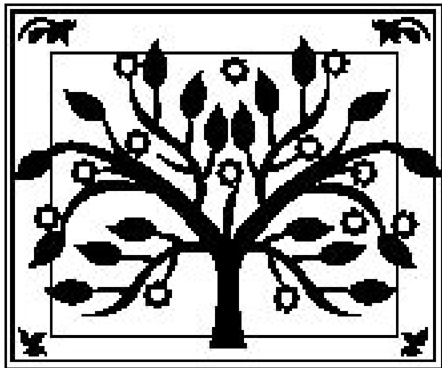
TALKING TO PATIENTS ABOUT DEATH AND DYING



Discussing Patient Concerns

Advance Health Care Directives (including *Anticipatory Directions* and *Medical Power of Attorney*)

This Booklet was prepared by Teresa Burgess and Dr Justin Beilby from the Department of General Practice at Adelaide University and Dr Mary Brooksbank from the Palliative Care Unit at the Royal Adelaide Hospital.

The information in the booklet was developed using a comprehensive literature review, focus groups with a variety of General Practitioners from rural and urban practices and extensive discussions with key stakeholders in the areas of general practice and palliative care.. The authors would like to thank all of those who have assisted with the preparation of this booklet, particularly those people who participated in the interviews, focus groups and review process which examined and refined the booklet. A copy of the Final Report can be obtained by contacting Dr Mary Brooksbank on 8222 2021

CONTENTS

Introduction ……………………………..…… 3

Key Issues …………………………………..... 4

Section One

Talking about Death and Dying …………….... 5

A Suggested Framework for Discussion ……… 7

Section Two

Completing Advance Health Care Directives … 12

Suggested Wording for Advance Health Care Directives ……………………………...…... 15

Often Asked Questions …………...……..…… 16

Resources. ……………………...……..…… 19

Key References ………………..……………… 23

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.[1,2,3] 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 the patient's last days as comfortable as possible.

Advance Health Care Directives (known also as ***Anticipatory Directions or Living Wills)*** 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 Health 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 Health 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 Health 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.
- The discussion must involve the family as early as possible.
- 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 Health 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 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 they are not alone.

It is important too, 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 – ie 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 are 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 practitioner's, and so definitions of all terms around end of life care should be clearly discussed.

- The skills required for these discussions are rarely natural – they are learned through experience and training

If you are uncomfortable in the area of Palliative Care, or feel you do not have the appropriate skills, there are a number of GPs with interest, skills and insights into caring for people who are dying to whom you may wish to refer your patients. These GPs can be identified through your local Palliative Care Team. *(Contact details can be found in the Resources section at the end of this booklet).*

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[2,3,5,] 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 still 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 eg 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 for the patient through the whole process – *"no matter what happens, I will be there for you"*.
- Initiate timely palliative care when 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 that 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 supporting the patient's belief system 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 (eg 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. (eg a priest or rabbi).

  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 a Medical Power of Attorney and/oran Advance Health Care Directive (if appropriate). Also see Section 2

- Completion of an Advance Health Care Directive is only a part of the overall process of planning for death and dying. The Advance Health Care Directive has been shown to provide "a language and framework for patients to organise their thoughts and articulate preferences"[8] and it is important that the form is seen as a tool rather than an end in itself.

- Singer et al[4] 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 Health Care Directive.

- Appointing a Medical Power of Attorney or Medical Agent provides an opportunity for the patient to discuss their wishes with their family, and for the medical practitioner to explain the options available to the patient and family together.

- When completing an Advance Health 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 family.

- When discussing the wording of an Advance Health 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 became 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 Health Care Directives

In South Australia, we have three options for making Advance Health Care Directives. Under *The Consent to Medical Treatment Act 1995,* the patient can appoint a *Medical Power of Attorney (Schedule 1)* or write an *Anticipatory Direction (Schedule 2).* The third option is for the patient to appoint an *Enduring Power of Guardianship* under the *Guardianship and Administration Act 1993* (contact the Office of the Public Advocate).

The Consent to Medical Treatment and Palliative Care Act (The Act) has six key provisions focussed around the importance of clear and ongoing communication processes between medical practitioners and patients, and the patient's right to self determination.

In particular, The Act allows for patients to state their wishes about future care:

> *Patients will be able to make advance decisions about the kind of treatment they want or do not want, in the event they are not able to decide for themselves in the future. A decision made in this way is called an* **Anticipatory Direction.**
>
> *Patients will be able to appoint representatives (known as medical agents) to make decisions about treatment on their behalf if they are not able to do so. The document which authorises the medical agent to act on behalf of the patient is called a* ***Medical Power of Attorney***

A Medical Power of Attorney can incorporate the patient's directions about death and dying, so some patients may feel it is unnecessary to complete an Advance Health Care Directive as well.

Directions about death and dying can also be included in the format of an *Enduring Power of Guardianship* in the same way that they can in a *Medical Power of Attorney.*

Whilst there is consensus that there should be an active partnership between patients and their doctors in determining their preferred treatment, there has been comparatively few Advance Health Care Directives actually completed. Any person over the age of eighteen years can sign an *Anticipatory Direction* or a *Medical Power of Attorney* provided they are of sound mind. These forms may be registered with *Medic Alert* and any medical practitioner can check the register as required.

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. In particular, the appointment of a ***Medical Agent,*** should patients become incapable of making their own decisions, requires detailed discussion between the patient, the physician and the Medical Agent.

It is often easier to speak to people about plans for death and dying when they are well and are not as emotional as following diagnosis of a terminal illness. Actually introducing the subject of signing an Advance Health 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 Anticipatory Direction is the 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.
- It may be easier to raise the issue of *Medical Power of Attorney* before the *Anticipatory Direction*

One of the most difficult aspects of the process is finding the time to discuss all the issues associated with the signing of these forms

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 had 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 should such a situation arise, and also specify who he would like make these decisions if he was no longer capable. Mr White was very interested, and made an appointment for the following the week to discuss the issue further.

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 eg 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"*[6]

Anticipatory Directions and Medical Power of Attorney are only binding if they are completed using the exact words and layout of the "Anticipatory Direction" and "Medical Power of Attorney" Forms provided by the South Australian Government. Copies of these can be found in the package with this booklet.

Be aware too, that Advance Health Care Directives should be reviewed regularly, in case patients' wishes change. The patient may wish to change the person appointed to be their Medical Power of Attorney, or other provisions in the Anticipatory Direction itself, and a new form should be signed and completed if any changes are required.

The Palliative Care Council of South Australia has developed a form called *The Good Palliative Care Plan* which can be used to document palliative care decisions, but it is not a legally binding expression of the patient's wishes.

Suggested Wording for Advance Health Care Directives

If I am in the terminal phase of a terminal illness or in a persistent vegetative state:

- I do not want life-sustaining treatment (including CPR) started. If life-sustaining treatments are started, I want them stopped.

CPR (cardio-pulmonary resuscitation) is a treatment to try to restart a person's breathing or heartbeat. CPR may be done by pushing on the chest, by putting a tube down the throat or by other treatment.

- I want the life-sustaining treatments that my doctors think are best for me.
- 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 when 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 (a 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 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 such care prolongs my dying or shortens my life.

Comfort care is care that helps to keep a person comfortable but doesn't make him/her get well. Bathing, turning and keeping a person's lips moist are types of comfort care.

(These suggestions have been adapted from the AAFP[6] and Molloy.[7])

Often Asked Questions

What if the family disagrees with the Advance Health Care Directive?

Once a patient signs an ***Advance Health Care Directive***, it is legally binding, and the family may not direct the medical practitioner to do otherwise than the *Directive*. However, disagreements are never pleasant, and the GP may be able to address these in a variety of ways. *Advance Health 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 patient's wishes rather than their own.

The most effective method of dealing with family conflict is to try to 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 (the inability to explicitly recognise facts because of unacceptable psychological consequences such as an overwhelming grief or guilt.) may produce displacement – a focus of concern on trivial but controllable matters.
- The medical practitioner's communication style may increase misunderstanding – eg 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 Consent to Medical Treatment and Palliative Care Act,* any person aged 18 years or over may sign an Anticipatory Direction or a Medical Power of Attorney. 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 their Palliative Care Teams and any other available resources as early as possible.

What of talking about death and dying with patients from other cultures?

In South Australia today, people come from a variety of cultural backgrounds, including European, Middle Eastern, Asian and Aboriginal and the Torres Strait Islands. All of these cultures have traditions and rituals around death and dying, and it can be difficult for the medical practitioner to determine the most appropriate end of life care.

It is important then 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 a priest or elder of the community.

Palliative Care Australia produces a book entitled *Multicultural Palliative Care Guidelines* which provides culturally specific information about death and dying in other cultures. It can be obtained by phoning ***8291 4137*** (for a small cost).

Death and Dying for Aborigines and Torres Strait Islanders has very specific cultural traditions, and again, listening and respecting the patient and their family is the first step. Further information can be obtained by contacting your local Aboriginal Health Service. *(Contacts for these can be found in the Resources section).*

Resources

Palliative Care Services in South Australia.

Metropolitan

Central and Eastern Adelaide Palliative Care Service
Royal Adelaide Hospital,
North Terrace, ADELAIDE 5006
(08) 8222 2021

Mary Potter Hospice, Calvary Hospital
89 Strangways Tce,
NORTH ADELAIDE 5006
(08) 8239 9144

Southern Adelaide Palliative Services
(Formerly Southern Community Hospice Program)
Daw House Hospice
Daw House, 700 Goodwood Rd,
DAW PARK 5041
(08) 8275 1732

Southern Adelaide Palliative Services
For services for **Noarlunga Hospital**; **Flinders Medical Centre** and the **Adelaide Health Care Alliance Inc** (formerly Ashford Hospital), please contact the Southern Community Hospice Program:
(08) 8275 1732

North West Area Health Service
Western Palliative Care Service/ Queen Elizabeth Hospital
Queen Elizabeth Hospital, 28 Woodville Rd, WOODVILLE 5011
(08) 8222 6825

Lyell McEwin Hospice
Lyell McEwin Health Service,
Haydown Rd, ELIZABETH VALE 5112
(08) 8182 9208

Phillip Kennedy Hospice
Phillip Kennedy Nursing Home, Everard St, LARGS BAY 5016
(08) 8242 1429

Northern Hospice Care Service
Modbury Hospital
Smart Rd, MODBURY 5092
(08) 8264 6000

Rural

Barossa and Districts Palliative Care Service
Barossa & Area Community Health Service, North St, ANGASTON 5352
(08) 8563 8544

Adelaide Hills Community Nursing Service. (Palliative Care)
PO Box 42, MOUNT BARKER 5251
(08) 8393 1888

Lower Eyre Peninsula Palliative Care Service
Port Lincoln Hospital,
PORT LINCOLN 5606
(08) 8683 2260

Murray Mallee Palliative Care Service
Murray Bridge Hospital, Swanport Rd,
MURRAY BRIDGE 5253
(08) 8535 6800

Northern Yorke Peninsula Palliative Care Service
Northern Yorke Peninsula Community Health Service, WALLAROO 5556
(08) 8823 3122

Port Pirie Palliative Care Service
Port Pirie Regional Health Service, Alexandra St, PORT PIRIE 5540
(08) 8632 1022

South Coast Palliative Care Service
South Coast Hospital,
VICTOR HARBOUR 5211
(08) 8552 1066

Gawler & Districts Palliative Care Service
Gawler Health Service, GAWLER 5118
(08) 8522 3890

Kangaroo Island Palliative Care Resource Person
Kangaroo Island Community Health Service,
KINGSCOTE 5223
(08) 8553 4231

15

Mount Gambier and Districts Palliative Care Service
Mount Gambier & District Regional Health Service, Will St North,
MOUNT GAMBIER 5290
(08) 8721 1460

Naracoorte Palliative Care Service
Naracoorte Community Health Service,
NARACOORTE 5271
(08) 8762 8160

Port Augusta Palliative Care Service
Port Augusta Domiciliary Care, 40 Flinders Tce, PORT AUGUSTA 5700
(08) 8648 5736

Riverland Palliative Care Service
Riverland Community Health Service,
BERRI 5343
(08) 8580 2500

Whyalla Palliative Care Service
Whyalla Domiciliary Care, Wood Tce,
WHYALLA 5600
(08) 8648 8190

Aboriginal Health Services in South Australia.

Adelaide

Aboriginal Health Council of SA,
PO Box 75
Fullarton. SA 5063,
Ph: 8431 4800. Fax: 8431 4822

Adelaide Parks Community Health Services
PO Box 2340
Regency Park SA 5942
Ph: 8243 5611. Fax: 8347 4221

Aboriginal Drug and Alcohol Council of SA
53 King William Street,
Kent Town SA 5067
Ph: 8362 0395. Fax: 8362 0327

Nunkuwarrin Yunti of SA Inc,
182 – 190 Wakefield St,
Adelaide SA 5000
Ph: 8223 521,. Fax:8232 0949

Rural Areas

Ceduna Koonibba Aboriginal Health Service
PO Box 314
Ceduna SA 5690
Ph: 8625 3699. Fax: 8625 2898

Kalparrin Inc Alcohol Rehabilitation Farm
PO Box 319
Murray Bridge SA 5259
Ph: 8532 4940. Fax: 8532 5511

Nganampa Health Service
PO Box 2232
Alice Springs NT 0871
0871 8950 5432
Umuwa – Ph: 8950 1569. Fax: 8952 2299

Port Lincoln Aboriginal Health Service
PO Box 1583
Port Lincoln SA 5606
Ph: 8683 0162. Fax: 8683 0126

Riverland Aboriginal Alcohol Program
3 Wilson Street
Berri SA 5343
Ph: 8582 2024,. Fax: 8582 2150

Yalata Maralinga Health Service
PMB 45
Ceduna SA 5690
Ph: 8625 6231. Fax: 8625 6268

Goreta Aboriginal Corporation
PO Box 244
Maitland SA 5573
Ph: 8836 7205. Fax: 8836 7295

Lower North Community Health Service
PO Box 239
Clare SA 5343
Ph: 8842 3355. Fax: 8842 3338

Pika Wiya Health Service
40 - 46 Dartmouth Street
PO Box 2021
Port Augusta SA 5700
Ph: 8642 9999. Fax: 8642 4456

Port Pirie Regional Health Service
PO Box 546
Port Pirie SA 5540
Ph: 8638 4500. Fax: 8638 4355

Umona Tjutagku Health Service
PO Box 166
Coober Pedy SA 5723
Ph: 8672 5255. Fax: 8672 3349

Web Sites

Palliative Care Council of South Australia Inc
www.pallcare.asn.au

Anti Cancer Foundation
www.acf.org.au

Office of the Public Advocate
www.opa.sa.gov.au

GriefLink
www.grieflink.asn.au

NSW Health
www.health.nsw.gov.au/health-public-affairs/mhcs/ publications

Books

Multicultural Palliative Care Guidelines
Andrew Taylor and Margaret Box
Palliative Care Council of South Australia Inc
202 Greenhill Rd
EASTWOOD SA 5063.
Ph: (08) 8291 4137

Organisations

Palliative Care Council of South Australia Inc
202 Greenhill Rd
EASTWOOD SA 5063.
Ph: (08) 8291 4137

Office of the Public Advocate
PO Box 213
PROSPECT SA 5081
Ph: (08) 8269 7575 or
1800 066969

Royal District Nursing Service
Main Office
31 Flemington St,
GLENSIDE SA 5063
Ph: (08) 8206 0000

Department of Human Services
Executive Services
Level 10, 11 Hindmarsh Square
ADELAIDE SA 5000
Ph: (08) 8226 6436

Key References

1. Singer, PA; Martin, DK; Lavery, JV; Theil, EC; Kelner, M; Mendelssohn, DC. 1998. Reconceptualising advance care planning from the patient's perspective. *Arch Intern Med.* Vol 158: 879 - 884

2. Steinhauser, KE; Clipp, EC; McNeilly, M; Christakis, NA; McIntyre, LM & Tulsky, J. 2000. In search of a good death: observations of patients, families and providers. *Ann Intern Med.* May 16. 132(10): 825 – 32

2. Lo, B; Quill, T & Tulsky, J. 1999. Discussing Palliative Care with Patients. *Ann Intern Med.* May 4. 130(9):744 – 9.

4. Singer, PA; Martin, K & Kelner, M. 1999. Quality end-of-life care. *JAMA.* Jan 13. Vol 281(2): 163 – 168

5. Balaban, RB. 2000. A physicians guide to talking about end-of-life care. *J Gen Intern Med.* Mar; 15(3): 195 – 200

6. AAFP. 1999. Sample Advance Directive Form. *http://www.aafp.org/afp/990201ap/617.html*. viewed 6/6/00

7. Molloy, W. *The Let me Decide Health and Personal Care Directive*. reproduced in Vaughn, K; Ingall, T and Hindmarsh, E. 2000. *Advance Care Directives in General Practice. A Pilot Trial.* The Division of General Practice, CSAHS. Report.

8. Martin, D; Thiel, E and Singer, P. 1999. A new model for Advance Care Planning. Observations from people with HIV. *JAMA.* Jan 11. 159: 86 – 92. P89

Talking about Death and Dying was developed by the
Palliative Care Unit of the Royal Adelaide Hospital and the
Department of General Practice at Adelaide University

Palliative Care Unit

DEPARTMENT OF GENERAL PRACTICE

FACULTY OF HEALTH SCIENCES

This booklet has been funded by a grant from:

South Australian
Department of Human Services