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## End of life and palliative care for children, teenagers and young adults

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### Summary

- Palliative care provides physical, emotional, social and spiritual support for newborns, infants, children, teenagers and young adults with a life-limiting illness and their families.
  - There may be a wide range of emotions to deal with after a diagnosis of a life-limiting illness.
  - There are strategies for families that can help them cope with a diagnosis of a life-limiting illness.
  - A range of specialist palliative care services for children, teenagers and young adults is available.
  - Palliative care for children, teenagers and young adults can be at home or in a hospital.
  - Peer support is important for teenagers and young adults.
  - There is support available if a baby, child, teenager or young adult dies.
  - Further information is available about palliative care for children, teenagers, young adults and their families.
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End of life and palliative care for infants and children is different to care provided for adults. Palliative care services for children provide an extra layer of support that can be combined with ongoing efforts to control or cure their condition. Do not give up hope as services work together to achieve the very best for your child and family.

The main focus of end of life and palliative care for children is on helping children and their families to live as well and fully as possible. Specialists in children's palliative care are very competent at caring for children with a wide range of illnesses. They have skills in managing symptoms such as pain, nausea and breathing difficulties. Specialists in children's palliative care also help families and the doctors caring for them to work through difficult medical decisions. They also provide information about access to more support. The course of an illness varies and can be uncertain. It may continue with ups and downs for many months or years. For some it may unfortunately be a short time, perhaps only days. A child's developmental stage, the type of condition they have and the uncertainty that can come with treatment and the course of the illness all impact on your child's and your family's needs. Palliative care services for children are tailored to help meet these needs and provide you and your family with the best possible quality of life.

### End of life and palliative care for teenagers and young adults

End of life and palliative care for teenagers and young adults is different to care provided for either children or adults. Teenagers and young adults have unique needs. Some services have a specific health professional such as a Key Worker to assist with care for teenagers and young adults facing the end of life. Palliative care includes physical, emotional, social and spiritual support. It focuses on improving quality of life for the teenager or young adult and their family. The main focus is on helping the teenager or young adult and their family to live as well and fully as possible. Depending on the teenager or young adult's age and other factors, you may be supported by specialists in children's palliative care or adult palliative care. Specialists in both areas help families and the doctors caring for them to work through difficult medical decisions. A teenager or young adult with a life-limiting illness may have an uncertain course of illness. It may continue with ups and downs for many months or years, or for a shorter time. Palliative care services provide ongoing support, including bereavement support, to help you and your family cope and spend quality time together.

### Coming to terms with a diagnosis of a life-limiting illness

If your child, teenager or young adult is diagnosed with a life-limiting illness, your family's world can be turned upside down and there may be a roller coaster of emotions and challenges.

If you are a teenager or young adult who has received a diagnosis, you may be going through a lot of difficult emotions. It is important to seek help if your feelings are overwhelming.

You and your palliative care team can together come up with specific strategies to support yourself, your siblings

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and other family members. You will be dealing with a range of issues that are physical, emotional, financial, social or spiritual in nature, and each issue may affect the other.

After a diagnosis of a life-limiting illness, children, teenagers, young adults and their families may feel a wide range of emotions including:

- confusion
- fear, shock or disbelief
- a sense of numbness or emptiness
- feeling overwhelmed or helpless
- sadness or anxiety
- anger
- guilt
- hopelessness
- denial
- other intense feelings.

You may understand what a diagnosis means, but still find it difficult to accept. It takes time to absorb information. Ask questions and consider your or your child, teenager or young adults' best interests.

At times you may feel frustrated, particularly when dealing with multiple services from a range of organisations. These may include disability, hospital, community, early childhood or teenager and young adult services and palliative care services. They are all there to assist you and ideally one health professional will be the key coordinator for you.

### **Balancing your children's needs when one has a life-limiting illness**

Parents often say that caring for a child with a life-limiting illness is a full-time job that impacts on their life, relationships, friendships, community involvement and their sense of identity. Some parents find it helpful to live one day at a time, to maintain some routine and be flexible with plans.

If your child's siblings seem to be coping, it can be easy to forget that they need attention as well. They may be left to their own devices and can sometimes take on additional responsibilities beyond their years. Palliative care services can provide emotional support and age-appropriate information for siblings and help them keep in contact with their sick brother or sister.

You may want to protect children from bad news. However, children often know more about their (or their sibling's) condition than families think or expect, so it is important to be as open and honest as possible.

### **Supporting teenagers and young adults with a life-limiting illness**

Teenagers and young adults with a life-limiting illness have different challenges as they start to develop independence. They may have a greater sense of the future and what their life may have looked like. They may be conscious of the physical effects of illness on their appearance.

If you are a teenager, support from your peers is very important. It is important to continue friendships to help maintain a sense of normality. This may include exploring sexuality and relationships as any teenager would. There is a range of support groups that can assist you and other teenagers to meet and share experiences.

Teenagers and young adults may seek to make meaning out of what is happening. They may need the space to talk about after-life issues, fears, regrets and hopes, or planning their funeral. Teenagers and young adults need adults to be honest with them, and have respect for their privacy. They also need to be able to make informed choices to help them feel in control.

Teenagers and young adults should be treated like adults. However, sometimes younger teenagers with a life-limiting illness may regress and need the care and support a parent usually gives to a child.

### **Choosing the right care for children, teenagers and young adults with a life-limiting illness**

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Children, teenagers and young adults with life-limiting conditions can use a range of paediatric, palliative care and disability services, as well as community-based support agencies and doctors.

Deciding on the right type of care is not always easy. Many children are cared for at home. However, your child can also have palliative care in hospitals and in places such as **Very Special Kids Hospice**. Many families move between home, hospital and hospice to meet the changing care needs of their child with a life-limiting illness.

Even if you decide to have palliative care for your child at home, there will always be a place in hospital for your child if a higher level of care is needed, or if you cannot cope with the demands of care at home. You are also free to change your mind if you try one type of care but decide that it is not appropriate.

Families of children, teenagers and young adults with life-limiting illnesses are encouraged and supported to spend quality time together. Palliative care services and some not-for-profit organisations provide this opportunity through their respite care programs. If you are feeling overwhelmed and need a break, talk to your doctor, healthcare provider or palliative care team about the options. They will have information on various support programs.

### **End of life and palliative care for children, teenagers and young adults at home**

You may want to care for your child, teenager or young adult at home so you can maintain a better daily routine and make them feel more secure. By living in their own home, your child is close to family members and friends who might be more able to help out with day-to-day care.

Speak to your doctor about palliative care providers in your local community. All providers have a range of services including nursing, counselling and, in some cases, complementary therapies such as music therapy and massage.

### **Hospital care for children, teenagers and young adults with a life-limiting illness**

While symptoms experienced by many children, teenagers and young adults with a life-limiting illness can be managed at home, some may need hospital care. You may be having difficulty providing the care required at home or your child, teenager or young adult may need procedures that require hospital care.

Most hospitals will provide a single room where possible and a welcoming environment for you and your family. While the person is in hospital, the hospital's healthcare team including doctors, nurses, social workers, youth support or pastoral care will support you and your family.

### **Hospice care for children with a life-limiting illness**

Palliative care can also be provided in a hospice. Very Special Kids Hospice in Melbourne is specially designed and built for children with life-limiting illnesses. The centre offers a homely environment where you and your child can stay while your child receives care.

For more information see, the **Very Special Kids Hospice** website.

### **Managing your child, teenager or young adult's end of life and palliative care**

Although a child, teenager or young adult may be receiving care from a wide range of health professionals, their parent(s), guardians or carers are the most important members of their care team.

You will no doubt want to learn more about your child's condition and what can be done to help them. By understanding the illness, being aware of the symptoms and knowing how to respond, you will feel more in control and confident in your decisions.

The palliative care team is there to provide support and guidance, and educate you on the types of treatment available. There will usually be one health professional who will coordinate services and make sure that the changing needs of your child, teenager or young adult and your family are met. Keep the lines of communication open by being honest and asking questions when you do not understand.

### **Learning to cope with your child having a life-limiting illness**

If your child, teenager or young adult is living with a life-limiting illness and you are having trouble making decisions

or simply getting through each day (or if you are a teenager or young adult and you are feeling overwhelmed or distressed), you may like to try some of the following:

- Ask your healthcare team to explain anything that you do not understand. There are no silly or wrong questions.
- It is okay to want to know all the details, or to limit the information when you are not able to cope.
- Make decisions that are right for you, your child and your family, not ones that you think are expected of you.
- Be honest with your healthcare team about when you are ready to talk about sensitive issues such as your or your child's future prospects, symptoms or the end of life.
- Get a second opinion from another doctor if you feel it is necessary.
- Look after your own health as a carer and set some time aside for yourself.
- Share the care around your family and friends and trust them to help.
- Set aside time to create memories with the teenager, young adult or child through special times together.
- Consider keeping a diary to write down how you are feeling.
- Accept the support you need. There will be another time when you can be the support person for someone else.
- Be open and honest with your family and talk about how you can manage what lies ahead.
- Talk about your feelings, fears and concerns with someone close to you.
- Seek professional help if feelings and emotions become unmanageable or too difficult to deal with.

You can find more information on support on the Better Health Channel's [End of life and palliative care services](#) page, under the 'Support for Family and Carers' tab.

### **If a baby dies**

When a baby dies, it can be a very traumatic event for the parents and family. The death of a baby can be due to a miscarriage or the baby being stillborn, or it could be a neonatal death (such as death due to sudden unexpected death in infants (SUDI), sudden infant death syndrome (SIDS) or a fatal sleeping accident).

There are many reasons why a baby dies. Often a medical examination and investigation is required to work out why this has happened. In some instances, the baby's death must be reported to the coroner.

For more information see [Death of a baby](#).

### **If a child dies**

The death of a child is often the most profound loss a family can experience. From the moment of their child's diagnosis, families experience a range of losses and you may begin to grieve in anticipation of your child's death.

Support is available and palliative care services can offer counselling – in some cases counsellors are professionals specialising in bereavement due to loss of a child.

### **If a teenager or young adult dies**

If a teenager or young adult dies, this can be a very difficult time for the family, friends and colleagues of the teenager or young adult. Specialist services can provide advice and support when dealing with the death of a teenager or young adult.

Grief is a normal experience. Everyone grieves in their own way and in their own time. Parents can feel overwhelmed by their feelings and have fear for their remaining children. Siblings' experience of grief will be influenced by their level of maturity, understanding and life experiences.

Palliative care services will support families through death and bereavement. Some services may offer counselling by professionals specialising in bereavement due to loss of a teenager or young adult.

You can find more information on the Better Health Channel's [End of life and palliative care services](#) page, under the 'Grief, loss and bereavement' tab, and on the page [What do so after someone dies](#).

## Referring a child, teenager or young adult for palliative care

Your child can be referred to palliative care services by:

- their doctor
- their local health provider
- community services staff
- you or a member of your family.

## Specialist palliative care services for children, teenagers and young adults

There is a range of specialist palliative care services available:

- **Victorian Paediatric Palliative Care Program (VPPCP)**
- paediatric services such as **The Royal Children's Hospital, Monash Health Women's and Children's Program**, and those in major regional health services
- **Very Special Kids**
- community and inpatient palliative care services.

The range of services provided by paediatric palliative care providers includes:

- specialist care
- advocacy and assistance in accessing care services
- sibling support
- counselling and emotional support
- bereavement support
- networking activities
- trained family volunteers.

The Palliative Care Australia publication Journeys: **Palliative care for children and teenagers** contains a range of questions to think about when considering different treatment options. These include:

- Is it safe?
- What are the expected or possible side effects?
- Do the benefits outweigh the risks?
- Will it interfere with the amount of quality time I have left with my child?
- Is it intended for the same condition my child has?
- Is it intended for children of my child's age?
- How does it work?
- Is there any proof that it works?
- Can I get a second opinion?
- Is it compatible with medications my child may be taking?
- Is my child allowed to continue with their current medications while on this treatment?
- Do care team members know about the complementary therapy we are considering?
- Is the person giving the therapy qualified or experienced?
- Are they an accredited member of a professional society or similar group?
- If I am worried or not satisfied, will I be able to say so?
- At what point do I review the treatment and how do I measure if it has worked?

## Where to get help

- **Victorian Paediatric Palliative Care Program** Tel. (03) 9345 5374

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- **Very Special Kids** Tel. 1800 888 875
- **Very Special Kids Hospice** Tel. 03 9804 6218
- **Palliative Care Australia – Teenagers and children** Tel. (02) 6232 0700 for practical resources for parents of children and teenagers living with a life-limiting illness
- **ONTrac** at Peter Mac – Adolescents and young adults Tel. (03) 8559 6880 for information on palliative care for adolescents and young adults with cancer
- **CanTeen** Tel. 1800 226 833 (general enquiries) for peer support information for teenagers and young adults with cancer, aged 12–25

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