come a time, when our illness or condition deteriorates and we move into our dying process. This may begin a period of more intense emotions, and our 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.

Today's statistics have the average life expectancy at approximately 80 years. Most of us will die of a chronic disease such as heart failure, stroke, dementia or cancer. With chronic ill health, death is an anticipated event you can plan for.

The two most helpful tools that will ensure you receive the care that you want at the end of life:

- An **Advance Health Care Directive/Plan (AHCD/P)** is a document completed when you are of sound mind, that sets 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 is sometimes called a Living Will.
- An **Enduring Guardian (EG)**is a standard legally binding document, made while you have capacity. It follows the same principles as the AHCD/P, except you are appointing a guardian or guardians to act on your behalf **after** you lose capacity. Both are described fully in information sheet 2.

Moving into palliative care or a hospice is not a failure, just as death is not a failure. It can be a great relief to everyone as they provide appropriate services for a dying situation: 50% of us will die in hospital and 30% will die in an aged care facility.

Palliative care services

Palliative care is provided for people of all ages who have a life limiting illness, who are going to die, and when the primary treatment goal is a good quality of life. It is built on the values of **dignity, empowerment, compassion, equity** and **respect**.

In palliative care there are specialist services with doctors, nurses and other staff trained in palliative care. These services are generally consulted in the last months of life, or longer to:

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

Palliative care integrates psychological, emotional, social and spiritual aspects of care, and offers a support system to help loved ones cope during a person's illness and in bereavement.

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.

Morphine

The use of Morphine and other strong painkillers called *opioids* is very common in end of life care. Questions often arise around addiction, tolerance and hastening death.

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Useful questions

Over time your information requirements may change. It may be that loved ones will want answers to questions the dying don't, or vice versa. That is ok and quite normal. Some questions that may be useful are:

- How long do other people with this illness usually live?
- What will the 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 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 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

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.

If you or someone you know is considering euthanasia, it may be about pain control, feeling burdensome, losing dignity or losing control. However most people who are approaching death do not end their own lives. It can be helpful to talk to someone whose opinion you trust.

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