

Wessex teenage and young adult cancer service

Information for young people



Why have I been given this booklet?

The Wessex Teenage and Young Adult (TYA) cancer service is here to help support young people who have been diagnosed with cancer.

Our team of specialists have expert knowledge in looking after young people with different types of cancer, including leukaemia and brain tumours.

This leaflet describes how our service is organised and how we hope we can make things easier for you in getting through what lies ahead.



What is the Wessex TYA service?

The Wessex TYA service provides cancer care for young people aged between 16 and 24 years of age who live in Hampshire and the Isle of Wight, Dorset, South Wiltshire, West Sussex and the Channel Islands. The NHS calls this the Wessex Region, so we are 'Wessex TYA', a network of services and professionals working together to provide care to young people like you.

We want to make sure everyone is treated fairly, and that you are offered the best treatment; specialist, age-appropriate care and the emotional, financial, practical, educational and social support that you may need. We are also able to support your family and friends.

We are based at a specialist unit at University Hospital Southampton (UHS). This is the NHS Principal Treatment Centre (PTC) for young people with cancer who live in the Wessex region. The centre links up with hospitals in Basingstoke, Bournemouth, Chichester, Dorchester, Guernsey, Isle of Wight, Jersey, Poole, Portsmouth, Salisbury, Winchester and Worthing. Some NHS hospitals are 'designated' to provide TYA cancer care in partnership with Southampton, and we aim to make sure young people are able to make choices about their treatment and if possible, have some of their care at a hospital closer to home.

For more information, please visit: www.uhs.nhs.uk/tyacancer

How are decisions about cancer treatment made?

The treatment of cancer requires a big team of experts to work together for each patient. This is called a multi-disciplinary team, or site-specific MDT for short. The team includes experts in diagnosing and treating cancer, who will confirm the diagnosis (type of cancer) and consider the best treatment for each patient, taking into account the best medical knowledge and up-to-date research. The patient, their family and the consultant will then talk about this together, and decide on the best plan.

How is this different for young people?

Cancer in teenagers and young adults is pretty rare, and a slightly different way of doing things is needed. 'Teenage and young adult MDTs' (or TYA MDTs for short) specialise in cancer in young people, and are based at principle treatment centres like the one in Southampton. The TYA MDT and site-specific MDT work together to deliver the best possible care for young people with cancer.

How can I have a say?

Everyone involved in your care wants to make sure you get the best possible treatment. Your views and opinions about your care are very important, so if there is something you want the TYA MDT to know, please tell your specialist nurse and they can make sure your views are heard. (For information about other ways you can tell your MDT what's important to you, see page 11).

Your site-specific MDT consultant or specialist nurse will let you know when they plan to talk to the TYA MDT about your care. Once the MDTs have done their bit, a written record of the treatment options and the decisions you make with your doctor will be filed in your medical notes, so everyone involved in your care knows the plan.



How does the TYA Wessex team find out about me?

So that you can have all the right experts working together for you, your team will pass on information about you, your cancer and the plans for your treatment to the TYA MDT, in line with NHS policy. The TYA MDT is run by staff at the Principal Treatment Centre in Southampton but its members come from across the Wessex region, from different professions and different organisations. However, we all work within the NHS.

Will my confidentiality be protected?

Yes. We are all required to keep our discussions confidential, limited to the teams involved in the TYA MDT and treating you. We only share information that is relevant to your cancer care. Please let the doctor, nurse or other professional with whom you have most contact know if you have any concerns about information being passed on to the TYA MDT.

Will my data be protected?

By law, some information about people with cancer is routinely shared with NHS Cancer Registration, to help improve the way cancer is treated. There is a leaflet explaining this in the hospital, and it also tells you how to opt out if you want to. If any organisation outside the NHS wants to collect information about you, they must ask you for your consent and let you know what they will do with it.

Wessex TYA will regularly review the information collected at the MDT to make sure everyone is being treated fairly, and to help improve the care we offer to young people in the future. Nothing which identifies you individually will be used in doing this.



Where will I have my treatment?

Some types of cancer treatment are only available at certain hospitals. You will receive your treatment at a hospital which specialises in the treatment you need. Your doctor will explain this further. Wherever you have treatment, you will be supported by the Wessex TYA team.

Young people between 16 and 18 years

If you are 16 to 18 years old you will be referred to receive treatment at the TYA service in Southampton, where staff are specially trained to support young people in your age group. Some tests and surgery may then be undertaken at other hospitals, following discussion with the TYA team.

Young people between 19 and 24 years

If you are between 19 and 24 years, you should be offered the choice to receive your treatment at the TYA unit in Southampton, with other people your age, or at the hospital designated for TYA care closest to your home. Your doctor or specialist nurse will discuss this with you and, whenever possible, offer you a visit to the TYA unit to meet the team.

There may be a lot to consider when working out the best place for you to receive your treatment. We suggest you talk to the team treating you, and to your family/close friends about this. You can also talk to the TYA specialist nurse for your hospital or the TYA team at Southampton.

Whatever you decide, you will receive treatment that has been approved by a site-specific MDT and the TYA MDT. You will get to see a TYA specialist nurse and you can be referred to the Young Lives vs Cancer social care team for extra support, wherever you are treated.

A bit about the TYA unit in Southampton

This unit is designed specifically for TYA patients, and is run by staff who have chosen to work with young people with cancer. It has six inpatient rooms each with a sofa that can be used as a bed to allow a family member, partner or friend to stay. There are day treatment spaces for people who do not need to stay in hospital overnight. There is also a 'social space' with a kitchen where you, your family and friends can spend time together. You can find out more about the unit on: www.uhs.nhs.uk/tyacancer.

If you go to Southampton for treatment, the team at your current hospital will ensure a safe transfer. A member of the Southampton TYA support team will meet you soon after your arrival and arrange a time to talk with you about what help is on offer and what you think you may need.

Young Lives vs Cancer offers self-catering accommodation at 'Jean's House' near the hospital. This is available free-of-charge to immediate family of children and young people receiving cancer treatment at University Hospital Southampton. Please see: www.younglivesvscancer.org.uk/what-we-do/a-free-place-to-stay/

If you are treated at Southampton, you might still be able to have some of your treatment at a hospital nearer home. We call this 'joint care', and means the two teams work together to make sure your treatment is given in a joined-up way, in two different hospitals.



What happens now?

One of the Wessex TYA team will contact you, either in hospital or at home, and offer to meet to talk to you about how you are doing, the decisions and choices which will require your input, and how we can help.

The Wessex TYA service is led by a lead nurse and lead clinician for TYA cancer. You can contact them through the Wessex TYA service administrator on **07827 880499** (office hours).

Useful websites

Bloodwise
Cancer Research UK
Young Lives vs Cancer
Macmillan Cancer Support
NHS Cancer registration
Teenage Cancer Trust
Wessex TYA cancer service

www.bloodcanceruncovered.org.uk
www.cruk.org.uk
www.younglivesvscancer.org.uk
www.macmillan.org.uk
www.ndrs.nhs.uk
www.teenagecancertrust.org.uk
www.uhs.nhs.uk/tyacancer

Introducing Wessex Cancer Alliance

Wessex Cancer Alliance is made up of local health and care organisations involved in cancer care and support across the Wessex region (which covers Hampshire, the Isle of Wight and Dorset).

They are responsible for improving services and support, and bringing innovation to the area so that local people will have the best possible experience and outcomes from their cancer care. Visit their website for more information: **<https://wessexcanceralliance.nhs.uk/>**



IAM Portal and Integrated Assessment Map

The IAM portal has been developed by the Teenage Cancer Trust to improve support for young people with cancer. It lets young people and health professionals work together to identify the emotional and clinical support they need as they go through cancer treatment.

On the portal you can complete the **Integrated Assessment Map**.

Your TYA nurse specialist will show you how it works and, if you like, can help you complete it. We hope that you will do this around the time you are starting treatment, as it is a way you can ensure you 'have your say' at the TYA MDT discussions about your care and support. It can help your team to understand you better as a person and think about what services and support they can offer you, based on what you say is important.

The idea is that we make sure you get the right sort of help to deal with the impact of your cancer and treatment.

As your priorities and needs are likely to change during and after your treatment, you can do an IAM as often as you want, and we can adapt the support to help you at that time.

The IAM website is also a place where you can find reliable information and resources, and access help when you need it.

www.iamportal.co.uk
www.iamportal.co.uk/resources
www.iamportal.co.uk/urgent-help

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University Hospital Southampton NHS Foundation Trust
Southampton General Hospital
Tremona Road
Southampton
SO16 6YD

Main switchboard telephone: **023 8077 7222**



For a translation of this document, or a version in another format such as easy read, large print, Braille or audio, please telephone **0800 484 0135** or email: **patientsupporthub@uhs.nhs.uk**.

For help preparing for your visit, arranging an interpreter or accessing the hospital please visit: **www.uhs.nhs.uk/additionalsupport**

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