

# Meaningful conversations with young people with palliative care needs as they transition to adult health services

A resource for health professionals supporting transition

This resource provides advice on transition and starting meaningful conversations with young people and their families and carers who may be wanting to learn more about palliative care as they transition to adult health services.

## Transition for young people who may need palliative care

When a young person is transitioning to adult health services, palliative care may be raised for discussion.

It is important to consider the requirements of the young person, aged 14-25 years, and their family and carers during this transition. When talking to the young person and their family and carers, you may consider the following.

- If it is still appropriate to transition care for the young person from paediatric to adult health services. Depending on the circumstances, some young people may not transition to adult palliative care straight away. However, their general practitioner (GP) or other health care teams can continue to provide the appropriate care and support as required. Ensure this is documented in their care plan.
- Educating the young person about their illness, including its progression, prognosis and likely outcomes of alternative care options.
- Defining the young person's key priorities in care and develop an advance care plan that addresses these issues. If a care plan exists, it should be reviewed before and after the young person transfers to adult services.
- Shaping future healthcare to fit the young person's preferences and values.

***'I was asked about my condition first when I would have appreciated a question directed at me as a person first.'***

**Jess, 19**

- Explaining that a handover to the new healthcare team will be completed and reassure them that while adult health services and hospitals may look different and run differently, the young person's care will continue.
- If the young person is known to Trapeze (Sydney Children's Hospital Network Transition Service) or the Agency for Clinical Innovation (ACI) Transition Care Service, support is provided to ensure a smooth continuity of care as the young person moves from paediatric to adult services.
- Resources are available to help ensure transition from paediatric to adult health services is as smooth as possible. Visit [Trapeze](#) and [ACI Transition](#).

***'I assumed my daughter would not be accepted [into palliative care] as I believed that she was not at an end of life stage. However, she was accepted, and after meeting the palliative care specialist, I quickly realised that palliative care would become part of the multidisciplinary approach to my daughter's overall care and would work collaboratively with her other team specialists.'***

**Parent of a teenager**

## Palliative care is...



## Decision making and consent

When discussing transition to adult services, please be aware of the following points.

- A large part of transition is the shift of decision making from parents and carers to the young person.
- There will always be a role for parents and carers to support decision making for their young person, although this will depend on the capacity of the young person and their individual circumstances. See Table 1.
- Young people with capacity over the age of 18 years have the right to make decisions about their healthcare; who else they would like involved in decision making; and who they would like information shared with.
- Young people over the age of consent should be encouraged to include family and carers when planning goals of care when appropriate. Carers and family may be involved at every opportunity or spoken with separately with the young person's permission.
- Young people under the age of consent, or who lack capacity, need to be given the opportunity to receive information while they have a trusted adult, such as a parent or carer, present with them.
- Please visit the [Consent to Medical and Healthcare Treatment Manual](#) for more information.

**Table 1: Maturity guide for minor's capacity to consent to medical treatment**

Level of maturity and understanding	Recommendation for obtaining Consent
<b>Immature and insufficient understanding</b> (may be 13 and under)	Consent from a parent or guardian must be obtained
<b>Intermediate understanding</b> (may be 14 and 15)	Consent from the young person may be sufficient. However, the consent of a parent or guardian should also be obtained, unless the young person objects to this (refer to Gillick Competence)
<b>Mature understanding</b> (may be 16 and 17)	Consent of the young person will be sufficient in most cases (refer to Gillick Competence)

**Reference**

NSW Health. Consent to Medical and Healthcare Treatment Manual 2020 [Internet]. Available from: <https://www.health.nsw.gov.au/policies/manuals/Pages/consent-manual.aspx>

## What is the value of palliative care?

When a young person is transitioning to adult health services, palliative care may be raised for discussion. Palliative care improves the quality of life of an individual, their family and carers, facing problems associated with a life limiting illness.

Adult palliative care services vary across Sydney and NSW and include, general practitioners, primary care, disease-specific specialists or services, Aboriginal health workers, community nursing and allied health services, and supportive care or specialist palliative care services.

## What is end of life care?

End of life is the time in which a person with a life-limiting illness is nearing death. It begins when it is recognised that the person is approaching death and extends through to death and bereavement care.

The needs of the young person, their family and carers are often greater at this time and additional support and services are often required.

## Advance care planning

While conversations around planning ahead can be difficult, it is helpful for all involved, to discuss, consider and plan for changes in advance.

An advance care plan can capture important information about your patient's decisions and wishes regarding treatment options and care plans. In the resources section there are links to help you to find out more about advance care planning.

This plan should be reviewed regularly as needs or wishes may change, and all parties should be encouraged and supported to discuss any aspect of the plan at any time.

## Facilitating palliative care discussions

The following will support you to hold productive conversations with the young person and their family and carers. There are online training modules to help further develop skills in these discussions. Please see the resources section.

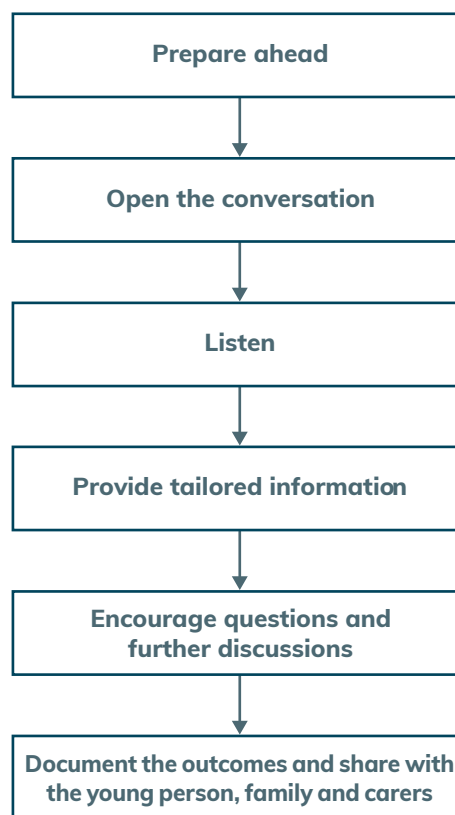
### Prepare ahead

- It is the responsibility of all healthcare teams involved in the care of the young person to facilitate these discussions, not just specialist palliative care teams.
- Young people require a developmentally appropriate approach to communication.
- Social workers may be able to provide advice on the cultural support available for young people and families from culturally and linguistically diverse backgrounds.
- Case conferences between paediatric and adult teams are worthwhile if transition is going ahead. The family and carers should be involved where possible.
- The use of virtual care, such as telehealth and video calls, is strongly recommended to allow all key stakeholders to be part of the discussions.
- If the specialist palliative care team is not involved, ensure appropriate referrals are made, if required.
- Most local health districts and the Sydney Children's Hospitals Network have Aboriginal palliative care health workers, who can provide culturally appropriate support for Aboriginal young people and families.
- In approaching the discussion, sensitivity to the developmental stage, the disease, gender, age, social and cultural contexts is required. This also includes ensuring appropriate language is used.
- Provide multiple opportunities to discuss issues including following up with the young person and family or carers for them to ask questions.
- Perhaps suggest that the young person or their family or carer can record the conversation or take notes and provide a copy of the actions agreed during your discussions.

***'The open, collaborative conversations were so important and I will be forever grateful for the help and guidance I received.'***

Parent of a teenager

## The keys to productive discussions



### Open the conversation

- Introduce the topic by asking the young person, 'How do you feel things are going with treatment?' 'Have you thought about how you would like to be cared for should your illness get worse?'
- Explain the rationale for palliative care and why it is an important part of their care. For example, 'I'd like to spend some time talking to you about your illness so that I have a clear understanding of what you would like to happen in the future when you get worse.'

### Listen

Acknowledge emotions and concerns throughout the discussion. If the person doesn't appear ready to have the conversation, stop. Respond to their distress where applicable. Involve family and carers to establish a person-centred approach that includes them as part of the team.

### Provide tailored information

Young people need reassurance regarding privacy, confidentiality and to be given the space to talk about end of life, after-life issues, fears, regrets, hopes and planning their funeral.

- Provide realistic information on prognosis, illness progression and treatment options, with an emphasis on how you expect their illness will impact their daily function.
- Offer to discuss what to expect, in a sensitive way. Young people value honesty and the information required to enable informed choices and a sense of control.
- Avoid using medical jargon, for example, use breathing machine instead of ventilator.
- Avoid being too exact with timeframes, unless the conversation is taking place during the final few days. Young people value honest explanations about uncertainty, limitations and unreliability of prognostic and palliative care information.

Tips for talking to the young person's family and carers.

- Ensure consistent information and the approach provided to everyone.
- Provide information about what to expect and sources of psychosocial support available to them.
- Reassure them that support, treatments and resources are available to control pain and other symptoms.
- Assess the need for grief counselling and be aware that some family and carers will be at different stages of acceptance or understanding. Be ready to provide appropriate referrals to other services.
- Arrange a follow up time for questions and clarification from original discussion.

***'When my daughter's paediatrician first suggested that she be referred to palliative care, I was horrified, even though he had explained that he was referring her so that she may receive additional medical and support services.'***

Parent of a teenager

### Encourage questions and further discussions

Talking about palliative care with the young person, their family and carers, can be overwhelming.

- Encourage questions and clarification; be prepared to repeat explanations.
- Check their understanding of what has been discussed and if the information provided meets their needs.
- Arrange additional support as required, for example grief support services, Aboriginal health worker or a multicultural health worker. Ensure interpreters are arranged if needed.
- Arrange a follow up time for questions and clarification from original discussion.

### Document the outcomes

When all the talking is done be sure to speak or write to other key healthcare providers involved in the young person's care.

At a minimum, this should include the patient's GP and all who participated in the discussions. This allows the young person, family and carers to absorb the information in their own time and refer back as needed.



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**This resource is to be used in conjunction with other transition and palliative care resources listed.**

## Related resources

### [Advance care planning](#)

NSW Health

### [Advance Care Planning Australia](#)

(funded by the Australian Government)

### [Australian bereavement resources and services](#)

The Australian Centre for Grief and Bereavement

### [Australian Child and Adolescent Trauma, Loss and Grief Network](#)

Australian National University

### [Authorised Care Plans](#)

NSW Ambulance

### [CareSearch](#)

Palliative care knowledge network

### [Clinical practice guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients.](#)

Hudson P, Remedios C, Zordan R, et al. PubMed.gov. J Palliat Med. 2012 Jun;15(6):696-702. doi: 10.1089/jpm.2011.0466. Epub 2012 Mar 2.

### [End of Life and Palliative Care Framework 2019-2024](#)

NSW Health

### [Good Grief](#)

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

NSW Health, 2021.

### [Palliative and end of life care, a blue print for improvement](#)

The Agency for Clinical Innovation

### [Paediatric Palliative Care, the role of the GP.](#)

Armitage N, Trethewie. The Australian Family Physician. Challenging life stages Volume 43, No.4, April 2014.

### [Transition related resources](#)

Agency for Clinical Innovation

### [Trapeze](#)

The Sydney Children's Hospitals Network

### [Youth health and wellbeing training resources](#)

NSW Health

## Aboriginal specific resources

### [Australian Indigenous Health Info Net](#)

Palliative Care information

### [Aboriginal and Torres Strait Islanders](#)

Palliative Care NSW

## Online training modules

### [HETI Shape end of life conversations](#)

### [End of Life online modules](#)

### [HETI Workshop for end of life conversations](#)

## 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.



## Acknowledgements

This resource was developed by the Agency for Clinical Innovation Transition Care Network and Palliative Care Network, with an Advisory Group of palliative and end of life experts, including consumers.



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