Living with a life-limiting illness as a teenager or young adult

Information and advice produced in collaboration with young people living with a life-limiting condition

This resource has been co-produced by young people living with a life-limiting condition.

The content of the resource is a direct result of information shared by the co-production team. We hope that it will be helpful for teenagers and young adults diagnosed with a life-limiting illness.

Hospice UK would like to thank Danyal, Elliot and Timothy, who shared their lived experience of living with a life-limiting condition and were fully involved in all stages of producing this resource.

When you have been diagnosed with a life-limiting illness

When you receive a diagnosis, your healthcare team will speak with you about what to expect. They'll talk you through what will happen next and your treatment plan options.

You may experience a range of different emotions during this time. It might be helpful to talk with your family, friends and the healthcare professionals who are involved in your care.

You may also wish to ask for a visit to the ward where you will be receiving treatment. This will help you to familiarise yourself with the environment.

> ***"Don't be afraid to ask if your hospital or unit offers a tour before your treatment starts, or what medical equipment may be used and what it looks like, so you know what to expect."***

Support with school, college and talking to friends

Following your diagnosis, it is important to keep school or college informed. Talk with someone, like your teacher or pastoral support, to explain your current situation. Make sure they know what support or adjustments you may require during your treatment.

Discuss a plan for your education with your teacher and the people who look after you – this could be your parents, carers or other guardians. Your discussions should include how to keep on top of schoolwork and what the realistic expectations are while you're receiving treatment or feeling unwell.

It is **your decision** how much information you share with your friends and peers at school about your illness. It may help to ask your teacher, parents or carers for support to talk to people individually or in groups. But remember that everyone is different – you should do what feels right for you.

> ***"I found it easier for my teacher to speak to my classmates first. It removed some of the pressure from me."***

> ***"I would have found it helpful if my school delivered an assembly to my year group or a class where I could tell everyone at once and explain what was happening to me. I know my friends meant well but it was difficult to have the same conversation over and over again."***

> ***"The teachers in my school spoke to classes separately about my illness during form time, so students could ask them questions about it in a classroom environment."***

The impact on loved ones

Your illness will have an impact on those close to you. If you have siblings, they are likely to experience lots of different emotions and have questions about what is happening.

Your parents, carers or guardians may be able to help you speak with family members and other loved ones about what is going on. It can be useful to seek out relevant resources to help with these conversations, as well as other support that may be available.

> ***"My sister found it really difficult, she was only little and was aware that something wasn't right especially when I had to spend a lot of time in hospital or attending appointments."***

Hospital admissions

Sometimes you may find yourself admitted to hospital unexpectedly. If this happens, it helps to have an emergency overnight bag prepared already. At times, the duration of your stay may be longer than expected. It can be helpful to think about any small, personal and practical items that you would need or like to have with you during this time.

> ***"Always have a change of comfortable clothes, toothbrush, toothpaste, a list of your current medication and a spare phone charger in your bag. It's also helpful to have a list of items ready if someone else needs to pack a bag for you if you are admitted to hospital unexpectedly."***

> ***"We had a bag packed ready for emergencies and I would take it with me if I had an appointment or attending the hospital for treatment. You never know what is going to happen or if you will be admitted so this way I was always prepared."***

Planning ahead

Planning ahead for future care is helpful if, at some point, you are no longer able to make decisions, communicate your wishes or are approaching the end of life.

It is important to think about what your choices and wishes may be in these scenarios and share them with important people in your life. This might include family, close friends and healthcare professionals involved in your care.

In the UK, planning ahead like this is known as advance or future care planning. You can ask for support to think about this from your GP or your local hospice.

> ***“It is hard to think about what will happen if my treatment doesn’t work. I have had conversations about it, and I like to think it as ‘life planning’. I plan for the worst but hope for the best.”***

> ***“To be diagnosed with a life-limiting condition is difficult but we want to live as well as we can during this time. We would hope not to think about our wishes for end-of-life care at this age, but it is important to have a safety net in place.”***

When treatment ends and transitioning back into 'normal life'

There could be a lot to adjust to once your treatments end – physically, mentally, and practically. It's okay to take things slowly.

If you are finding it difficult, try and reach out for support.

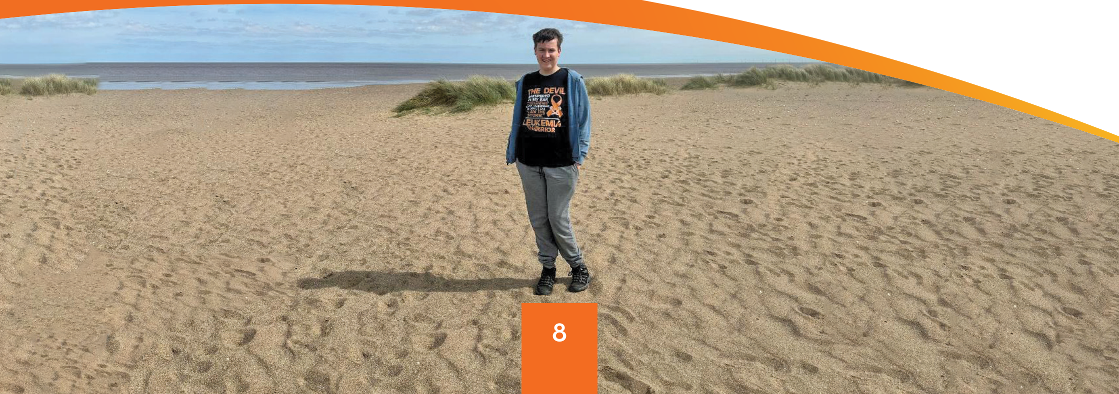
> *I've seen a psychologist and counsellor to process all the stuff that's been thrown at me with my illness."*

> *I had a Physiotherapist and Prosthetist to help me adjust to my new body. I felt trapped during treatments, but once it finished, I embraced the new challenges and I spoke to a Psychologist every two weeks."*

> *In terms of transitioning back to normal life I feel like making sure that school or college are aware of what is going on, and keeping dialogue open is very important as it makes any adjustments easier when coming back. Sometimes institutions can be a bit stubborn and hard to deal with which is why I think advocacy groups can be very useful in such situations."*

There are lots of ways you can get support.

We have listed some resources on the following page which can act as a starting point. They may be helpful in finding support that's right for you.



Websites and resources you may find useful

Hospice UK: www.hospiceuk.org

As the national champion for hospices, Hospice UK fights for hospice care for all who need it, for now and forever. We offer information on palliative and end of life care, bereavement support, and how to find hospice services in your area.

Together for Short Lives:
www.togetherforshortlives.org.uk/get-support/supporting-you/helpline

Together for Short Lives supports children and young people with life-limiting and life-threatening conditions and their families. Services include a helpline and the Together for Short Lives' Family Group, which is an online supportive community.

Sibs: www.sibs.org.uk tel: 01535 645453

Sibs is a charity for the siblings of disabled children and adults. Services include an online information service for children and young people aged 7-17, and a range of services to support adults.

Macmillan Cancer Support: www.macmillan.org.uk

The Macmillan Support Line is for anyone affected by cancer. It offers emotional support and practical information about all aspects of cancer.

Young Lives vs Cancer: www.younglivesvscancer.org.uk

Young Lives vs Cancer is a charity that helps children and young people with cancer and their families.

The Dying Matters campaign, run by Hospice UK, aims to open up conversations about death, dying and grief.

Sign up to our newsletters for more support, stories and advice: **hospiceuk.org/dm-newsletter**

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www.hospiceuk.org

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