

What is palliative care?

A resource for families and carers of young people transitioning to adult health services

This resource provides palliative care information for families and carers of young people as they transition from paediatric to adult health services.

There are illnesses and conditions in children and young people that cannot be cured and unfortunately, some of these illnesses or conditions shorten a young person's life.

In NSW, the health system is designed to ensure that palliative care and end of life care is focused on the person's needs regardless of age. Families and carers are recognised and supported during care and they play a key role in how health services are coordinated.

A young person has the right to fully understand what care is being proposed, where care will be provided and who will be involved in providing care. Families and carers are encouraged to be involved with decisions about care in discussion with their young person.

Moving to adult health services

Adult health services and hospitals are very different to children's health services and hospitals, including systems, set up and appearances. It may take some time to get used to the new clinicians and the surroundings. Ask as many questions as you need. You need to be comfortable with the transition process.

Preparing early for transition to adult services can help you and your young person to adjust to these changes. Helpful ideas for a smooth and successful transition can be found at the [Trapeze](#) and the [ACI Transition Care](#) websites.

Please talk to your healthcare team if you have concerns and questions about moving to a new team. Be assured that the new doctors and clinicians will receive all the information about your young person's medical history from the teams who cared for them in the children's health services.

Your general practitioner (GP) or family doctor will also receive this history.

Decision-making and consent

A large part of this transition is the shift of decision-making from parents and carers to the young person. Clinicians in adult services may not assume that parents and carers will lead the decision making. This is a different way of thinking and you may take a little time to get used to it.

There will always be a role for parents and carers to support decision making for your young person, though this will be dependent upon the capacity of the young person and their individual circumstances. The young person's healthcare team and transition coordinators can support parents and carers through this period of adjustment.

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Palliative care involves support, treatment and care that improves the quality of life for people living with life-limiting illness.

It is beneficial at any stage of illness, not just for end of life. The healthcare team will do everything they can to support a young person's healthcare needs and their participation in life – this is sometimes known as 'supportive care'.

'Families need to be made aware about what palliative care actually means, who is eligible for palliative care and what services it can provide. Once families are informed, then the conversations can begin.'

Parent of a transitioning young person

Adult palliative care services vary across Sydney and NSW. Some health providers that may be involved include the GP or family doctor, disease-specific specialists and services, Aboriginal health workers, community nursing or allied health services, supportive care or specialist palliative care services.

If a young person has complex symptom issues, or when their illness or condition is more advanced, a referral to a specialist palliative care team can be made by local health care teams.

What is end of life care?

End of life is the time in which a person with a life-limiting illness is nearing death. The needs of the young person and their family and carers is often higher at this time and additional support and services are often required.

Supporting a young person

A young person with a life-limiting illness or condition may have an uncertain course of illness. It can continue with ups and downs for many months or years, or for a shorter time. The following are important points to keep in mind when supporting a young person.

- Ask the healthcare team to explain anything that you do not understand. There are no silly or wrong questions.
- Raise any concerns with new healthcare teams about difficult symptoms, such as pain or emotional distress.
- Young people value honesty and have a need to develop the trust of adults who are involved in their care. This can help them to feel safe and open about planning for their end of life and identifying what is important to them.
- It is very important to involve the young person in decision making about their own end of life care planning.
- Be open and honest with your family and talk about how you can manage what lies ahead.
- Plan to create memories as a family by ensuring you have special times together. For example, create a bucket list or decide on some favourite places to visit.
- This may be an isolating time for a young person with a serious illness. It may also be a difficult time for their siblings, partner and friends. Plan to involve these people where possible. It may be useful for them to speak with a religious person, a counsellor or a psychologist during this time.
- Discuss spiritual or cultural beliefs and connections to nature or art and share with your healthcare team.
- Some young people may be eligible for Make a Wish. Please speak to the social worker or visit [makeawish.org.au](https://www.makeawish.org.au)

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Advance care planning

Advance care planning is a discussion identifying goals and plans for a person's future medical treatment and overall care. Plans should be reviewed regularly as the young person's needs or wishes change. Any aspect of the plan can be discussed at any time with the healthcare team involved in caring for your young person.

Looking after yourself

As the family or carer of a young person with life-limiting illness, it is important to ensure you are looking after yourself by taking care of your own health and emotional wellbeing.

Remember, you are not alone and there are lots of people who can help. If you need to talk to someone outside the healthcare team, ask your GP or a member of the healthcare team to help find a counsellor or other professional to talk to both before and after your young person's life ends.

There are also support groups and organisations that can help both emotionally and practically, so be sure to ask your healthcare team for more information.

'A distinction between palliative care and end of life care definitely needs to be made very clear, and that end of life care is only one component of what palliative care can provide.'

Parent of a transitioning young person

About the artwork

The beautiful watercolour that brightens this document was painted by Sarah Tuntevski in 2020.

Sarah was among the young artists who had their work displayed at Sydney Children's Hospital, Randwick, in an Autumn Art Exhibition. The exhibition was titled, My Illness won't stop me, and the artists were members of the Chronic Illness Peer Support (ChIPS) program.



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Palliative care information and support

For ideas on how to look after yourself and more information, including organisations and support groups, please explore the websites below.

[Aboriginal and Torres Strait Islander care information](#)

CareSearch, palliative care knowledge network

[Adolescent Medicine](#)

Sydney Children's Hospital Network

[Advance care planning](#)

NSW Health

[Advance Care Planning Australia](#)

Funded by the Australian Government

[Authorised Care Plans](#)

NSW Ambulance

[Bear Cottage](#)

[Difficult Conversations](#)

O'Doherty C, Black J. London: Together for Short Lives; 2015.

[Making an Advance Care Directive information booklet](#)

NSW Health, 2021.

[NSW Paediatric Palliative Care Programme](#)

[Paediatric Palliative Care](#)

John Hunter Children's Hospital, Newcastle, NSW

[Palliative Care and End-of-Life Care information](#)

Australian Indigenous HealthInfoNet

[The Groundswell Project](#)

[Time for truth: how to face the end of a life lived well](#)

Power J. Sydney Morning Herald; 2013.

[Transition to Adult Services](#)

Together for Short Lives (UK)

[Understanding the palliative care journey: a guide for individuals, carers, Communities and family](#)

Hunter S, Waight C. Victorian Aboriginal Community Controlled Health Organisations; 2019.

[Welcome to our Journey](#)

Clarke M, Waight C. Collection of end-of life stories. Victorian Aboriginal Community Controlled Health Organisation; 2014.

Carers websites

[Carers Australia](#)

[Carers NSW Australia](#)

[CareSearch](#)

palliative care knowledge network

[Young Carers NSW](#)

Bereavement resources

[Aboriginal Health and Medical Research Council of NSW](#)

Journey to Dreaming Diary

[Australian bereavement resources and services](#)

Australian Centre for Grief and Bereavement

[Bereavement support](#)

Australian Centre for Grief and Bereavement

[Beyond Blue](#)

[Grief and loss](#)

Australian Child and Adolescent Trauma, Loss and Grief Network

[Good Grief](#)

[GriefLine](#)

[GriefLink](#)

[Palliative Care Australia](#)

[The Compassionate Friends NSW](#)

[WellMob](#)

Grief and healing resources

Acknowledgements

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