

Information for Teenagers and Young Adults with Cancer

(Thames Valley Region)



Why have I been given this leaflet?

We know that this must be a very difficult time for you. Being diagnosed with cancer will have come as an enormous shock and can feel like your life has turned upside down.

You may have some treatment ahead of you which, along with the initial shock of the diagnosis, may disrupt your normal routine and plans.

The Teenage and Young Adult (TYA) Cancer Team at Oxford are a dedicated team of specialists who have expert knowledge in looking after young people with different types of cancer.

This leaflet explains how the TYA Cancer Team is organised and how we hope we can make things easier for you in getting through what lies ahead.

Why am I being referred to the Teenage and Young Adult (TYA) Cancer Team at Oxford?

Oxford University Hospitals NHS Foundation Trust is the Principal Treatment Centre (PTC) for teenagers and young adults diagnosed with cancer in the Thames Valley Region.

We link with teams at the Royal Berkshire NHS Foundation Trust, in Reading; Great Western Hospitals NHS Foundation Trust, in Swindon; Milton Keynes University Hospital, in Milton Keynes; Wexham Park Hospital, in Slough and Stoke Mandeville Hospital, in Aylesbury. These hospitals may provide some or all of your cancer care, in partnership with the team in Oxford.

Our aim is to make sure that you are offered specialist age-appropriate care and the psychological, emotional, financial, practical, educational and social support that you, your family and friends might need.

How did the TYA Cancer Team find out about me?

Cancer care for people of all ages is guided by specialists who work together in multidisciplinary teams (MDTs). Each MDT is made up of people who are experts in the care of different types of cancer. This helps us to make sure that everyone with cancer is offered the best care for their particular situation.

Your diagnosis and treatment will have been discussed by the MDT team with expert knowledge of the kind of cancer you have been diagnosed with. Your MDT team will pass on information about you, your cancer and treatment planned to our specialist TYA Cancer MDT.

At our TYA Cancer MDT we will assess what additional help and support we can offer to you, and to your family, to help you deal with your cancer diagnosis and its treatment.

The TYA Cancer MDT is run by staff at the Principal Treatment Centre in Oxford. All our discussions are confidential and we only share information about you that is important for your cancer care. Any recommendations made by the TYA Cancer MDT are always shared with the team treating you.

Do I have a choice about where I'm treated?

If you are 16-18 years of age you will be referred for treatment at the Principal Treatment Centre in Oxford, but it may be possible to have some of your treatment at your local hospital.

If you are 19-24 years of age you should be offered the choice of receiving your treatment at Oxford or in your local designated TYA hospital. This will depend on the type of cancer you have or if you need a particular treatment that is only available at Oxford.

Wherever you have your treatment, you will always have access to the TYA Cancer Team.

What happens now?

Once we know about you, one of the TYA Cancer Team will contact you. We will offer to meet with you, to talk about how you are doing, the choices you need to make and how we can help.

We can help with the following:

- emotional support for you and your family
- psychological support (to help you to talk about how you feel and what you are thinking about)
- peer support – arranging for you to talk to other people who have had a similar experience
- advice on how to continue or manage your education
- advice on how to deal with employment issues
- information about your diagnosis, treatment and side effects
- information about fertility/sexual health
- information about exercise, diet and nutrition

You might feel unable to keep up with friends due to the physical and emotional effects of your diagnosis and treatment. These effects can have a huge impact on your social life. We plan social events and residential trips, where you can mix with other young people who are also experiencing the challenges which can come with cancer and its treatment.

We will also help to support your family and friends and those who are most important to you.

A point of contact

The team will try to answer any questions you may have. Remember, there is no such thing as a silly question! We do not want you to struggle through this experience, or to feel that you are on your own, so please call us whenever you need to.

If we are unable to answer your questions, we will point you in the right direction or find out the information for you.

Dedicated TYA facilities

We understand that having a communal space for young people is important; it can help you to socialise and relax. At the Churchill and John Radcliffe Hospitals we have designed and developed some rooms which are dedicated areas for you. They are modern, fresh, vibrant rooms fitted with a large plasma screen TV, computers and games consoles, as well as comfortable places to sit and chat.

These rooms offer a space which will give you the opportunity to meet other people of the same age who are going through similar experiences. We hope this will help you to feel less isolated; knowing that you are not going through this alone.

You are welcome to use the rooms if you are an inpatient, outpatient or coming for specific activities planned by the TYA Cancer Team.

Here are some of the people you will meet

Teenage Cancer Trust Lead Nurse

The Teenage Cancer Trust Lead Nurse can help with any problems you may have with your care or with the TYA service. Their role is to lead the TYA service and make sure we provide the best care possible. They also provide care, support and information to you, your family and friends.

Tel: **01865 572 281**

Mobile: **07774 225 249**

(Messages can be left and your call will be returned as soon as possible. Office hours are 8am - 5pm, excluding weekends and bank holidays.)

Senior Specialist Nurse

The TYA Senior Specialist Nurse can provide advice, support and signposting to other services for you and your family. The Specialist Nurse also has an active role in providing education and training for staff caring for young people with cancer.

Tel: **01865 572 281**

Mobile: **07774 205 748**

(Messages can be left and your call will be returned as soon as possible. Office hours are 8am - 5pm, excluding weekends and bank holidays.)

MDT Coordinator/Service Administrator

The MDT Coordinator/Service Administrator works closely with the Lead Nurse to build and maintain links with site-specific MDTs across the Trust and the region. They facilitate the weekly MDT meetings and provide admin support to the TYA Team, also coordinating and managing TYA projects.

Tel: **01865 572 281**

(Messages can be left and your call will be returned as soon as possible. Office hours are 8am - 5pm, excluding weekends and bank holidays.)

CLIC Sargent Team

The CLIC Sargent Team are able to provide a wide range of support to you and the people who are important to you, to help you cope with the emotional impact of cancer.

They will help you deal with any concerns you may have around your finances (help with accessing grants and benefits), school, college, university, employers and housing. They may also be able to help with practical issues, such as getting to and from hospital, parking and accessing accommodation nearby.

Whatever is worrying you, you can have a chat with them and they'll do what they can to help.

Tel: **01865 227 403**

(Messages can be left and your call will be returned as soon as possible.)

Clinical Psychologist

Clinical Psychologists provide support and psychological assessment for young people with cancer. This support may be offered to you (and your family) if you are feeling very anxious or distressed about what having cancer means to you or the treatment you are having. They can also support you after your treatment has finished.

If you are feeling anxious or distressed and feel you would like to see our Clinical Psychologist, please speak to a member of the TYA Cancer Team and they will make a referral.

Tel: **01865 572 281**

Teenage Cancer Trust Youth Support Co-ordinator (YSC)

The Youth Support Co-ordinator can provide you with individually tailored support, activities in hospital and off-site and any extra advice or information you may need. They are here to listen and, if you'd like, can talk with you about your experiences of cancer or anything else that affects you and your wellbeing. This might be things like sex and relationships, body image and self esteem, your work experience and/or job, drugs and alcohol, etc. If you want a chat, a distraction, or a change of scenery, have a chat with your YSC.

Tel: **01865 572 281**

Mobile: **07769 165 169**

Teenage & Young Adult Therapy Radiographer

If you are having radiotherapy as part of your treatment, the Therapy Radiographer will support you through the planning and administering of treatment. They will also be able to advise and help you manage any side-effects you may have.

Tel: **Radiotherapy Reception 01865 235465**

Useful contact details for Oxford University Hospitals:

Department	Phone Number
Main switchboard number for the Churchill Hospital, Horton General Hospital, John Radcliffe Hospital and the Nuffield Orthopaedic Hospital	0300 304 7777
Oncology Ward, Churchill Hospital	01865 235 012/3
Clinical Haematology Ward, Churchill Hospital	01865 235 048/9
Haematology Day Treatment Unit, Churchill Hospital	01865 235 554
Oncology Day Treatment Unit, Churchill Hospital	01865 235 558
Triage Assessment Area, Churchill Hospital	01865 572 192
Radiotherapy Reception, Churchill Hospital	01865 235 465
Cancer and Haematology Outpatients Reception, Churchill Hospital	01865 235 566/565
Brody Cancer Centre, Horton General Hospital, Banbury	01295 224 197/8
Kamran's Ward, Children's Hospital, John Radcliffe	01865 234 068/9
Kamran's Day Care Children's Hospital, John Radcliffe	01865 234 062

Some useful websites

www.ouh.nhs.uk/tya

Oxford University Hospitals NHS Foundation Trust website for the TYA Cancer Team, providing a single point of access and lots of information for young people with cancer being treated in the Thames Valley region.

www.teenagecancertrust.org

A charity devoted to improving the lives of teenagers and young adults with cancer.

www.clicsargent.org.uk

Information and support for young people with cancer.

www.youthcancertrust.org

A charity which provides free holidays in Bournemouth for teenagers and young adults with cancer.

www.jtvcancersupport.com

Website for people who have been affected by cancer. Connect with others who are going through similar experiences.

www.teensunitefightingcancer.org

Aims to help improve the lives of young people aged between 13-24 with cancer and other life limiting illnesses.

www.maggies.org

Maggie's centre is based at the Churchill Hospital and provides information, guidance and support to anyone affected by cancer. Macmillan Oxford Citizen's Advice Bureau benefits service is also based here.

www.willowfoundation.org.uk

Provides quality time for seriously ill young adults through special days of your choice.

www.macmillan.org.uk

Provides information and support to people affected by cancer.

www.trekstock.com

Trekstock delivers practical and social support programmes for young adults, to give them a better chance of living well through and beyond cancer.



If you need an interpreter or would like this information leaflet in another format, such as Easy Read, large print, Braille, audio, electronically or another language, please speak to the department where you are being seen. You will find their contact details on your appointment letter.



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Oxford University Hospitals NHS Foundation Trust
www.ouh.nhs.uk/information

Making a difference across our hospitals

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OXFORD HOSPITALS CHARITY (REGISTERED CHARITY NUMBER 1175809)

