

1. What is Palliative Care?

Palliative Care Australia defines Palliative care as “ a person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary goal is to optimise the quality of life.”

It can be offered for years. It is far more than just the last few days of life.

It applies to all conditions regardless of their nature, the age of the person affected and the stage of the illness.

It helps people to live life as fully and for as long as possible, taking into consideration the physical, psychological and spiritual needs of the patient and their family.

To access these services, ask your GP or specialist for a referral or visit

pallcare.asn.au/palliative-care-services/

2. Who can apply to receive Palliative Care services?

Anyone who has been diagnosed with a life-limiting illness can receive Palliative Care services. We recommend people start their journey with Palliative Care once the diagnosis is confirmed. Treatments and Palliative Care can be undertaken at the same time.

3. What kind of palliative care services are available?

Based on a person’s individual needs, the palliative care services offered may include:

- Pain and symptom management
- Equipment needed to aid care at home
- Assistance for families
- financial support
- cultural needs
- emotional, social and spiritual support
- Referrals to respite care services
- Grief and bereavement support

You can ask a GP, doctors, nurses or a Hospital Liaison Officer for a referral to palliative care and negotiate the services you need with the palliative care team. You and your family can also contact the palliative care services in your region that are listed on PCSA’s website

pallcare.asn.au/palliative-care-services/

4. Is it correct to say that Palliative Care is non-medical care?

Palliative Care provides both medical and non-medical care. As well as bringing comfort for symptoms, the social, spiritual and cultural aspects of a person’s life are also supported.

5. Does palliative care help with pain and symptom management?

Pain and symptom management is a major part of palliative care.

Your doctor or nurse can talk to you about your medicines. It is ok to talk about the costs of medicines as well. You should also talk to them about any concerns or worries you have in providing medicines to the sick person.

Practical tools such as a medications checklist can help you remember when and how to take your medicines.

Remember to always check with your GP or palliative care team before beginning a new type of pain and symptom management treatment. You should also discuss any natural or traditional medicines, the person may be taking.

Community pharmacists are a useful resource and can help to manage and supply your medicines, telling you how to take the medicines safely and receiving the best benefit from them.

Community nursing in your care team can work closely with your community pharmacist and together can teach you about administering medicines at home.

Working closely with your doctor and the nurse will support you in providing medicines safely at home to keep the person comfortable at the end of life.

6. Is Palliative Care only for people living at home?

No. You can choose to use Palliative Care at home with community services and supports, at hospital, in a hospice or within Residential Aged Care Facilities (RACF). Public hospitals, hospices, some private hospitals and some RACFs are able to provide Palliative Care. To find a nearby Palliative Care provider please go to Palliative Care SA's website through this link <https://pallcare.asn.au/palliative-care-services/>. If, you are unsure if people involved in your care are trained to do so please ask them about their skill levels and experience in this area.

7. How do people acquire the skills for palliative care at home?

There are training packs such as [Caring@home](#) which can support family members and carers to learn the skills necessary to administer medications. Community nurses or visiting specialists can do home visits to teach and assist with these daily tasks.

8. How is the transition between home or nursing home to hospital managed? Would you lose the connection with your Palliative Care team as you enter in the hospital because they have their own medical and nursing team?

When a transfer is required from home or the RACF to a hospital, the South Australian Ambulance Service (SAAS) may be called. SAAS has a team of Extended Care Paramedics who are able to support dying in place and based upon their assessment and support, the appropriate action will be taken. The Specialist Palliative Care team has the capacity to visit in the community and at the hospital and so the transfer should be seamless.

9. What financial support is available?

Covering the costs of Palliative Care depends upon many factors associated with the nature and location of services (e.g. at home, hospice, hospital).

If you have a Medicare card Medicare will cover your GP's time but you may need to pay a gap fee. If you are a public patient, the South Australian Health system provides hospital and community support. If you do not have a Medicare card and your private health cover is insufficient some public hospitals may have a repayment program and/or a hardship assistance program.

If you use private health services, some hospice programs and community supports are available, but check with the health provider and the private insurance fund for eligibility.

If you are over 65 and eligible for a Home Care Package through My Aged Care, you can have palliative care services at the same time but please check the coverage of each services to avoid additional costs.

For all age groups unpaid carers (e.g. family members) may be eligible to apply for carer payments, carer allowance or respite. You may need to pay extra costs to hire specialised equipment for use at home.

Funerals are also a significant cost and costs can vary significantly. You may choose to plan ahead and join a pre-paid plans or take out insurance.

For a good summary of costs check the [Department of Health](#) website.

10. If the disease is under control (i.e. a cancer) do I need Palliative Care services?

When a disease is under control and therefore is no longer described as “life-limiting”, Palliative Care can also be suspended. Advance Care Planning focusing upon the things that matter the most can still be encouraged and used. The social aspects of family supports and goal-setting can continue even when treatment for physical conditions stops.

11. What is an Advance Care Directive?

Life is unpredictable so being prepared in advance can help you make important choices regarding the end of your life and ease the responsibility for your loved ones.

Preparing an Advance Care Directive helps to make your wishes and choices respected. This includes your spiritual needs and appointing someone you trust to take decisions for you if you are no longer able to do so.

You do not need a lawyer or a doctor to fill in an Advance Care Directive. Download the booklet or fill in an Advance Care Directive online at advancecaredirectives.sa.gov.au and look for forms and guidelines . If you want a paper copy you can also click on the link on this page to "Purchase Advance Care Directive Kit".

Make sure you that you discuss your wishes with the person that you want to speak on your behalf. Check that they are happy to do so.

12. Where do we send the Advance Care Directive (ACD) once we have prepared it?

You keep it with you, you do not send it anywhere. Make sure your Substitute Decision Maker (SDM) and/or your family members know where you keep it. You may even give your SDM a copy.

13. Do we update the Advance Care Directive?

Yes you can, anytime you want to or feel it is necessary due to changes in circumstances. In that way it is like a will.

14. Is the Advanced Care Directive a legal document?

Yes. The Advance Care Directives Act 2013 (SA) was approved through the SA Parliament and brought into law on July 1st 2014.

15. What happens if I have prepared my Advanced Care Directive but my husband, or my Substitute Decision Maker (SDM) thinks differently?

The ACD allows for you to nominate an SDM who will support your wishes. If they do not agree with your wishes, it is probably in your best interests to appoint an SDM who will.

16. Can a doctor challenge the Advanced Care Directive in court?

No. The ACD is a legal form. Doctors and other health workers are required to follow the instructions presented in ACD.

17. I have an enduring power of Guardianship and not the Advanced Care Directive, should I make one? What are the differences?

An Advance Care Directive empowers you to make clear legal arrangements for your future health care, end of life, preferred living arrangements and other personal matters. It takes over from any Enduring Powers of Guardianship, Medical Power of Attorney and Anticipatory Directions as a single Advance Care Directive Form. If you choose not to update to an ACD, the former directions in the documents listed above still apply.

18. I have an Enduring Power of Attorney and not the Advanced Care Directive, should I make one? What are the differences?

An Enduring Power of Attorney dictates who makes decisions about your finances and legal matters. The ACD allows you to write down your wishes, preferences and instructions for your future health care, end of life care, living arrangements and personal matters. You can appoint Substitute Decision-Makers to make decisions for you when you are not able to do so in the future. An ACD cannot be used to make financial and legal decisions. Preparing an ACD remains a choice at all times.

19. When is a good time to make an Advanced Care Directive?

You can write an Advance Care Directive at any stage of life – whether you are young, older, healthy or unwell. To write an Advance Care Directive, it must be your choice and you must:

- be 18 years old or over
- know what an Advance Care Directive is
- know what it will be used for and
- know when it will be used
- demonstrate capacity to make these decisions .

20. Who will supervise my Substitute Decision Maker? How can I trust them? How can I be sure they will respect my wishes?

At the time of appointing your Substitute Decision Maker, it is important that you trust them and believe that they will respect your wishes. If at any time, this trust changes, then you can amend your Advance Care Directive and change your Substitute Decision Maker. There is no organisation or authority that supervises Substitute Decision Makers. This makes the choice of your Substitute Decision Maker (s) even more important.

21. Who will supervise the medical team to make sure that they are following the instructions as per Advance Care Directive?

All medical teams work within their structures of accountability. They have to meet professional standards and are responsible to their professional registration bodies. However, there is no formal structure outside of this to act as a supervisory body to ensure that your instructions within the ACD are followed.

22. Is euthanasia included in the Advance Care Directive?

Voluntary Assisted Dying (VAD or euthanasia) is, at this time, not legal in South Australia. Current VAD legislation in Australia requires that the person requesting VAD has a terminal illness and is of sound mind. The Advance Care Directive cannot be used to direct VAD if competency has been lost. It is not an option to be included in your Advance Care Directive.

23. How can I place a complaint if I think that my rights are not respected?

In South Australia the Health and Community Services Complaints Commissioner exists to deal with all complaints from consumers relating to the health system. You can access information on the Commission at <https://www.hcsc.sa.gov.au/> .

You can also ask for an interpreter to help at your appointments.