

# Welcome to the teenage and young adult cancer unit

Information for patients and visitors



We are one of several Teenage Cancer Trust units across the UK which have been specially designed for young people.

Our six single rooms and day treatment area have been designed to offer a relaxed ward environment, where our specialist staff look after young people aged 16 to 24 who are receiving chemotherapy or other treatments for cancer or related conditions.

This booklet tells you about our facilities and what you can expect while you're here, and gives you some information about the local area.

## Accommodation

All of our rooms have en-suite bathrooms and are equipped with televisions including films on demand, DVD players, MP3 speakers, games consoles and access to wireless internet. As well as your clothes and personal items, you can bring your own bedding if you would like to, along with your mobile phone, tablet and laptop. For safety reasons, all electrical items need to be checked by our maintenance team. Please note, it's your responsibility to look after your personal items.

Each room has a sofa that can be used as a bed to allow a friend, family member or partner to stay with you overnight if needed. Camp beds may also be available. People staying overnight must be aged 18 or over, or aged over 16 with their parent/guardian's permission.

When you come to stay on the unit, we will do our best to ensure a bed is available for you. However, it may be that all of our rooms are occupied. If this happens, we will aim to offer you a room on another cancer care ward within the hospital. You will then transfer to the TYA ward once a room has become available.



## Isolation and special precautions regarding infection

There are times when some patients need to be cared for 'in isolation', which means they need to stay in their room. This is to protect them from infection or to protect other patients. If this applies to you, we will explain exactly what is needed and why; and how your family and friends can help. This may be by wearing protective clothing and being extra careful about hand washing, for example. There might be other special precautions needed too – we will explain all of this at the time.

## Social space

This is our communal area where you can spend time with other young people, your friends and family during your stay. The area has sofas, TV with Sky HD, a gaming area, jukebox and pool table. There is a kitchen and dining area with an oven, microwave, toaster, fridge/freezer and dishwasher. This area allows you the freedom to make your own meals, snacks and drinks when you feel like them. The social space is open 24-hours a day but please keep noise levels down after 10pm.

## Food hygiene

TYA patients and family/carers are welcome to prepare food using the kitchen facilities at your own risk, but please do not prepare food for other patients or share what you have cooked.

Everyone using the kitchen must follow the rules below:

- Home-cooked food must not be bought in for reheating due to the risk of infection. It's fine, however, to bring in shop-bought, pre-packaged food and drink.
- Store your food in the fridge in your room, not in the kitchen. Food must be labelled with your name and date of opening.
- Raw chicken carries an infection risk and should not be brought in, prepared or stored on the premises.
- Other meat (bacon, ham etc.) should be stored in a sealed box in the fridge to avoid contaminating other items.

- Eggs should be washed with soap and water before use or storage (chicken poo residue on eggshells can be a source of salmonella).
- Food waste must be disposed of into the bins in the kitchen area, not in the side rooms.
- Remember to wash your hands before preparing food, and do not leave the area while it is cooking for fire safety reasons.
- When you go home, remember to throw any remaining food away, or take it with you.
- Leave the kitchen clean and tidy when you are finished and please consider other people using this space.

## Family sitting room

This is an area near to the social space where your family are able to take a bit of a break without leaving the ward. The room has comfortable sofas, magazines and a radio.





### **TYA day care bay**

This area has four treatment spaces (chairs and beds) where young people can have chemotherapy or medical procedures as an outpatient. Patients attending for day treatments have full access to all the other facilities in the TYA unit.

### **Visiting hours**

We have an open visiting policy, meaning your family and friends can usually visit with no restrictions. All we ask is that visitors are well (so please stay away if you have a sore throat, cough, cold or upset stomach, for example). All visitors should wash their hands and use alcohol gel before and after visiting a patient to help prevent infections.

Due to the very high risk of infection for some of our patients, we do not allow children under the age of 12 years to visit the ward.

Evening visitors are asked to keep noise levels down to a minimum to allow other patients to rest. We expect everyone to respect our staff, other patients and visitors.

### **Smoking, alcohol and drugs**

The hospital has a no smoking policy across its grounds. Vaping (E-cigarettes) is also not allowed. However, there are designated smoking areas on the hospital perimeter, if required.

A doctor can prescribe you nicotine patches or spray, so if you want to try them please just ask.

If you would like help to stop smoking we can ask the local stop smoking support service to get in touch with you, or you can contact them on 023 8052 5221, or text WELL to 88020.

No alcohol is to be brought onto the ward for either patients or visitors.

No illegal drugs or herbal products are to be brought into the hospital under any circumstances. However, if you do have something with you please tell one of the TYA staff. With your agreement we can arrange for this to be dealt with confidentially so that any illegal drugs are safely destroyed by the pharmacy.

If you have taken something and feel unwell or worried please let one of the staff know so they can get you medical help if needed. If you are worried about alcohol or drug use please ask a member of staff and we will arrange for you to talk to someone who can help.

### **Mealtimes**

**Breakfast is served at 8.30am, but this can be flexible to suit you**

**Lunch is served between 12noon and 1pm**

**Dinner is served between 5.30pm and 6pm**

You can select your choices from the menus available from the ward hostess. These include 'special diet' menus, which your doctor may have advised you to use, depending on your medical needs. Please ask a member of staff if you have any questions.

## Observations, medication and some other ward routines

The nurses and healthcare assistants will be regularly checking observations, usually every four hours. This means measuring your blood pressure, pulse, oxygen levels and temperature. These are all completely painless.

You will also be weighed on a daily basis, where necessary.

Medication is given as prescribed morning, lunchtime, evening and night. You are likely to have intravenous drugs which might mean having an electronic IV pump during the day and/or night to make sure these drugs are always given at the correct speed.

We try to keep the ward area quiet and dark at night time to help patients sleep better. Noise at night is not usually a problem on our ward as everyone has their own bedroom. There are ear plugs and eye masks available if you want them though, so please ask a nurse.

A doctor will see you every day Monday to Friday, and over the weekend if there is an urgent need. Your consultant usually does a ward round once weekly. The ward nurses will be able to tell you which day.

Swabs will be taken from your nose, groin, line sites and wounds on admission and then weekly to check for MRSA, one of the infections we want to protect patients from.

## Research

Research is an important part of our work as a leading cancer hospital and we have a dedicated team of research staff, doctors and nurses. You may be asked to consider taking part in a trial or other research study. Whether or not you take part is entirely up to you, and if you decide not to, that's perfectly alright.

## Your education

If you are aged 16-17 years, tutors from the hospital school can visit you on the ward to help you continue your education. The nursing team will ensure the school can support you during your day.



## Your hospital team

You will probably have already met your consultant. Whilst on the ward as an inpatient, you will be cared for by a team of doctors overseen by your consultant. The doctors will discuss your care with you and your parents/ carers or partner before any treatment is started. If you have any questions about your treatment, please ask your doctor or one of the nursing staff – we are all here to help.

### So many uniforms...

You will see lots of people in different uniforms. There is a notice on the ward explaining what the different colours mean, and a photo board featuring the staff you are most likely to meet.

### Here's what these people do:

#### Matron

matrons are in charge of a group of wards and take responsibility for ensuring excellent patient experience and safety.

#### Ward manager

the senior nurse is responsible for the day to day running and management of the ward.

#### Ward sister/ charge nurse

the ward sister or charge nurse manages the whole ward. You can ask to see them if you have any concerns.

#### Staff nurse

each day and night you will have a named staff nurse responsible for looking after you, although all the nurses are there for you if you need anything. Sometimes we are helped out by staff nurses from one of the other cancer wards.

#### Agency nurses

provide help if one of our regular nurses is off work unexpectedly. They are all qualified nurses, but as they might not be so familiar with our ward they will always be supervised by our regular ward nurses. They usually wear a white uniform.

#### Healthcare assistants

support the qualified nurses in delivering your care on the ward.

#### Housekeeper

responsible for looking after our ward.

#### Domestic staff

keep the ward clean and tidy, wear a green uniform.

#### Ward hostess

serve meals and refreshments, wear a beige uniform.

#### Clinical nurse specialists (CNS)

nurse specialists visit the ward and clinics to offer expert advice and support. You will probably get to know a CNS who specialises in your cancer type, and one who specialises in caring for young people with cancer – they work closely together.

#### Nurse practitioners

work alongside doctors to provide medical care. They wear a navy blue tunic and trousers.

#### Research nurses

if you are taking part in research you will be allocated a nurse who coordinates the research study and can answer any questions you have about this.

#### Students

we are a teaching hospital, so there may be a range of student health and care professionals involved in your care. They will identify themselves to you.

#### Young Lives V Cancer workers

offer practical, financial and emotional support to you and your family all the way through your cancer treatment and for a while afterwards. They will see you in hospital and at home too, if you wish. They do not have a uniform but will have a hospital identity badge.

#### Youth support coordinator

provides day-to-day support on the ward to help you deal with being in hospital for treatment, and can help you find things to do to make the time you are in hospital more bearable. Wears a t-shirt or sweatshirt with Teenage Cancer Trust Logo and their job title.

### Clinical psychologist

can help with emotional wellbeing. Does not wear a uniform but will have a hospital identity badge.

### Physiotherapists

supporting and maintaining your mobility, their uniform is a white tunic with navy piping.

**Occupational therapists** supporting your recovery, their uniform is a white tunic with green piping.

### Therapy assistants

their uniform is a turquoise polo top.

### Dietitian

offering help and advice about nutrition and eating. They do not wear a uniform but will have a hospital identity badge.

### Ward admin staff

these staff help with the day to day running of the ward. They do not wear a uniform but will have a hospital identity badge.

### Lead TYA nurse

this is the person who has overall responsibility for cancer services for teenagers and young adults in our hospital and the region. They do not wear a uniform but will have a hospital identity badge.

## Your views and opinions count

### Patient support services: 023 8120 6325

Patient support services can offer a range of advice and support for patients and their families and carers. They can provide information about NHS services, as well as being available to listen to any concerns or suggestions you may have, or helping to resolve problems quickly on your behalf.

If you wish to make a formal complaint, please talk to one of the ward nurses, or if you prefer, you can contact the patient support services team on the number above. A member of the team will discuss your concerns with you. Alternatively, you can submit a complaint via email at [patientsupportservices@uhs.nhs.uk](mailto:patientsupportservices@uhs.nhs.uk)

## Going home checklist

We try to have everything ready so patients can go home in the morning. A bit of advance planning is needed and you can help us by checking what you might need with your nurse, a couple of days before you expect to go home, if possible.

- Do I need any tests before I go home?
- Have I got my medications to take home?
- Is it safe for me to take 'over the counter' medicines such as paracetamol (Panadol) and ibuprofen (Neurofen) while I am out of hospital?
- Do I have the right equipment to take home to care for my line?
- Do I need a district nurse to flush my line and redress it at home?
- When do I need to come back?
- Do I need to make an outpatient appointment?
- If I need hospital transport for my next visit, has it been arranged?
- Do I have a thermometer at home to check my temperature?
- Do I know what to do if I have a high temperature/ fever or feel unwell while I am out of hospital?
- Do I have a card with the 24-hour emergency advice line phone number (called the acute oncology service or AOS) to keep with me at all times? (at University Hospital Southampton this number is: 023 8120 1345)
- Have I packed all of my belongings?
- Have I taken all my food out of my fridge, cupboards etc? (it will be thrown away if left)

### Our promises to you

We want you to feel this unit is a safe, friendly and positive place where you can be yourself, keep your independence, make choices about your care, and even have some fun if possible!

The people working on this unit have chosen to work with young people with cancer. Each of us will do our best to make sure you get the expert care and support that we believe all young people deserve.

### Working together as a team

- We will offer you safe, compassionate care that takes into account your particular needs and circumstances.
- We will discuss your diagnosis, treatment and care honestly with you, and include the important people in your life such as family or partners in these discussions when you want us to.
- We will respect you as an individual and listen to your opinions and choices, and will speak up for you, and on behalf of all young people when needed.
- We will respect your right to patient confidentiality, and so will not share information about you with other patients or their families.
- We will keep you informed about what is planned and how things are going, and answer your questions honestly so you can make decisions.
- We will teach you what you need to know so you can take good care of yourself in hospital and at home.
- We will communicate with other teams involved in your treatment so we can work together to give you the best possible care.
- We will welcome your feedback and ideas, and will act on your suggestions when it is safe and feasible to do so.
- We ask you to respect our staff and the other young people who use the unit, along with their families and friends. If there is a problem, please tell a member of staff and they will try to help sort it out.

## Other support services

### Jean's House

Young Lives V Cancer offers self-catering accommodation close to the hospital. It is available free of charge to the immediate family of children and young people receiving cancer treatment at University Hospital Southampton.

### Macmillan Information and Support Centre

The Macmillan centre at University Hospital Southampton provides a relaxed, friendly and confidential environment for people with cancer and their families, friends and carers. It is run by hospital staff and trained volunteers and offers lots of different services including:

- complementary therapies
- counselling
- benefits advice
- a wig service

The Macmillan centre is located: B level East Wing, their phone number is **023 8120 6037**.

### Maggie's Centre

Maggie's centres across the UK offer a free, drop-in service to help anyone who has been affected by cancer. The specially-designed building at Southampton offers a range of services and support including:

**Cancer support** – Access free, one-to-one help and information from our professional team or join groups and activities that are right for you.

**A calming space** – Come in for a cup of tea, meet people who understand what you're going through or just take a moment to gather your thoughts.

**Where to find Maggie's at Southampton General** – Located next to the blue carpark entrance (off Tremona Road), close to the radiotherapy unit, Compton House.

Telephone: **023 8212 4549**

Website: <https://www.maggies.org/our-centres/maggies-southampton/>



## Useful websites

Cancer Research UK [www.cruk.org.uk](http://www.cruk.org.uk)

Young Lives V Cancer [www.younglivesvscancer.org.uk](http://www.younglivesvscancer.org.uk)

Macmillan Cancer Support [www.macmillan.org.uk](http://www.macmillan.org.uk)

Maggie's Centre Southampton

[www.maggies.org/our-centres/maggies-southampton/](http://www.maggies.org/our-centres/maggies-southampton/)

Teenage Cancer Trust [www.teenagecancertrust.org.uk](http://www.teenagecancertrust.org.uk)

Southampton TYA cancer service [www.uhs.nhs.uk/tyacancer](http://www.uhs.nhs.uk/tyacancer)

I Am Portal [www.iamportal.co.uk/resources/services/wessex](http://www.iamportal.co.uk/resources/services/wessex)

## Useful information

### Parking

Discounted parking is available for cancer patients attending for day case treatments and for regular visitors. Please ask a member of ward staff for current details of reductions available. If you receive an income-related benefit, for example income support/ESA, you can claim travel expenses. Please discuss this with your CLIC Sargent worker.

### Buses

There are bus stops near to the hospital. Find details of routes and timetables at the main entrance.

### Taxis

There is a taxi rank outside the hospital and a freephone telephone to a local taxi firm in the main entrance and at West Wing 'B Level' entrance, near the physiotherapy department reception (the next floor down, below the TYA unit).

## Other facilities in the hospital for patients and visitors:

- A Natwest cashpoint on C Level, near children's x-ray

In the main hospital entrance on C Level:

- Subway
- Costa Coffee
- WH Smith
- Marks and Spencer Simply Food
- M&S Café
- Stock Shop for clothing and gifts
- Hospital pharmacy chemist shop
- Feast restaurant (for staff and visitors) on B level

## Directions to the nearest supermarkets

### Tesco Express Cxford Road

[SO16 6LN](#) (walking time approximately ten minutes)

Leave the hospital at level B West Wing, under the TYA unit.

Turn right onto Cxford Road.

Continue straight and cross Lordswood Road at the traffic lights.

### Tesco Tebourba Way

[SO16 4QE](#) (walking time approximately 25 minutes)

Leave the hospital at level B West Wing.

Turn left onto Cxford Road.

At the end of the road turn left onto Warren Avenue.

Turn right at the set of traffic lights onto Winchester Road.

At the next set of lights go straight across.

At the next set of lights turn right into William McLeod way.

### **Sainsbury's Shirley Rd**

SO15 5LL (walking time approximately 17 minutes)

Leave the hospital at level B West wing

Turn left onto Coxford Road.

At the end of the road at the mini roundabout turn left onto Warren Avenue.

Straight across set of lights onto Medina Road.

At the end of the road turn right onto Anglesea Road.

Take the next left onto Victor Road (by the Griffin pub) where you will find the car park on your right hand side.

Sainsbury's can be found on Shirley Precinct.

Iceland can also be found in Shirley High street opposite Sainsbury's.

### **Sainsbury's Lordshill**

SO16 8HY (walking time approximately 20 minutes)

Leave the hospital at level B west wing (under the TYA unit)

Turn left onto Coxford Road.

Turn Right at the double mini roundabouts onto Olive Road.

Follow the road until you get to the roundabout. Turn Left onto Aldermoor Road. Down to mini Roundabout, turn Right onto Lordshill Centre.

At the next roundabout turn Right into Sainsbury's.

There is a Post office on Warren Avenue, and one at Lordshill Centre near Sainsbury's. A post box is located outside the hospital main entrance.

### **Places to visit nearby**

If you are able to leave the ward for a while you may like to visit one of the places below. Please don't forget to check with the nurses before you go.

The following places can usually be reached within half an hour:

#### **Southampton Common SO15 7NU**

This is a large park in central Southampton, located very close to the hospital. There's parking available on Hill Lane. The common is relatively flat with easy footpaths and lots of green space. It can get busy on weekends and holidays, especially Saturday mornings when it's best avoided.

#### **Calshot SO45 1BS or Lepe Beach SO45 1AD**

Here you can see the sea and get a bit of fresh air, and it's easy to park.

#### **Weston Shore and Royal Victoria Country Park, Netley SO31 5GA**

There is a flat walk to see Southampton Water. Royal Victoria is a nice place for a stroll. Both offer plenty of parking.

#### **Manor Farm Country Park SO31 1BH**

Offers pleasant woodland with access to short walks by the river. Located 30 minutes to an hour away:

#### **The New Forest**

Offers an enjoyable drive in the countryside, and the opportunity to see New Forest ponies and other animals. Bear in mind that the traffic in Lyndhurst can get busy on weekends and during school holidays.

#### **Beaulieu SO42 7YB**

A small, quiet village on the Beaulieu River, on the eastern edge of the New Forest, with good parking. There is also a pleasant drive to Bucklers Hard (SO42 7XB)

#### **Titchfield Haven Nature Reserve PO14 3JT**

There's a coffee shop and parking available here, and the chance to see the sea and watch boats go by.

#### **Lee-On-Solent PO13 9LB**

This is a stony beach, but there's a flat path alongside it for a stroll. There is good parking on the seafront and views across the Solent to the Isle of Wight

#### **Mottisfont, National Trust SO61 0LP**

This National Trust property offers a stately home, coffee shops, paths alongside the River Test and beautiful gardens to stroll around. There is an admission charge.

## Glossary – medical words and phrases

Below are some of the terms that might be used by nursing and medical staff about your treatment. If you don't understand something we say to you, please tell us.

### A

**Alopecia** - hair loss

**Anaemia** - when the blood is not able to carry the normal amount of oxygen needed. This can make a person pale, tired and breathless.

**Analgesia** - pain relief

**Anti-emetic** - anti-sickness drug

**Audiometry** - a simple hearing test

### B

**Blood cultures** - sample of blood taken to test if infection is present in your blood

**BP** - blood pressure

**Bone marrow** - the body's 'blood factory' in the middle of some of the larger bones, particularly the pelvis

**Bone marrow aspirate** - to take a sample from your bone marrow

**Bone marrow transplant** - donation of bone marrow to the patient

### C

**Cannula** - small plastic tube put into a vein (to receive drugs and take blood, for example)

**Central venous catheter (central line)** - a long, fine tube which provides access directly into the bloodstream

**Clotting screen** - blood sample to see if blood is clotting normally

**Creatinine clearance test** - test to assess kidney function by collecting all urine over a 24-hour period

**CSF** - Cerebral spinal fluid - fluid around the brain and in the spinal cord

### D

**Diuretic drug** - medication given to help you pass urine

**Drug levels** - blood test taken to check correct dose of certain drugs

### E

**Electrolytes** - chemicals in body vital to normal function of all essential organs; essentially potassium and sodium

### F

**FBC Full blood count** - a test to look at the cells being produced by your bone marrow

**Fluid balance** - an essential part of monitoring fluid intake and output

### G

**GCSF** - an injection to stimulate growth of white blood cells

**GFR (glomerular filtration rate)** - test to measure how well your kidneys are able to filter blood

### H

**Hb** – haemoglobin; the amount of iron carried by the red cells in the blood

**Hickman** – a type of central line

### I

**Immunosuppression** - when the immune system is less able to protect the body from infection

**Intrathecal** - medication put directly into the fluid around the spine and brain, this is usually done by a lumbar puncture

**Isotope** - a radioactive substance sometimes used in medical scans

**IV** - intravenous; into a vein

### L

**LFT's** - liver function test, to assess organ function

**LP** - lumbar puncture, procedure where samples of spinal fluid are taken by putting a fine needle into the back of the spine

**Lung function** - test to assess how well the lungs are working

**M**

**MSU** - mid stream urine, urine sample to test for infection

**Metastases** - also known as secondary tumours, these come from a first (primary) tumour in another part of the body

**Mouthcare** - use of toothbrushing and/or various mouthwashes to help prevent infection in the mouth

**N**

**Neutropenic** - low white blood cell count (the cells that protect you against bacteria) When a neutrophil count is less than 1.0, there is a greater risk of serious infection

**O**

**Obs** - observations; primarily temperature, pulse, oxygen levels and blood pressure

**Oedema** - visible swelling in face, ankles or hands caused by retention of fluids

**P**

**Peripheral bloods** - sample of blood taken from a vein; usually from the arm

**PBSC** - peripheral blood stem cell; a type of transplant

**Phlebitis** - inflammation of veins

**Platelets** - cells that help with normal blood clotting. If platelets are low, you could bleed or bruise more easily

**Prosthesis** - an artificial replacement, of a bone for example

**Pyrexia** - above normal body temperature, or fever

**R**

**Relapse** - recurrence of disease

**Remission** - no evidence of disease by routine investigation

**S**

**Septicaemia** - infection in the blood

**Stem cell** - very immature cells that develop into other blood cells

**Stomatitis** - mouth ulceration

**Sub-cutaneous** - under the surface of the skin

**T**

**Thrombocytopenia** - low platelet count

**T.P.N** - total parental nutrition; a type of intravenous feeding

**TTO's** - to take out; medication to go home with

**U**

**U&E's** - urea and electrolytes; the normal body salts in the blood

**UTI** - urinary tract infection; an infection in your bladder/urethra

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

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