The ROYAL MARSDEN NHS Foundation Trust

Teenage and Young Adult services for 16-24 year olds at The Royal Marsden

Information for young people, carers and their families

Oak Centre for Children and Young People





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This booklet is evidence based wherever the appropriate evidence is available, and represents an accumulation of expert opinion and professional interpretation.

Details of the references used in writing this booklet are available on request from:

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Should you require information in an alternative format, please contact The Royal Marsden Help Centre.

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Thanks to supporters of The Royal Marsden Cancer Charity, we raised £16 million to build the Oak Centre for Children and Young People. Opened in September 2011 by TRH The Duke and Duchess of Cambridge, it is one of the largest comprehensive children and young people's cancer centres in Europe.

The Royal Marsden Cancer Charity raises money solely to support The Royal Marsden, a world-leading cancer centre. We ensure our nurses, doctors and research teams can provide the very best care and develop life-saving treatments, which are used across the UK and around the world.

From funding state-of-the-art equipment and groundbreaking research, to creating the very best patient environments, we will never stop looking for ways to improve the lives of people affected by cancer.

The Royal Marsden Cancer Charity For a future beyond cancer.



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Introduction

eing diagnosed with cancer can turn your life upside down.
Some of the treatment you

Some of the treatment you have had or are having may disrupt your routine and your plans, which is where we can help you.

The Teenage and Young Adult (TYA) service offers specialist, age-appropriate care, as well as emotional, psychological, practical and social support and advice to people aged 16 to 24 who have been diagnosed with cancer. We can also offer some support to your family, friends and others who are important to you.

Do I have a choice about where I receive my treatment?

ational guidance promotes that teenagers and young adults should receive their care in an environment that is suitable for their age group. rather than one designed for children or older adults. The guidance advises that teenagers aged 16 to 18 years old must be cared for at one of the 13 principal treatment centres (hospitals) in the UK designated to offer such care. The Royal Marsden is one of those hospitals.

Young adults aged between 19 and 24 years old can choose to be treated at either a TYA-designated local hospital or at The Royal Marsden. The aim of this booklet is to help you to make that decision. You can speak to the team directly for advice (please see page 32 for contact details).

Will I receive the best treatment?

herever you choose to have your care, your treatment plan will be discussed and planned in a specialist multi-disciplinary team (MDT) meeting to ensure you are receiving the very best treatment.

At The Royal Marsden, you will have access to a ward where we treat only teenagers and young adults. It is designed and run differently to wards for adults or children. We also have a wide team of staff to support you and your family.

You may be eligible to be entered on clinical trials that are appropriate for both your cancer and age. You can decide if you would like to take part and your care will not be affected if you choose not to be part of a clinical trial.



Will other young people of my age with cancer be on the unit?

he Royal Marsden is a Principal Treatment Centre (PTC) for teenagers and young adults with cancer so you will meet other young patients on the Teenage Cancer Trust Unit (TCTU). We run regular peer support events both in the hospital and off site, giving you an opportunity to meet other young people in a similar situation. This includes trips to the theatre, meals out and cinema outings. These are either just for young people having treatment at The Royal Marsden or linking in with young people being treated at other hospitals through charities such as Teenage

Cancer Trust and Ellen
MacArthur Cancer Trust.

If you are on the unit, we have a range of social developmental activities including a weekly friday 'mocktails' night, music sessions and other creative activities. If you have a particular hobby, interest or idea, please let us know. Our youth support coordinator can work with you to facilitate these.

You can find out about events with other young people through our instagram **TYA_royalmarsden** or you can ask the lead nurse or youth support coordinator for more information.

The TYA instagram account

he TYA_royalmarsden instagram account is for young people aged 16-24 years being treated at The Royal Marsden. It allows young people to connect with others in a similar situation and find out about upcoming events and opportunities, including peer support events at the hospital, residential events and meet ups locally

and in London. The account is also used to feed back suggestions and to get involved in developing our services.

For more information, please ask your specialist nurse.

How do I get involved in developing services?

he Royal Marsden is committed to ensuring that effective patient involvement is a key part of our work and our services. Your experiences as a patient can really help make a difference to the care that is provided now and in the future.

The Royal Marsden has a Patient and Carer Advisory Group looking at wider issues and services throughout the hospital. If you are interested in getting involved, please ask a member of staff for more information or visit the website www.royalmarsden. nhs.uk/getting-involved/ patient-and-carer-advisorygroup

The Youth Forum is for young people aged 18–24 years. It is a patient forum that works on improving services specifically for young people with cancer. You will have the opportunity to work on tackling issues relevant to your age group, speak at schools/conferences, get involved in media work and contribute to creative projects such as an LGBT+ mural display which has recently been unveiled on the TCTU.





What facilities are available for TYA patients at The Royal Marsden?

At The Royal Marsden, there are specific TYA areas for both outpatient and inpatient treatment. Outpatient treatment is treatment where you can go home the same day. Inpatient treatment is treatment that requires overnight stays in hospital. You might be admitted to hospital for planned treatment, or if you have become unwell at home. you might need to be admitted to hospital as an emergency.

Accommodation

Our unit has nine inpatient beds. This includes five single/side rooms and two bays which are single sex. Each single/side room has an en-suite bathroom, wireless internet, a TV, DVD player and storage. As well as your clothes and personal items, you can bring your own bedding if you wish. You can bring your mobile phone. tablet and laptop but 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 which can be converted to a bed to allow friends or family to stay with you. Every patient bed on the TCTU has an additional bed next to it for a parent or partner (over the age of 16 years) to stay. Accommodation for a second carer is available but this is very limited and is subject to a charge. Showers and washing facilities for parents and partners are available in the parents' room which is based next to TCTU's entrance.

There are two washing machines and tumble dryers on the TCTU which are free to use, but you will need to bring your own detergent. The TCTU is a social place where we hope you will be able to mix with people your own age, so we encourage bed curtains to be open during the day whenever possible. We try to keep the ward area guiet and dark at night time to help patients sleep better. Noise at night is not usually a problem on our

ward; please be considerate of others at night. Ear plugs and eye masks are available, so please ask a nurse if you would like these.

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 will advise how your family and friends can help. This may be by wearing protective clothing and being extra careful about hand washing, for example.

Food

There is a cook on the ward from 9.30am–7pm seven days a week, who provides all meals and snacks to patients. This kitchen can only be used by The Royal Marsden catering staff. Snacks, tea, coffee, sugar and milk, a microwave and a fridge are also available in the chillout zone throughout the day.





Parents or partners can use most of the facilities on the TCTU but not the food or drinks provided for patients. There is a separate kitchen for parents and partners to store food and make simple meals. Please note that take away meals **must not** be brought onto the unit. The fridge in the kitchen has individual sections that can be locked. A kev can be obtained from a member of the TCTU staff for a deposit of £10 (refundable).

Things to do

There are two social areas on the TCTU:

- 1) The chill out zone where people can meet to watch TV, make snacks and play games. It has two TVs (including Sky channels), DVDs, PS4 and Xbox One consoles and two computers (PC and Mac). Informal workshops take place here eg. arts and crafts, music making and film nights.
- 2) The hub where schoolwork and group activities take place, such as music, art and pizza nights. It also has a pool table, football table and a

drum kit. Both areas are open every day. The TCT Youth Support Coordinator runs these areas and is around most weekdays to help with activities.

Outside and quiet spaces

If the weather permits, there is a roof terrace with artificial grass, chairs and fresh air. There are two areas on the TCTU that are designed to be peaceful – the pod in the chill-out zone and the quiet room behind the reception desk.

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 are experiencing sore throats, coughs, colds or upset stomachs, for example). All visitors should wash their hands and use alcohol gel before and after visiting the unit to help prevent infections. We ask evening visitors 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. A doctor can prescribe vou 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. Alcohol is **not** allowed to be brought onto the ward for either patients or visitors. Illegal drugs and herbal products are **not** 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.

Observations, medication and ward routines

The nurses and healthcare assistants will regularly check your observations, usually every four hours. This will include taking 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 (IV) 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. A doctor or advanced nurse practitioner (ANP) will see you daily from Monday to Sunday, or more frequently if there is an urgent need.

Your consultant usually does a ward round once or twice a week; 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. This is to check for MRSA, one of the infections we want to protect patients from.

TYA day-care bay on the TCTU

This area has three treatment spaces 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 TCTU.

Chelsea site

Some TYA patients have part of or all of their treatment at The Royal Marsden in Chelsea, as this is where certain specialist services, major surgery and critical care take place. There is no dedicated TCTU here, but the team will still offer support.

Cavendish Square

Some patients accessing care privately at The Royal Marsden will receive their

outpatient care and clinic appointments here. Whilst there is no dedicated TYA unit, the wider TYA team can provide additional support to TYA patients receiving their treatment here.

Planned admissions

We will discuss the date for your admission with you and will always try to give you a choice of dates.

On the day of your admission, please arrive at the unit at 10am. We know that this is early, however it allows us the time to complete all the required pre-treatment checks, order your treatment and ensure that treatment can start on time.

Please bring any medications that you normally take at home as you will require these during your stay.

On admission, please inform the nurse, doctor or pharmacist of any medications that you require on discharge.

We will always try to accommodate all of our planned admissions, however there may be occasions when we do not have a bed available. If this happens, we may need to either delay your treatment or offer you a bed on an alternative ward. We will aim to inform you of this as soon as possible. If treatment has to be delayed, this will be discussed with the medical team and the senior team within the hospital – these decisions are made on the basis of need and safety.

Discharges

We will aim to have you ready to leave the unit by 10am on the day of discharge, however, this will depend on the treatment regime that you are receiving. We are happy for patients to be discharged late in the evening if medically fit. We understand that you may need to wait for somebody to pick you up - if this is going to be late in the day, we may ask you to leave your bed space to allow someone else to start their treatment. You are welcome to stay on the unit and use

the facilities while you wait for your lift home.

In some circumstances, The Royal Marsden offers transport for patients. If you require transport home, please let us know on admission. Our patient transport is need-assessed.





Useful information - getting to the hospital

he Royal Marsden has three hospitals, one in Sutton, Surrey, one in Chelsea, London and one in Cavendish Square, providing outpatient treatment for private patients.

Sutton

The hospital has a cash point, staff and visitors' restaurant and a small shop (open Monday to Friday, 9.30am to 4pm). The nearest village is Banstead. There is no direct public transport from the hospital to Banstead, but if you have a car it's a 10 minute drive

Sutton town centre is also 10 minutes by car. The S3 and S4 buses go from the hospital to Sutton, and the 80 and 280 buses also go there from nearby roads. Please visit www.tfl.gov.uk for timetables.

The nearest railway station to the hospital is Belmont (10 minutes' walk). Please ask the team caring for you for more information on local facilities.

Chelsea

It is difficult and expensive to park close to the hospital but it is well-served by public transport. The nearest tube station is South Kensington which is on the Circle, District and Piccadilly lines, and many buses go past or close to the hospital.

Cavendish Square

The nearest tube station is Oxford Circus as parking is limited.





Your hospital team

W

hilst on the ward as an inpatient, you will be

cared for by a team of doctors and advanced nurse practitioners (ANPs) overseen by your consultant. The doctors or ANPs 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.

A range of staff members work on the TCTU so 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 a brief summary of what the different staff members do:

- Matron: in charge of a group of wards and takes responsibility for ensuring excellent patient experience and safety.
- Lead Nurse: works with the team at The Royal Marsden and Teenage Cancer Trust to develop the service and make sure you are provided with specialist care.
- Teenage and Young
 Adults Advanced Nurse
 Practitioner (ANP):
 primarily covers inpatient
 and day care TYA
 patients (16–24 years)
 working with the medical
 and nursing teams to

- provide comprehensive care including physical assessment and prescribing medication.
- Teenage and Young Adult Stem Cell Transplant **Clinical Nurse Specialist:** if as part of your treatment you require a stem cell transplant, the TYA stem cell transplant CNS will become your key worker, and will be there to coordinate your care. both in the lead up to and following transplant. They will support both you and your relatives through this process and will work closely with the consultants. They will also liaise with local hospitals and GPs to support them when required in your ongoing care.
- Teenage Cancer Trust Youth Support Coordinator: supports you during your inpatient stay by enabling you to develop skills, hobbies and interests, provides emotional support and can introduce you to other young people at peer meet ups.

- Ward Manager/Sister: the nurse in charge of running the inpatient ward. This is where you will stay if you need to stay in the hospital overnight.
- Staff Nurse: works alongside the Sister 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 staff nurses from one of the other cancer wards will help on TCTU.
- Agency Nurse: provides 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.
- Student: there may be a range of student healthcare professionals involved in your care. They will identify themselves to you.
- Receptionist/Ward Clerk:
 helps with the day to day running of the ward.

- Care Support Worker: supports 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.
- Ward Hostess: serves meals and refreshments.
- Physiotherapist: assesses and treats a wide range of physical problems that you may develop. By carrying out ongoing assessment of your needs and applying skilled treatment which is vital for your independence and functional ability, your physiotherapist can help to improve your quality of life.
- Occupational Therapist:
 helps you to remain
 independent and continue
 with activities of daily living
 that may have become
 difficult for you to manage.
- Speech and Language
 Therapist: assesses and advises on communication difficulties related to speech, language and swallowing. They provide

- support to help you manage these difficulties according to your individual needs and lifestyle.
- Dietitian: offers help and advice about nutrition and eating. They will also provide guidance if additional nutritional supplements or alternative feeding is required to support your intake.
- Young Lives vs Cancer
 Worker: offers 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.
- The Symptom Control and Palliative Care Team: we have a dedicated service for all TYA patients, aged 16–24. This includes both inpatients and outpatients and is available at all stages of your illness. The team consists of specialist nurses and doctors.

They can help with physical problems such as pain, sickness and other symptoms, provide emotional support and ensure coordination of care between the hospital and community palliative care services.

- Psychological Care
Service: this multidisciplinary team offers
confidential advice,
therapy and support for
issues including anxiety,
depression, anger, identity,
self-esteem, family and
relationship issues, side
effects of treatment and
uncertainty. Support can
also be offered for issues to
do with school or college,
memory and concentration.

Service for young people aged 16 and 17 years

The service is offered by Paediatric and TYA Clinical Psychologists. You can contact us directly on 020 8661 3676 or ask any member of staff to refer you.

Service for young people aged 18–24 years

The team consists of counsellors/psychotherapists (including art therapy and psychosexual therapy), psychologists, mental health nurses and a psychiatrist. You can contact us on 020 7808 2777 or ask any member of staff to refer you.

Key worker

very patient receiving treatment at The Royal Marsden has a key worker as a point of contact for questions about your treatment. Your key worker will work closely with the teams involved in your care to ensure you know who to contact for information,

support and advice. Your key worker is just one part of the team looking after you – other team members will be happy to answer any queries you may have.

A key worker may change, if appropriate, during the course of treatment.

| My key worker is |
|------------------|
| TAT 1: 1 |
| Working days |
| Telephone |
| 1 010 p 110 110 |
| Email |



Further Support

nthony Nolan

A resource for people undergoing a stem cell transplant. They provide patient information, application for grants, an online forum, telephone emotional support and support family days.

Website:

www.anthonynolan.org

Telephone: 0303 303 0303

Blood Cancer UK

A resource for people diagnosed with a blood cancer. They provide useful information about treatment and offer advice on work, finances and living with blood cancer.

Website:

www.bloodcancer.org.uk

Freephone: 0808 2080 888

Cancer Research UK

Provides up to date statistics and data on every cancer diagnosis and current treatment options available in the UK

Website:

www.cancerresearchuk.org

Nurse Helpline: 0808 800 4040

Changing Faces

A charity that supports people who have visible physical differences. They provide advice, support and psychosocial services to children, young people and adults. This includes a confidential helpline, peer support group, and a free skin camouflage service.

Website:

www.changingfaces.org.uk

Support line: 0300 012 0275

Children's Cancer and Leukaemia Group (CCLG)

CCLG provides useful information and support for family members who have questions about the treatment pathway for young people (up to the age of 24) diagnosed with cancer.

Website: www.cclg.org.uk
Telephone: 0333 0507 654
Ellen MacArthur Cancer

Trust

A charity that supports young people with cancer from the age of 8-24 years to believe in a brighter future through sailing and outdoor activities.

Website: www. ellenmacarthurcancertrust. org

Telephone: 01983 297 750 Look Good Feel Better

A charity that provides advice through workshops and online tutorials on makeup and styling for people receiving cancer treatment. Workshops are run regularly at venues including the Teenage Cancer Trust Unit at The Royal Marsden.

Website: www. lookgoodfeelbetter.co.uk

Telephone: 01372 747 500

Lymphoma Action

A charity dedicated to lymphoma that provides support for you and your family from diagnosis, through treatment and beyond. Support includes a helpline, wellbeing videos, self-management advice, support groups, and a buddy service.

Website: lymphoma-action.

org.uk

Freephone: 0808 808 5555

Macmillan Cancer Support

Macmillan provides information to help you make the best decision about your treatment and guidance about dealing with its effects. They also offer financial support and emotional support for you and your family.

Website:

www.macmillan.org.uk

Support line: 0808 808 0000

Maggie's

A cancer charity that works with The Royal Marsden to provide practical and emotional support to people living with cancer, their friends and family. The Maggie's centre is located close to the Teenage and Young Adult Unit in Sutton. It's a light, spacious and uplifting building with comfy sofas, Wi-Fi and free tea and coffee for visitors. The team of professional staff are experienced in oncology and are also available to provide advice and support. The centre is open Monday to Friday, 9am-5pm.

Website: www.maggies.org

Telephone: 020 3982 3141

MOVE Charity

Provides practical and online support to help you get moving. This includes an 8 week online physical activity programme to help improve the short and long-term effects of cancer, and a cancer community support running group called 5k your way.

Website: www.movecharity.org

Sarcoma UK

A charity that offers advice for people with sarcoma as well as their family and carers. Resources include patient guides, information on clinical trials, support groups, a support line and a podcast.

Website:

www.sarcoma.org.uk

Support line: 0808 801 0401

Shine Cancer Support

Support for people in their 20s–40s diagnosed with cancer. They run workshops, retreats, an annual conference, and have support available 24/7 via their Facebook group, Shine TV, and podcasts.

Website: www. shinecancersupport.org

Teenage Cancer Trust

A charity that supports 13–24 year olds diagnosed with cancer. They provide support on living with and beyond cancer and signpost to age-appropriate services on wellbeing, nutrition and lifestyle.

Website: www. teenagecancertrust.org

Telephone: 020 7612 0370

The Brain Tumour Charity

Provides information on treatment and management of side effects for people diagnosed with a brain tumour. They have support networks including a Facebook group and a young adults service.

Website: www.

the brain tumour charity. org

Support line: 0808 800 0004

The Little Princess Trust

A charity that supplies real hair wigs and styling for free, for children and young people up to the age of 24 years old.

Website: www.

littleprincesses.org.uk

Telephone: 01432 352 359

Trekstock

Helps young adults in their 20s and 30s with cancer to get moving again physically, socially and psychologically. They provide practical and social support programmes to support living well through and beyond cancer.

Website:

www.trekstock.com

Young Lives vs Cancer

Young Lives vs Cancer Social Workers or Community Workers can provide support with day-to-day issues. There are also opportunities to connect with other young people with cancer, such as participation groups, events to help boost confidence and career opportunities, and the chance to influence our work to make lives better for young people with cancer.

Website: www.

younglivesvscancer.org.uk

Telephone: 0300 330 0803





Glossary

Below are some of the terms and abbreviations 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.

Α

Alopecia - hair loss

Anaemia – when the blood is not able to carry the normal amount of oxygen needed – this can make you pale, tired and breathless

Analgesia – pain relief

Anti-emetic – anti-sickness drug

Audiometry – a simple hearing test

B

Blood cultures – samples 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 – a sample taken from your bone marrow

Bone marrow transplant – donation of bone marrow to the patient

C

Cannula – a 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 – a blood sample to see if blood is clotting normally

Creatinine clearance test

a test to assess kidney function. There are two different ways to test this.
 One involves collecting all urine over a 24 hour period.
 The other is called an EDTA and involves injecting a dye and then blood tests over several hours after.

Cerebral spinal fluid (CSF)

 fluid around the brain and in the spinal cord

D

Diuretic drug – medication given to help you pass urine

Drug levels – a blood test taken to check the correct dose of certain drugs

Ē

Electrolytes – chemicals in the body which are vital to the normal function of all essential organs; essentially potassium and sodium

Enteral nutrition – a type of feeding that is given via a tube into the stomach

F

Full blood count (FBC) – 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

Glomerular filtration rate (GFR) – a test to measure how well your kidneys are able to filter blood

Н

Haemoglobin (Hb) – the amount of iron carried by the red cells in the blood

Hickman – a type of central line

Ī

Immunosuppression – when the immune system is

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

Intravenous (IV) – into a vein

Isotope – a radioactive substance sometimes used in medical scans

L

Liver function test (LFT) – blood tests that tell us how well the liver is functioning

Lumbar puncture (LP) – a procedure where samples of spinal fluid are taken by putting a fine needle into the back of the spine

Lung function – a test to assess how well the lungs are working

M

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

Mid-stream urine (MSU) – a urine sample to test for infection

Mouthcare – use of tooth brushing and/or various mouthwashes to help prevent infection in the mouth

Mucositis – a side effect of some chemotherapy and radiotherapy which causes a sore mouth and ulcers

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

0

Observations (Obs) – primarily temperature, pulse, oxygen levels, blood pressure

and respiratory rate

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

P

Peripheral bloods – a sample of blood taken from a vein, usually from the arm

Peripheral blood stem cell transplant (PBSC) – a type of transplant that involves receiving stem cells

Phlebitis – inflammation of veins

PICC line – a type of central line that is in your upper arm that enables bloods to be taken and medication to be given

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

Port-a-cath – an implanted access device that enables easy access to your veins to take blood and give medication

Prosthesis – an artificial replacement, of a bone, for example

Pyrexia – above normal body temperature, or a 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 – a mouth ulceration

Sub-cutaneous – under the surface of the skin

т

Thrombocytopenia – low platelet count

To take out (TTO) – medication to go home with

Total parental nutrition (TPN) – a type of intravenous feeding

U

Urea and electrolytes (U&E)

 blood tests that tell us the level of electrolytes (normal body salts) in your body and also your urea and creatinine levels which tell us about your kidney function

Urinary tract infection (UTI) – an infection in your bladder/urethra

We would like to acknowledge and thank University Hospital Southampton NHS Foundation Trust for allowing us to review their patient information leaflet in the development of this booklet.







