

# End of life care for children and young people: information for carers

Information for the public

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## End of life care for children and young people: the care you should expect

This information is about making sure a child or young person who has a life-limiting condition gets the best possible care. It applies to babies, children and young people under 18 with life-limiting conditions. Although we say 'your child' throughout, children and young people may want to read this information for themselves to help them make decisions about their care. There is also a section about [supporting parents and carers](#).

This information explains NICE's advice about end of life care for children and young people. Your care team should know what NICE has said. Talk to them if you don't think you are getting the care described here. If talking to your care team doesn't help, you can go to the local Patient Advice and Liaison Service (PALS). There is more information about PALS and how to find your local service on [NHS Choices](#).

## Why is this important for you?

The NICE advice aims to improve care by making sure that you as a family are at the centre of all decisions about your child's care. It also aims to:

- help you plan your child's treatment and care early
- make sure you get all the information and support you need.

It doesn't look at treatment or care for specific medical conditions – see [where can I find out more?](#) for how to get more information.

## What is end of life care?

End of life care can mean caring for your child from the time you find out they have a condition that may shorten their life (called a 'life-limiting' condition). You might have found out recently or you may have known for a long time – sometimes people find out even before their child is born.

Having end of life care doesn't always mean your child is going to die soon. Often, it's difficult to say how the condition will affect your child over the course of their life. End of life care is about making sure children and young people have a good quality of life from the time they are diagnosed. It starts early on to allow you to make plans for your child's care, and to reduce stress and uncertainty. It means helping your child to feel as well as possible, while also making plans for dealing with things that might be difficult in the future.

## About your care team

Families should be supported by a team of professionals working closely together. Everyone who is involved in your child's care is part of the team. It will include hospital doctors, nurses, pharmacists and your GP but also other kinds of professionals, such as:

- social workers
- teachers

- family support workers who can help with the practicalities of end of life care (such as transport to hospital)
- counsellors who can provide emotional support
- chaplains (people you can talk to about beliefs that are important to you).

You should have someone in your care team who is your main contact and who coordinates your child's care. You can go to them first if you have any questions or worries. Staff changes in the team should be kept to a minimum so that you and your child see the same people regularly. You should be told if anyone new will be joining your team.

Exactly who is in your care team will change over time as your child's needs change. The person who coordinates your child's care may change too. When your child is first diagnosed, the team may focus on helping them live their life without their condition getting in the way. Later on, palliative care specialists may join the care team. They will be able to provide care and treatment to manage your child's symptoms and keep them comfortable.

The care team will regularly discuss your child's needs, and they should invite you to any meetings about care planning.

## Questions you or your child could ask

- Will everyone in the care team know what support we need?
- Who should we speak to if we have questions or worries?
- Who should we contact if we need urgent help?

## What information and support should we expect?

When your child is first diagnosed with a life-limiting condition, your care team should explain what this means and what changes to expect as time goes on. They should give you more information whenever you need it, and make sure you understand it.

Both you and your child will need chances to talk and ask questions, and your care team

should make sure there is someone who is able to answer them. Whenever something new happens – like a change in your child's condition or the type of care they need – or if you feel worried or uncertain, a member of your team should ask if you want to talk.

They should be led by what you want to discuss. For example, what is most important to you and is there anything that particularly worries you? Is there anything you don't feel ready to discuss yet?

Everyone in your care team should be sensitive, honest and realistic, and open about anything in your child's condition or treatment that is uncertain.

## Who will help explain things to my child?

Many of the professionals in your care team will be experienced in working with children. They may ask you first how much your child understands about their condition and what you are happy to discuss with them.

It might help to ask your child if there is someone in the care team they prefer to talk to. You should expect this person to:

- talk to your child in a way they can understand – some children might prefer to explore information and ask questions using play, music or art, while others might want to use the internet or talk one-to-one with a trusted professional
- adapt information to suit your child if they use a communication aid or need an interpreter
- ask your child if they would like to involve someone close to them (like a friend, boyfriend or girlfriend) in their care, and help them think about how this person could support them.

## Making decisions

Families should be kept at the centre of all planning and decision-making. Your care team should:

- find out how you would like to be involved in decisions – you don't have to decide things alone

- take time to listen to the beliefs and values that matter to you
- give you time and support when difficult decisions are needed. You should not feel rushed and should have the information you need to decide.

There is more information on our [website](#) about involving people in their care. It also has advice about children and young people agreeing (giving consent) to treatment.

## Questions you or your child could ask

- Please explain more about my child's condition and how it is likely to change in the future.
- Can you give us more information, like a leaflet or a website we can go to?
- Are there any support organisations in our local area?
- Can you help me explain things to my child?
- Can you give us information suitable for my child's age and level of understanding?

## Emotional support

Living with a life-limiting condition will be distressing for your whole family. It can have an impact on many areas of your lives, including family relationships. Your care team should support you and ask regularly if you would like to talk about how you are coping. They should make sure you know about the emotional and psychological support and treatments that are available.

Things may seem especially upsetting when something new is happening in your child's life or their condition is changing, and at these times your care team should talk with you about what extra emotional support you might need.

When your child feels distressed or their condition gets worse, your care team may be able to arrange an urgent appointment with a therapist or counsellor. If things feel overwhelming and you or your child can't cope, you should be referred for emergency psychological care.

## Questions you or your child could ask

- What kinds of emotional and psychological support are available?
- If my child has a learning disability or communication difficulties, what specialist support can you provide?

## Making a care plan

The care team should involve you in writing a care plan for your child. This is called an Advance Care Plan. It is a written record of your wishes – and your child's wishes – and includes everything that professionals who support your family need to know. It is often known as a 'passport to care', and can help you get the support you need. Helping to write it gives you a chance to decide what is right for your family, and to prepare for things ahead that might be difficult. It is also a chance to talk to your care team about the pros and cons of different care options.

Your care team should start thinking about the care plan as soon as possible after your child is diagnosed with a life-limiting condition. If you find out during your pregnancy that your baby has a life-limiting condition, your doctor, midwife and any relevant specialists (such as specialists in your baby's condition) should begin discussing the care plan with you before your baby is born. This gives you time to think carefully about important decisions.

## What should go into a care plan?

The plan should have information about your child's medical condition, outlook (prognosis) and treatment. It should also include:

- who can give consent (you might need to consent on your child's behalf)
- what information about your child will be shared with other professionals
- your child's ambitions and wishes, and information about their life, like school and social activities
- any religious, spiritual or cultural beliefs your child has and how these affect their care

- decisions you have made, like where your child will be looked after at the time of their death, what happens if they need emergency treatment, and any wishes you have on organ and tissue donation.

## Can we change the plan?

You can change it whenever you need to. It should be updated whenever something new happens. It should be checked regularly to make sure it is up to date and you should have your own copy.

## Who will see the plan?

Your care team should think about who needs to see the care plan. For example, professionals in the ambulance service, your child's school, and at your hospice or respite centre (if you have one) might also need to see it so they know how to care for your child. Everyone should be given a new copy when the plan is updated.

## Questions you or your child could ask

- What kind of decisions should we record in our care plan? What if we don't feel ready to think about some of these decisions?
- Can you help us decide the best care options for my child?
- Who do we speak to if we want to make changes to the care plan?

## Thinking about organ and tissue donation

For some children and young people, it is possible to become an organ or tissue donor (tissue includes things like heart valves and the cornea of the eye). Deciding to donate an organ or tissue can mean giving the gift of life to another person.

Your care team should choose a time when you feel ready to talk about donation to ask you and your child how you feel about it. They should explain which organs or tissues your child may be able to donate. If donation is not an option, they should explain why.

If organ or tissue donation is something you or your child would like to consider, your care

team should give you some written information about what's involved and answer your questions. You will need to decide on your child's behalf if they can't give consent.

It's important to remember that being a potential donor may affect where your child can be cared for at the end of their life. You should be given more information about this. You can change your mind at any time.

NICE has written advice for people who are potential organ and tissue donors [here](#).

## Questions you or your child could ask

- Is organ or tissue donation a possibility for my child?
- If my child wants to become an organ or tissue donor, what would this involve? How would it affect our care options?

## Choosing where your child will be cared for

The care team should talk with you and your child about where you want them to be cared for and where you both want to be when they die. Together you should discuss your wishes, what is available in your area and what is safe and practical. The care team should write what you have agreed in your child's care plan and should support your choices.

If your child will need to be transferred, you'll need to plan how and when this will happen and who will take over their care. There may be a rapid transfer service in your area that can help if your child's condition suddenly worsens. This means they can be moved quickly to the place you have agreed. But you might need to think about whether it is in their best interest to move them – your team should help you decide what is best for your child.

## What if something changes?

Sometimes things change. You might change your mind about your plans or the available options might change – if this happens the care team should help you to think about a new plan. They should also discuss with you any uncertainties in your child's condition that might affect your plans.



## Can my child have care at home?

If you choose to care for your child at home, you should be fully supported to do this. You should be able to have home visits from paediatric nurses (who care for children) when you need help, at any time of the day or night. You should also be offered:

- advice whenever you need it (this might be over the phone) from a doctor specialising in palliative care
- home visits from a palliative care professional to manage your child's symptoms
- practical support, for example equipment to give oxygen and medicines to your child
- medicines to store at home (and training in how to store them) so that if your child develops certain symptoms these can be treated quickly (called anticipatory prescribing).

## Questions you or your child could ask

- If I want my child to have care at home does it affect what treatments they can have?
- How will having care at home affect siblings and other family members?
- Can we change our mind if we struggle to manage at home?
- Who should I speak to about any concerns if my child is cared for at home?
- What happens if our child's condition changes suddenly?
- Who will be there to help us if our child dies at home?

## Keeping your child comfortable

Your care team will keep your child as comfortable and free from pain as possible. If your child has symptoms that are distressing them, the palliative care specialists in the care team will help with these. If needed, they will involve other specialists (such as pharmacists and specialists in your child's condition).

If your child seems agitated or confused, it helps to make sure they can see familiar people and things around them. Physical touch, such as holding them, can also reassure them.

Speaking calmly, keeping lighting and noise low and playing music can help too. If these methods don't work to soothe your child, the care team might talk with you about giving them medicine to calm them.

## Controlling pain

There are different ways to ease your child's pain. Simple methods can help, like using hot or cold compresses, playing music and touching, holding or massaging your child. They can also be given medicine. The doctor or nurse should talk with you about which medicines might work best. Some, such as opioids, can cause side effects like constipation and sedation (sleepiness). Your doctor or nurse will keep these under control by adjusting the dose and providing help to treat the side effects if needed. You might need to try more than 1 medicine to get the balance right.

## If your child has a seizure

Some conditions can cause seizures (these used to be called fits). Seizures can be frightening or upsetting, and if your child is at risk you should be told how to recognise a seizure and what to do. You may be given medicine to give your child if they have a seizure. The care team should explain how and when to use this.

## Breathing problems

Your child may at times seem breathless or have noisy breathing and the care team should reassure you that this is common. It can be caused by different things, but it can help to move your child into a more comfortable position, encourage them to relax and to talk about any anxious feelings. They can also be given oxygen or medicine.

If the care team suspects there is a new medical problem that needs treatment they may ask a specialist to examine your child.

## Questions you or your child could ask

- Can you explain what type of pain relief might work best for my child?
- How can we make sure my child is not distressed or in pain?

- Who should I contact if I am concerned about my child's symptoms?

## Support during the final days

If your care team believe the end of your child's life is near they should be open with you about this. It might not be easy to judge this accurately, even for an experienced professional, and they should be honest if they are unsure. They should prepare you for what to expect in the next few hours or days.

You know your child best, and sometimes parents or carers are the first to recognise that their child will die soon – the team should respect and listen to your feelings.

## What should we expect from our care team at this time?

At such a painful time your care team should treat you and your child with empathy and compassion and help you address your fears and worries. They should recognise that:

- both you and your child may feel a huge range of emotions that might be difficult to express
- your child might want to ask if they are dying but need support to do this
- you and other family members might also need support to talk to each other, and to your child
- you and your child may need some private time together.

## Following your wishes

It's important to check that your care plan is up to date (see [making a care plan](#)) so that you and your child's wishes can be followed. The care team may suggest changes to your child's treatment plan if they feel they are in your child's best interests, but they should also support your choices.

The care plan should state clearly what plans you and your care team have agreed for resuscitation if your child's heart or breathing stops. The professionals looking after your

child should never assume that you do not want resuscitation. Talk to your care team if you think the resuscitation plan needs to change.

## Eating and drinking

Your care team should support your child to eat and drink for as long as they are able to. If they can't or don't want to eat or drink they should be given ongoing mouth and lip care to stop any dryness and keep them comfortable.

Your care team should talk with you about the options that could help your child. This could involve giving food and fluids through a tube or, in very rare situations, through a drip (intravenously). You may have already made choices about this in advance, but the care team should discuss regularly with you whether you would like to continue. It is important to remember that continuing with intravenous feeding may affect where your child can be looked after towards the end of their life.

## Stopping treatments that aren't helping

If your child becomes seriously ill, some treatments they are having may no longer be in their best interests. This might be because they are painful or uncomfortable for your child, or they may not be helping very much. If this is the case, your care team should discuss stopping these treatments with you. They can help you think about what is right for your child.

## What if we disagree with our care team?

Professionals and families usually agree on what care is needed, and when to stop treatments that aren't helping. However, you may find that you disagree with your care team on a particular part of your child's care. If this happens they should discuss it with you so that you can decide what is best for your child together. You may want to get a second opinion from another healthcare professional, or involve someone like a chaplain who can help you to discuss the problem with the care team.

## Questions you or your child could ask

- Who can offer support to our family at this time?

- Is it in my child's best interests to continue intravenous food and fluids?
- If we choose to withdraw invasive treatments can you advise on the best time to do this? Please explain what will happen next.

## Supporting parents and carers

This section explains what NICE has said about practical and emotional support for parents, carers and other family members.

### Practical help

You will need practical help and support at different stages of caring for your child. Your care team should help with things like:

- adapting your home (this might involve changing your living arrangements)
- supporting your child to carry on their education
- arranging respite care for when you need a break
- training you to give medicines to your child
- finding out about financial support.

### Bereavement support

A member of your care team who has training in bereavement support should be supporting you when the end of your child's life is approaching. They should make sure you, your family, and other people who are important to your child know what support to expect. You should also be given some written information about the bereavement support that is available.

Your care team can help you think about the kinds of support you might need and who can provide it. With their help you should make a bereavement support plan for you and your family. Options to think about include visits with some of the healthcare professionals closely involved in your child's care. This could enable you to discuss shared memories and events with someone who knows your child well.

## Helping you plan ahead

You should be encouraged to plan what you want to happen at the time of your child's death. Your child may also have views that they would like to express about this. The team can help prepare you for the difficult decisions that will be needed by explaining the options. They will ask you to think about your wishes for the care of your child after death, and about funeral arrangements.

You should also be encouraged to think of how you would like create positive memories of your child. For example, you might think about taking photographs or hand prints, taking a lock of hair, making a social media memorial page, or by carrying out rituals that are personal to your beliefs.

## Questions you or your child could ask

- How do I need to adapt my home to care for my child?
- What other practical help and advice is available?
- My child has made decisions about what they would like to happen after their death. Who should I talk to about our wishes?
- What support is available for our family during this time?
- What equipment is available to help me care for my child after death? (For example special cooling mattresses, and fans and air conditioning units.)

## Where can I find out more?

- [Helen & Douglas House](#), 0186 579 4749
- [Sands \(stillbirth and neonatal death charity\)](#), 0207 436 5881
- [Shooting Star Chase](#), 0193 282 3100
- [Teenage Cancer Trust](#), 0207 612 0370
- [Together for Short Lives](#), 0808 808 8100

You can also go to [NHS Choices](#) for more information on end of life care and specific

medical conditions.

NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

NICE has also written advice to help you if your child will soon be [moving from children's to adult services](#).

## What are NICE guidelines?

NICE gives advice to staff working in health and social care. Our guidelines help them to give the best care to people with different conditions and needs. We wrote this guideline with parents of children and young people with life-limiting conditions, and with staff who support them. We also asked young people with life-limiting conditions what they thought about the care they received. All the decisions are based on the best research available. You can read the [guideline](#) written for people who work in health and care services.

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