We acknowledge the support of the South Australian Government Department of the Premier and Cabinet in making the resource available.

Palliative Care aims to comfort, not to cure; to relieve pain and distress for people who are dying; and to support patients, families and friends in approaching death and in healing grief.
Palliative Care South Australia Inc.

Vision:
All South Australians facing death and bereavement are supported to live, die and grieve well.

Mission:
Palliative Care SA seeks to influence, foster and promote access to quality palliative care through public awareness, policy development, advocacy and education. We work to create networking opportunities for people working in health care and the wider community to learn more about palliative care and its benefits for people living with a life limiting or terminal illness and their families.
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Introduction

Talking about death and dying can be an extremely difficult process for the medical practitioner and their patients. For both the medical practitioner and the patient, a variety of cultural and personal constraints have meant that death and dying are almost taboo subjects.

Recent research has shown that whilst pain relief and the ability to make decisions for themselves are extremely important issues for dying patients, of equal importance are spiritual and social issues. For many medical practitioners, raising and discussing these issues has proven difficult, and so one of the aims of this booklet is to assist medical practitioners to explore the patient’s perception of their illness and prognosis and plan for their end of life care.

In many states of Australia, Parliament has enacted laws which give patients the right to make known their wishes regarding their end of life care, and palliative care has provided a process for medical practitioners, nurses, allied health workers, patients and their families to work together to make their patient’s last days as comfortable as possible.

**Advance Care Directives** are one of the tools available to the medical practitioner in the discussion about death and dying and care at the end of life. These Advance Care Directives may be discussed when a patient is healthy, as a means of making their wishes known should they become extremely ill, or by patients who are terminally ill, as a means of retaining control over their treatment.

This booklet is therefore divided into two sections – Section 1 deals with talking about death and dying with terminally ill patients and Section 2 discusses Advance Care Directives with both well people and those who are terminally ill. You may choose which section of the booklet is most appropriate for the information you wish to obtain.
**Key Issues**

- It is the expectation of most patients that the medical practitioner will initiate discussion around death and dying when appropriate.
- Discussing death and dying takes time and is better suited to a prolonged consultation.
- Advance Care Directives can provide a framework for the discussion.
- Open-ended questions and empathic listening are the two major elements of initiating and guiding the conversation.
- For this conversation the person may want to have a support person with them and you should try to ensure this occurs.
- Exploring spiritual and religious issues may be very important for the patient at this time, and the medical practitioner should facilitate this either through supporting the patient in their beliefs or referring the patient to the appropriate expert.
- There are a variety of palliative care supports available for the patient and the medical practitioner, and the medical practitioner should not hesitate to access them.
- A particularly appropriate time to initiate a discussion about Advance Care Directives is during the 75+ Health Check.
Section One

Talking about Death and Dying

Patients have identified the following characteristics that make up quality care towards the end of their life:1,2

- Receiving adequate pain and symptom management
- Avoiding inappropriate prolongation of dying
- Achieving a sense of control
- Relieving burdens and strengthening relationships with loved ones
- Clear decision making
- Preparation for death
- Completion (attending to unfinished business and saying good bye)
- Contributing to others
- Affirmation of the whole person (being seen as a person, not as an illness).

One of the most difficult issues for medical practitioners can be initiating discussions about death and dying. Some practitioners worry that such discussions may remove hope from their patients, but this has not been found to be the case – rather “for dying patients and their families, preparation does not preclude hope – it merely frames it.”4 Other medical practitioners may feel they should wait until the patient raises the topic, but studies have found that patients overwhelmingly feel that this is the responsibility of the doctor.

Medical practitioners may be anxious that talking about death to patients and their families may open up strong emotions which the practitioner is powerless to deal with. However, these emotions will occur whether the doctor brings them up or not, and the doctor may in fact be able to alleviate much of the fear and anxiety, and allow the patient and family to feel that they are not alone.

It is important for the medical practitioner to be aware that they do not need to “fix” everything for their patients – that “being a fellow traveller who understands and listens carefully to insoluble problems often is therapeutic”.3

Whilst planning for dying is often discussed in negative terms – i.e. what the patient doesn’t want (pain, helplessness), it may be more productive to discuss care in terms of what the patient does want (comfort, control, compassion).

Before beginning any discussion about death and dying with patients there are some issues that the medical practitioner themselves will need to address.
This summary has been taken from a review of the published literature and from focus groups and interviews with GPs and incorporates information from both the medical practitioner and patient viewpoint.

- Talking about death and dying and planning care is a time consuming process and will require more than one prolonged consultation.
- Active listening and empathic communication are two vital elements in the discussion of death and dying. Open-ended questions are better to explore these issues. Don’t be afraid to ask the patient what they mean by their answers.
- The family will need to be involved in discussions at some point and the doctor’s knowledge of the patient and their family is likely to be the most important factor in deciding when this should be.
- Families and individual family members will vary in their coping styles including their willingness to discuss issues around death and dying. If possible, each family and patient should be allowed to move forward at their own pace.
- The medical practitioner and family should never assume that they know what the patient’s wishes are in relation to the time around their death, as research has shown this to be consistently inaccurate.
- Attention to spiritual, religious and existential issues is vital in palliative care, and the medical practitioner will need to encourage the patient to explore these with the most appropriate person for that patient.
- Be aware of the spectrum from sadness to clinical depression, and that it may be appropriate to explore the diagnosis of depression in more depth.
- It is extremely important to remember that patient and family understanding of certain terms may be different from the medical practitioners and so definitions of all terms around end of life care should be clearly discussed.
- The skills required around these discussions are rarely natural – they are learned through experience and training.

If you are uncomfortable discussing death, dying and end-of-life care, or feel you do not have the appropriate skills, there are a number of options for assistance and support. You can contact the Specialist Palliative Care service in your area to discuss your situation or how to make a referral to them. You can find contact details at www.pallcare.asn.au/services.
A Suggested Framework for Discussion

The medical practitioner has four major roles in assisting patients who are dying:

- Ensuring the patient is physically comfortable and free from pain.
- Ensuring the patient knows they will not be abandoned and left to face death alone.
- Assisting the patient to define and then achieve goals and tasks for their remaining time.
- Ensuring patients have a sense that they are in control of what is happening to them.

The following framework has been developed using both the literature and suggestions from general practitioners facing these situations daily. The course of a terminal illness will vary markedly between patients and between illnesses, and there may be certain patients the medical practitioner finds can never face this discussion. It should be remembered too, that this discussion will occur over a series of visits and involve a variety of people as appropriate (partners, other family members, spiritual advisers, etc).

In the discussion around death and dying, open ended questions which allow the patient to articulate their fears and wishes are the most appropriate way of initiating a dialogue, and this requires time which is better suited to a prolonged consultation. The questions suggested below represent a mixture of closed and open questions, as GPs suggested that the closed questions (such as “do you have any questions about your illness?”) could be used to lead into a more open discussion.

The diagnosis of a serious illness inevitably raises in the patient’s mind questions about death and dying and these may be explored at any point in their illness. When a patient is facing a terminal illness, it does not mean that their life cannot be lived to the full.

**Step 1 – Choosing the right time**

- This is very much up to the individual situation, and your knowledge of the patient and their family.
- It is important that this discussion occurs when the patient and medical practitioner have faith and trust in each other. This may already exist because of previous contact, however if it does not, it may be appropriate to provide practical assistance e.g. symptom relief, before beginning the deeper discussions required.
- Often the decision to go from curative to palliative care is uncertain and ambiguous, particularly if a variety of practitioners are involved.
- When it has been decided to institute palliative care rather than curative care, a discussion about death and dying may be appropriate. Thus, if someone is diagnosed with early stage breast cancer, the major medical effort will be curative, however if this fails, and metastases are diagnosed, a more palliative approach may be decided upon and the discussion around death and dying commenced.
• It is important to be aware that studies have shown that patients prefer to discuss planning for death and dying sooner rather than later, particularly before they become extremely ill or require hospitalisation.

• For chronic, non cancer illness where the prognosis is less certain, it may be possible to use the period following a crisis situation to begin the discussion.

Do you have any questions about your illness?

Is now a good time to discuss what’s going to happen in the future?

It seems the treatment may not be working as well as we hoped. What do you think is happening?

Step 2 – Developing a treatment plan/Clarifying prognosis

• Provide guidance in understanding medical options and be aware that a patient’s understanding of what is happening may be very different from the medical practitioner’s.

• Many patients want to know how they will die – “What will happen to me?” or “Will I be in pain?” Be direct, yet caring in answering these questions.

• Be truthful, but sustain spirit.

• Use simple, everyday language.

• Acknowledge how this illness has created a sense of uncertainty.

• Make recommendations regarding appropriate treatment.

• Affirm that you will be there to guide the patient through the whole process.

• Initiate timely palliative care where appropriate.

What concerns you most about your illness?

What worries you about what might happen to you?

How is treatment affecting you or your family?

Where are things up to for you?

What do you see in the future?

Step 3 – Tying up loose ends

• There are often many practical and emotional tasks for patients at this time, and the medical practitioner can assist them by facilitating the discussion around remembering, reunion and reconciliation.

• People often need to talk about “how to say goodbye” and their sense of being a burden for their family.

If you haven’t said the things you want to say to your family, do you want to say them now?

Are there things you need to do?
Step 4 – Sorting out spiritual/religious issues
- Facing death can raise many questions relating to the meaning and purpose of life. Often the questions here arise from the patient – “Why me? What have I done to deserve this?” There are no answers to these questions, but the medical practitioner can reaffirm the patient’s worth and the meaning of their life as reflected in their achievements and their relationships with people around them.
- It is extremely important to recognise and acknowledge the spiritual and/or religious needs of the patient at this time.

Some medical practitioners may find discussion of these issues difficult because of their own beliefs, however the issue is one of support for the patient and helping the patient to find someone they will be comfortable to discuss such issues with.

- Be aware that spiritual issues differ from religious issues. The medical practitioner should remember that there are other members of the palliative care team (e.g. counsellors and pastoral care workers) to whom they can refer the patient, whilst still maintaining the care relationship. It may also be appropriate to ensure the relevant religious advisor is aware (e.g. a priest or a rabbi or imam).

Is faith important to you?
Do you have someone to talk to about these matters?
What does spirituality mean for you?

Step 5 – Filling out an Advance Care Directive (if appropriate). Also see Section 2
- Completion of an Advance Care Directive is only a part of the overall process of planning for death and dying. The Advance Care Directive has been shown to provide “a language and framework for patients to organise their thoughts and articulate preferences” and it is important that the form is seen as a tool rather than an end in itself.
- Singer et al. found that patients were very concerned about potentially leaving the burden of decision making on their family and this was a strong motivation for making decisions about end of life care and signing an Advance Care Directive.
- Appointing a Substitute Decision Maker provides an opportunity for the patient to discuss their wishes with him or her, and with their family, and for the medical practitioner to explain the options available.
- When completing an Advance Care Directive that has instructions about death and dying, it is important that the patient be as specific as possible in describing what is and what isn’t acceptable, in terms of quality of life and treatment options.
• It is also important to ensure that all terms used are understood in the same way by the medical practitioner, the patient and the patient’s Substitute Decision Maker.

• When discussing the wording of an Advance Care Directive, it is important to ensure the patient understands exactly what they are requesting and what is important to them:

You have previously said to me that when your time comes, you want to let nature take its course. I will make sure that you are comfortable at all times and that ultimately, you are able to die comfortably. Do you still feel that way?

If you ever become so ill that you were unable to speak for yourself, who would you want to make decisions regarding your medical care?
Section Two

Completing Advance Care Directives

In South Australia, the *Advance Care Directives Act 2013* makes it possible for patients to appoint a Substitute Decision Maker (or more than one) to speak on their behalf at any time they are unable to do so themselves, and/or record their values, wishes and preferences for future care including legally binding refusals of specific medical treatments.

Previously, under the *Consent to Medical Treatment Act 1995*, a person could appoint a *Medical Power of Attorney* (Schedule 1) or write an *Anticipatory Direction* (Schedule 2), or under the *Guardianship and Administration Act 1993*, appoint an *Enduring Guardian*.

If any of these are in place, they will still be recognised in the new legislative environment. Any person over the age of eighteen years is encouraged to complete an Advance Care Directive, and if possible appoint a Substitute Decision Maker.

The Advance Care Directive form is available as a DIY kit online (www.advancecaredirectives.sa.gov.au) or as a hard copy from Service SA $5 or the Office of the Public Advocate $5.

It is generally acknowledged that planning for care at the end of life should involve an active partnership between patients and their doctors, with agreed goals of care. But it is important to realise that planning for dying does not occur solely within the context of the medical practitioner/patient relationship but also within relationships with close loved ones, and so the process of planning care must involve those supports requested by the patient.

It is often easier to speak to people about plans for death and dying when they are well and not as emotional as following diagnosis of a terminal illness. Actually introducing the subject of signing an Advance Care Directive can be difficult for many medical practitioners; however, there are a variety of opportunities, which arise during consultations when the subject can be raised:

- A particularly appropriate time for the discussion of the Advance Care Directive is during a 75+ Health Check.
- Patients often discuss the illnesses of friends or neighbours – for example, the onset of Alzheimer’s disease or a diagnosis of cancer. The medical practitioner may use this opportunity to ask if the patient had ever considered what would happen should this occur in their family, and if the patient proves receptive, an appointment can be made to discuss the process further.
One of the most difficult aspects of the process is finding the time to discuss all the issues associated with the signing of the Advance Care Directive form, but there are now a number of different avenues for patients to get advice about the form in general e.g. Legal Services Commission, or your own legal adviser, as well as your GP.

In giving advice to the patient, the medical practitioner should ensure that the patient understands the importance of being as specific as possible when recording directions and wishes. It is important to clearly discuss the implications and ramifications of either continuing or refusing certain treatments and if the patient is terminally ill, the medical practitioner must be very honest about the prognosis, as unrealistic expectations of survival and quality of life mean that both the doctor and patient cannot plan effectively.

The patient should be encouraged to be as precise as possible in their direction e.g. the patient statement “I don’t wish to be a burden on my family” gives no indication of specific care. A clear direction would be as follows:

“I do not want artificial nutrition and hydration started if they would be the main treatments keeping me alive. If artificial nutrition and hydration are started, I want them stopped.”

Advance Care Directives completed on the prescribed form are the preferred instrument for making values and wishes about medical treatment known and can be completed either on line or in writing on the form in the Advance Care Directives DIY kit.

Be aware, that Advance Care Directives should be reviewed regularly, in case patient’s wishes change. The patient may wish to change the person appointed

Mr White is a 55 year old man who has just retired. He came to see his GP for a routine physical check up. During the visit, he mentioned that one of the reasons he came was because his best friend has just been diagnosed with prostate cancer, which was quite advanced and that his friend was very frightened about what would happen to him. Dr Wilson explained that he has just checked Mr White’s prostate and could feel no abnormality, however it may be timely for Mr White to think about what would happen in his family if he or his wife was diagnosed with a life threatening illness. Mr White admitted that he had never thought about it, but that he would hate to “be kept alive as a vegetable”. Dr Wilson mentioned that Mr White could specify the care that he wished for or did not want should such a situation arise, and also specify who he would like to make these decisions if he was no longer capable. Mr White was very interested, and made an appointment for the following week to discuss the issue further.
to be their Substitute Decision Maker, or other provisions in the Advance Care Directive itself. To do so use the ‘Cancelling my Advance Care Directive’ form which is included in the Advance Care Directives DIY Kit. Remember, a new form should be completed.

In the event the patient has no capacity to complete a legally binding Advance Care Directive, Palliative Care South Australia developed a form called The Palliative Care Plan, which can be used to document the goals of care and decisions about palliative care decided between the family, medical practitioner and other staff. This form is available at www.pallcare.asn.au

Suggested Wording for Advance Care Directives

• If I am permanently unable to communicate, or recognise my family and friends, I only want medical treatment that keeps me comfortable.

• If I am in the terminal phase of a terminal illness I do not want life-sustaining treatment (including CPR) started. If life-sustaining treatments are started, I want them stopped.

• I will accept all health care and medical treatment which will give me more time with my family, if considered appropriate.

• I do not want artificial nutrition and hydration started if they would be the main treatments keeping me alive. If artificial nutrition and hydration are started, I want them stopped.

Artificial nutrition and hydration is where food and water are fed to a person through a tube. The tube can be inserted through the nose to the stomach or directly into the stomach (gastrostomy) or it can be a needle in the vein.

• I want artificial nutrition and hydration even if they are the main treatments keeping me alive.

• Please keep me warm, dry and pain free. Do not transfer me to hospital unless absolutely necessary. Only use measures which may enhance my comfort or minimise my pain. Please use no x-rays, blood tests or antibiotics or operations unless they will improve my comfort.

• I want to be kept as comfortable and free of pain as possible even if it prolongs my dying or shortens my life.

(These suggestions have been adapted from the AAFP6 and Molloy7, as well as the SA Advance Care Directive DIY Kit)

Often Asked Questions

What if the family disagrees with the Advance Care Directive?

Once a patient signs an Advance Care Directive, and includes specific binding refusals of particular health care which are relevant and applicable to the current situation, it is legally binding, and the family may not direct the medical practitioners to do otherwise than the Directive. However, disagreements are not pleasant and the GP may be able
to address these in a variety of ways. Advance Care Directives may be useful too, where there is disagreement within the family itself about treatment, as they allow the medical practitioner to focus the family on the patients’ wishes rather than their own.

The most effective method of dealing with family conflict is to try and prevent it initially by involving the family as much as possible in all decisions about death and dying, however it is recognised that this may not be possible in all situations.

There are many reasons a family may disagree with a treatment plan, and it is worthwhile considering a list of potential reasons:

- Denial of what is really happening.
- The medical practitioner’s communication style may increase misunderstanding e.g. the use of jargon, or non-specific statements.
- Families obtain information from multiple sources, none of which may agree with each other, or may lead to unrealistic expectations.
- The family will be coming to terms with their grief, and cannot yet accept the diagnosis.
- Guilt associated with having to make decisions that may shorten a loved one’s life.
- The family may believe that economic considerations are influencing treatment decisions.

By identifying the underlying reasons for conflict, and intervening to address them, it may be possible for the medical practitioner to help the family become reconciled to the wishes of the patient.

Talking to Adolescents about Death and Dying

Under the Advance Care Directives Act 2013, any person aged 18 years or over may sign an Advance Care Directive or appoint a Substitute Decision Maker. However, there may be situations where adolescents under eighteen are diagnosed with a terminal illness and may wish to give directions regarding their care whilst they are dying, particularly if they have been ill for some time and understand its terminal nature.

If an adolescent returns to their community to die, it can be a very traumatic time for all concerned, including the medical practitioner. In most cases, co-operative decisions will be made between the medical practitioner, the parents and the adolescent. The medical practitioner should recognise that many adolescents are capable of making health care decisions, and they may be asked to act as an information source and facilitator if conflict around treatment arises.

The medical practitioner should also recognise that they do not have to undertake the full burden of care in these cases, and should access Palliative Care Services and any other available resources as early as possible.
Cultural considerations in death and dying?
Cultural backgrounds are extremely important in palliative and end-of-life care. Each culture has traditions and rituals around death and dying, and it is important the medical practitioner considers culture in determining the most appropriate end of life care.

It is important to approach each patient and family as individuals, and explore with the family the best way of planning care. Usually, medical practitioners can talk sensitively about alleviating suffering and managing illness, and if the medical practitioner listens actively and respects the patient, a way forward can be negotiated. Do not hesitate to ask the family about relevant cultural practices or to contact an elder of the community, or a priest, imam or rabbi.

Aboriginal and Torres Strait Islander people have very specific traditions relating to death and dying and again, listening and respecting the patient and their family is the first step. Further information or support to care for Aboriginal and Torres Strait Islander patients can be obtained by contacting PCSA or your local Aboriginal Health Service. Contacts can be found in the Resources section.
Key References:


2. Steinhauser, KE; Clipp, EC; McNeilly, M; Christakis, NA; McIntyre, LM & Tulsky, J. In search of a good death: Observations of patients, families and providers. *Ann Intern Med.* 2000, 132(10): 825-832.


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Disclaimer

The information contained in this booklet is for general guidance only. Whilst every effort has been made to ensure that the patient care recommendations in this book are correct and in keeping with accepted standards of practice at the time of publication, neither the authors nor the publisher can accept any legal responsibility for any errors or omissions that may be made. It is the responsibility of the reader, before using any medication, technique or procedure to seek appropriate professional advice.

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### Important Contacts

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My Advance Care Directive is kept:

My Enduring Power of Attorney is kept:

My Will is kept:
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