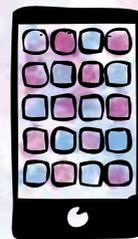
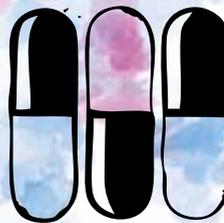


FOR
NHS
CANCER
SERVICES
TEENAGERS
& YOUNG
ADULTS



FOR NHS CANCER SERVICES TEENAGERS & YOUNG ADULTS

THE STANDARDS OF CARE YOU CAN EXPECT

Hearing that you have cancer can leave you feeling overwhelmed. It can be difficult to understand what's happening to you, and where to turn. That's why NHS England, Teenage Cancer Trust and CLIC Sargent have developed this summary to help you. It explains the general standards of care you can expect from the NHS, and offers some of the information you may need to make choices about your care.

When you are diagnosed with cancer as a young person, your needs are very different to those of either children or older adults. Because your body may still be developing, this can affect the type of treatment that you need and how your body responds to it.

Cancer may also affect you emotionally and in your everyday life. Education, starting work, relationships and becoming independent from your family can be complicated for any young person; it's even harder when you are facing cancer.

It might be difficult sometimes to carry on with everything you want to do, both during and after your treatment.

Your family, friends and partner may need support, too. You will meet many professionals who have the knowledge and skills to provide you with the best possible care, and who understand what you're going through.

THERE'S A LOT TO TAKE IN SO WE HAVE KEPT THIS SHORT. BUT IF YOU WANT TO KNOW MORE, AT THE END OF THIS SUMMARY WE'VE ALSO POINTED YOU TOWARDS SOURCES OF MORE DETAILED INFORMATION.

NHS SERVICES TO MEET YOUR NEEDS

Meeting these unique needs requires special knowledge and skills, so NHS England has stated that there should be cancer services especially for teenagers and young adults (TYA for short, in NHS language).

These services are aimed at young people between the ages of 16 and 24.

The NHS also treats other very rare cancer-like conditions in young people. Sometimes these young people receive their care in TYA cancer services.

Your choices depend partly on your age, but you should receive high quality care wherever this is provided, and no matter how old you are.

**Ages
16-18**

Your treatment should be provided at a Principal Treatment Centre (PTC) for young people. These are certain hospitals that have been recognised as specialist experts in TYA cancer. It might not be the hospital that is closest to your home, but it will be the one that is qualified to give you the best treatment.

**Ages
19-24**

You should have the option of having your treatment at a Principal Treatment Centre (PTC) for young people with cancer. Or you can choose a hospital that has been approved to provide cancer care for young adults, within its overall adult cancer services. Your treatment would still be supervised by specialists at the PTC.

So much depends on your individual situation, for example where you live or the type of cancer you have. For more details, it's best to ask your doctors and nurses to explain what is happening, who can provide your treatment, and what your options are.

QUALITY REQUIREMENTS FOR TYA CANCER SERVICES

Cancer services for young people must be of very high quality, and the NHS has to meet certain standards for your care. These are explained below.

Quick diagnosis and treatment

- Whether it is your GP, an A&E doctor, or another hospital doctor, if they suspect cancer you should be referred to a specialist cancer doctor
- Any young person with cancer should have tests quickly, and treatment should start as soon as you need it

Key worker

Every young person with cancer should have a key worker. This is a healthcare professional who has your permission to co-ordinate your care. They also provide you with support and advice. It really helps to have this person who can get to know you well. You can turn to them any time you are worried or need to solve a problem.

Clear plans and good communication

- Your cancer service should make it very clear where you will go for your care, who will look after you, and what tests, treatment and support you can expect
- Sometimes this is called a 'care pathway'. This means the route you follow through your treatment and through different parts of the NHS, and the care you receive at each step
- Care pathways are set up locally but they should always meet national requirements. For TYA cancer services, the main guidance is from the National Institute for Health and Care Excellence (see the end of this summary for more details)
- Your care should be co-ordinated smoothly. All the professionals involved in your care should keep one another informed, tell you the same thing, and work together as a team

Support at every stage

- You should get the right information and support to make choices about your care, and understand what is happening. Your family should also get clear information
- Everyone in the TYA cancer service should always listen to what you say about your care, and act on what they hear. They should pay attention to your family and whoever is caring for you at home, too
- If you need to move on to an adult cancer service when you are older, you should have information and support to make this a smooth transition for you
- You should also have support after your treatment is finished, to help you manage any on-going physical or emotional issues that may come up

Best medical care

- You should have the right tests and the right treatment for your particular type of cancer. Your care should be safe, effective and right for your age
- Your team should follow recognised medical guidelines and NHS England service specification and policies when they give you treatment
- In some cases where there are no guidelines, they should follow a protocol. This is a step-by-step plan drawn up by cancer experts
- You should be offered the chance to participate in a clinical trial (taking part in a medical study of new treatments)
- Your care should happen in an environment that suits your age and needs

The right staff

- Your TYA cancer service should have enough staff to give you good care, safely
- These professionals should have the right qualifications and experience
- They should work as a multidisciplinary team (MDT). This means different professionals with a range of skills, working together to meet all your medical, emotional and social needs

PALLIATIVE AND SUPPORTIVE CARE

If treatment is unlikely to cure your cancer you still have the right to receive high quality support and care that is suitable for your age. You should always be given a choice of how and where you receive this care, and you should have the time and support to discuss this with your family. This is a very skilled area of medicine and nursing, which is set up to manage both physical and emotional needs and give support and honest advice. This specialist care can make a very positive difference to you and your family.

IF YOU ARE UNHAPPY WITH THE CARE THAT YOU GET

If you think your care doesn't meet these standards, the first step is to talk to one of the senior doctors or nurses. They should make sure the problem gets solved. If that does not help, or if you aren't comfortable taking it up with your doctors and nurses, you can get help from:

- The PALS team (Patient Advice and Liaison Service) in your hospital, who can help you try to solve the problem, or explain the complaints procedure to you
- Your local authority (council), which can tell you about free advocacy services in your area. An advocate is an independent person to support you if there's a problem with your NHS care

Never be afraid to tell someone if there is a problem with your care. The NHS has a duty to make sure young people can speak out and be heard. You have a right to receive the high standards of care explained here, and everyone in the NHS wants this for you.

INVOLVING YOU

NHS England is keen to involve you and your family to continually improve care. This is why we have asked Teenage Cancer Trust and CLIC Sargent to help explain the service specification to you. We would welcome your comments on this summary to help us improve it in the future.

FIND INFORMATION AND SUPPORT

Teenage Cancer Trust

Teenage Cancer Trust exists to support young people with cancer. From diagnosis, throughout treatment and beyond, our specialist staff provide personalised treatment and care to 13-24 year olds right across the UK. We support hundreds of young people every year at our purpose-built NHS units, while our expanding Nursing & Support Service is designed to ensure that every teenager and young adult with cancer can access age-appropriate care, wherever they are. We also spread awareness of cancer by working in schools, supporting GPs and publishing a wide range of online and printed resources.

www.teenagecancertrust.org

CLIC Sargent

When cancer strikes young lives CLIC Sargent helps families limit the damage cancer causes beyond their health. Cancer doesn't discriminate. Today, 11 more children and young people will hear the devastating news that they have cancer. From diagnosis, CLIC Sargent's specialist care teams will step in, ready to help, support and guide. We provide a specialist package of support tailored to each young cancer patient and their family. CLIC Sargent will fight tirelessly for children and young people with cancer, often when they feel they can't. We do this individually, locally and nationally, so that they can focus on the important things, like getting well. And if the worst happens, we will work with bereaved families to get them support, to help them cope with their emotional pain.

www.clicsargent.org.uk

NHS England

Here you can find the full requirements (service specification) for TYA cancer services. This is a contract between your local NHS services and NHS England.

www.england.nhs.uk

(Search for 'TYA cancer services')

National Institute for Health and Care Excellence (NICE)

NICE guidance explains how the NHS should treat cancer in young people. Meeting these guidelines is one part of the TYA cancer services contract (service specification). The main guideline is called: Improving outcomes in children and young people with cancer.

guidance.nice.org.uk/CSGCYP

(NICE also has many detailed guidelines on treatments and care for specific types of cancer.)

NHS Choices

This is the general NHS website for patients and families. You can learn about health conditions, including cancer, and find local services.

www.nhs.uk

Macmillan Cancer Support

This charity offers detailed information on diagnosis, treatment and all aspects of living with cancer. There are also local help centres and a telephone support line.

www.macmillan.org.uk

Cancer Research UK

This is another charity that provides detailed information about cancer and treatment. You can also find out about clinical trials or talk to a cancer nurse on the phone. www.cancerresearchuk.org



We endeavour to ensure that the information provided is accurate and up-to-date at time of printing. NHS England, Teenage Cancer Trust and CLIC Sargent cannot accept liability for any loss or damage resulting from any inaccuracy or omission in this publication. Please note that although the general standard of care provided by the NHS should be uniform across England, individual cancer services will vary.

NHS England, Teenage Cancer Trust and CLIC Sargent do not accept any responsibility for information and services provided by third parties, including those signposted to in this leaflet.

Ref: 16397
Version 2, February 2017
Next review due: February 2018

This user-friendly guide is based on the NHS Standard Contract for Cancer: Teenagers and Young Adults - service specifications. For further details about sources used to put this publication together, or if you have any comments or questions about it, please email info@clicsargent.org.uk or call 0300 330 0803 and ask to speak with the Information Manager.

