

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

Information for the public

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What to expect from your care team: information for young people with life-limiting conditions

NICE has written advice about making sure that all children and young people who have a condition that will shorten their life (called a 'life-limiting condition') get the best possible care.

All the professionals in your care team should know about what NICE has said. The information here tells you some of the ways your care team should support you. You can find more details in the [information](#) we've written for families to read together.

Talking and listening

You should always be able to talk to someone in your care team who you trust.

What should they do?

- explain things to you in a way that you can understand
- listen to what matters to you (for example, going to school, being able to see your friends, or living at home)
- respect your wishes and beliefs
- be open and honest – if anything in the future is uncertain they should tell you this
- let you talk about your worries or fears when you need to
- answer your questions (and if they can't answer them, they should find someone who can).

Planning and deciding what you want

Your care team should help you think about the future.

What should they do?

- involve you in making decisions about your care and treatment
- make sure you know who the people in your care team are
- write a care plan with you and your parents or carers, so that everyone around you knows what you want, like:
 - where do you want to have your care, now and later on?
 - are there any treatments you do not want?
 - what equipment and practical help do you need?
- help you decide what you want by telling you what the different options are

- give you time to think about decisions, and to change your mind
- make sure your care plan is shared with everyone who needs it
- help you find solutions if you and your parents don't agree.

Supporting you

Your care team should be there when you need them.

What should they do?

- make sure you can speak to a professional who can help you plan to do the things you want to in life (for example helping you to do the things other people your age do)
- give you treatments and support if you are in pain or feeling ill
- give you emotional support to get through difficult feelings, like sadness or anger
- help you talk about difficult things with your family and friends
- arrange for you to talk to someone (for example a therapist or counsellor) if there's anything you feel you can't discuss with your parents or care team
- help you think of how to involve someone close to you (like a friend, boyfriend or girlfriend) in supporting you
- arrange for you to talk to a therapist if you feel overwhelmed
- make sure you can speak to someone (for example a chaplain) about making your religion or beliefs part of your care
- help you connect with other young people living through similar situations
- support your parents, carers, brothers and sisters.

Who are NICE?

NICE gives advice to staff working in health and social care. We help them to give the best care to people with different conditions and needs. We wrote this advice 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 [advice](#) written for people who work in health and care services.

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Accreditation

