

The ROYAL MARSDEN
NHS Foundation Trust

Information on the
Principal Treatment Centre
(PTC) for children and
young people at
The Royal Marsden and
St George's University
Hospitals



NHS

**Information for patients,
parents and carers**

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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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No conflicts of interest were declared in the production of this booklet. The information in this booklet is correct at the time of going to print.

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

Please note that references to your child within this booklet will be referred to as 'CYP' (child or young person).

Having a CYP diagnosed with cancer can have a huge impact on the whole family.

The Principal Treatment Centre (PTC) offers specialist age-appropriate care, plus emotional, psychological, practical and social support and advice to CYPs who have been diagnosed with cancer.

Care is given by a team of professionals with a special interest in the care of CYP and is made up of:

- doctors
- nurses
- scientists
- clinical nurse specialists (CNS)
- advanced nurse practitioners
- lead nurse for TYA

- youth support coordinators
- play specialists
- teachers
- speech and language therapists
- social workers
- psychologists
- physiotherapists
- dietitians
- occupational therapists
- chaplains
- cleaners
- cooks.

Most of the team work on both the Sutton and London branches of The Royal Marsden.

We work closely together to help provide the best possible expert care. We will be open and honest with you, and answer your questions to the best of our knowledge.

The team at The Oak Centre for Children and Young People aim to give the best care and attention to your CYP. We recognise this is an immensely challenging time for the whole family and friendship network when a CYP is diagnosed with cancer or haematological disorders requiring intensive therapy. We work within our Trust values and follow The Oak Centre's values of being Caring, Collaborative, Competent and Respectful.

We expect our patients and families to work collaboratively and respectfully with us. We recognise that patients and families may wish to raise concerns and we support this being done in a polite and respectful manner. Physical or verbal abuse towards any staff at The Royal Marsden or our partner Trust St George's will not be tolerated. Any concerns with regards to care or service should be appropriately raised to the nurse in charge of the unit or our

Patient Advice and Liaison Service (PALS), to enable prompt management. Any verbal abuse, or aggressive behaviour, inappropriate language or physical abuse will be managed by the nurse in charge, sister, matron or divisional director according to its severity in line with the Trust policy.

We thank you for your co-operation in expected behaviours whilst receiving care from the team at The Oak Centre for Children and Young People.

The model of care



The Royal Marsden, Sutton and St George's, London together form the Principal Treatment Centre (PTC) for children and young people with cancer, living in South East London, Kent, Sussex and Surrey.

The Royal Marsden, a specialist cancer hospital, provides investigations, diagnosis, chemotherapy, radiotherapy, bone marrow transplant and drug development services. St George's also provides investigations, diagnosis and chemotherapy as well as other specialist care including general surgery, neurosurgery, neurology, hearing tests, high dependency and intensive care.

The Royal Marsden also has links with the CYP neurosurgical and liver units at King's College Hospital (KCH), London and the cardiology (heart), renal (kidney) and paediatric intensive care services at Evelina Children's Healthcare, London.

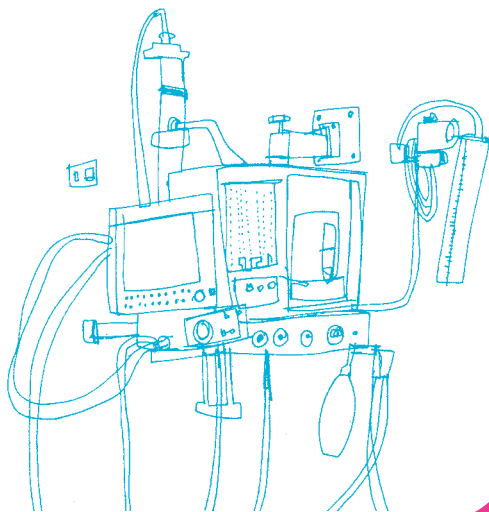
This leaflet gives an introduction to the care and services at the Principal Treatment Centre. Other leaflets describing elements of the service in more detail are available.

Will my child be getting the best treatment?

4 our CYP's treatment will be discussed and planned by a specialist multidisciplinary team (MDT), consisting of doctors, nurses and allied health care professionals, to ensure they are receiving the best treatment to meet their needs.

Your CYP may be eligible to be treated on appropriate clinical trials for their age and cancer type – this will be discussed with you by your CYP's consultant.

Your CYP will be cared for on a ward or daycare unit that only treat children and young people, and is designed and run specifically to meet both their and your needs.



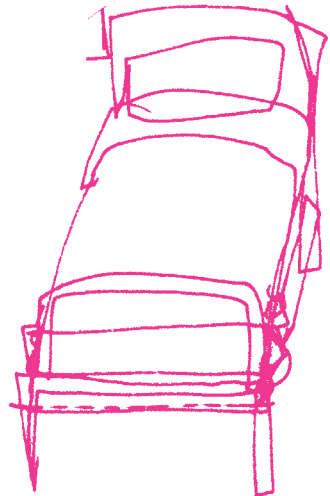
The Royal Marsden

The Royal Marsden is one of the largest children's cancer centres in Europe. The Oak Centre for Children and Young People (OCCYP) is based at the Sutton site. There are two clinical areas for children under the age of 16 years, and a ward for teenagers and young people (a separate booklet is available for this area).

- McElwain Ward is a purpose built inpatient ward with 18 beds for children and teenagers up to the age of 16 years.
- Children's Daycare is the department where children and young people have treatments or procedures as outpatients.

Your stay on McElwain Ward

To assist you during your stay on McElwain Ward, the following information has been compiled by staff at The Royal Marsden together with input from the parent of a former patient.



Family held records

“Family held records – a nurse will give you a folder when you are admitted. It is a universal document for all children with cancer and will provide you with further information about your child’s medical needs while receiving treatment. You will be able to track their progress and have easy access to important phone numbers and guidelines for what to do when your is child unwell.” J

Food

There is a cook on the ward from 8.30am to 6.30pm seven days a week, who will provide meals and snacks to inpatients and CYP in daycare. The ward kitchen can only be used by The Royal Marsden catering staff, but there is a separate kitchen

for parents and carers to make simple meals and store food.

This is closed for cleaning once a week, 11am – 12pm (noon) therefore you will not be able to use it during this time.

Tea, coffee, milk and bread are supplied free of charge to all parents/carers. Locked fridge compartments are available in the parent’s kitchen. You can obtain a key for a deposit of £10, which will be returned on your child’s discharge.

Please ensure you wash up after using the facilities, otherwise the kitchen may be taken out of service.

“Tip for the hobs – when you place a pan on the hob the heat comes on and when you remove it the heat goes off!” J

The Cherry Tree Café is open 7.30am – 6pm Monday to Friday and 7.30am – 2pm Saturday and Sunday. The Cherry Tree Restaurant is open 7.30am – 10.30am for breakfast and 11.45am – 2pm for lunch – both serve hot and cold food and drinks. Outside these hours, food (including microwavable meals), is available from vending machines. Patients and visitors are permitted to eat and drink in either restaurant, however, for hygiene and infection control reasons, takeaway food **must not** be brought into the hospital.

Some patients may be subject to dietary restrictions. The medical staff will discuss this with you.

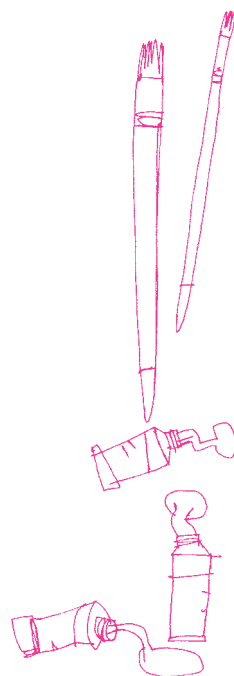
The playroom

This is for younger children and is open at all times, unless it is being cleaned.

“The playroom is run by a team of lovely play specialists who also organise activities which take place here, and can help you access different toys/games/crafts that your child may like. You can also

find a selection of ‘the beads of courage’ here to mark your child’s journey.

The play specialists work Monday to Friday and divide their time between the ward and outpatients. They support children under procedure and help prepare them alongside the nurses. There is sometimes a play specialist at weekends; it appears to be ad-hoc but a good resource when it is available! It is a good idea to stock up on games or craft for the weekend.” J



The pod

The pod is next to the parent's kitchen and is for children aged 10 years and over. It has games consoles, computers, and age appropriate books, DVDs and games. Please ask a member of staff for the access code.

Play Specialists or the youth support worker on the OCCYP provide activities for children and teenagers.



The schoolroom

This is used for schoolwork and group activities such as music, art, cooking and parties. The schoolroom is open term time from 10am – 3pm. A team of teachers works on the unit.

We encourage all CYPs to attend on a regular basis, to aid socialisation and routine.

Sleep

CYPs beds have a TV, DVD player, a wardrobe and storage as well as patient controlled lighting. We ask CYPs and parents to be mindful of others when using TVs or playing music. The

ward staff will enforce quiet time from **7pm** onwards, which means lights need to be dimmed and noise levels kept to a minimum to promote the rest and sleep of the patients.

Headphones will need to be used after this time.

“You can get bed sheets from the linen room (next to the shower room). If you are staying more than a few days it is worth considering home comforts like your own pillow and a single duvet – discuss with your ward nurse. You would need to bring enough covers to change regularly.” J



A patient and nurse in the
Oak Centre for Children
and Young People



Televisions

These are present for each patient, but unfortunately the speakers are at the back which can make noise an issue. Please be respectful to others and give consideration to younger children or people trying to sleep, keeping the volume at an acceptable level, or using the headphones provided. All patients are expected to use headphones after **7pm** to ensure the comfort of everyone on the ward.

Nurse call system

Pressing the large orange button on the nurse call handset will alert the ward staff that you need assistance. They will try to come as quickly as possible; however please be patient if, on occasion, they are not able to come immediately. Nursing handovers take place from 8am – 8.30am and 8pm – 8.30pm, so please only use the nurse call if absolutely necessary.

“When you press this button a light flashes above your child’s bed/room. Don’t feel that you

have to try and locate a nurse on the ward as they are very happy for you to use the call button. Sometimes when they are busy with other patients they are unable to respond straight away but they will come as soon as they are able to.” J

Emergency call

If you need help in an emergency whilst at your CYP’s **bedside**, please pull out the red button that sticks out from the wall. If you are in the **bathroom**, please pull the red emergency pull cord and a nurse will come as quickly as possible.

“This is only to be pulled when your child needs urgent medical assistance. When this button is activated, all staff have to stop what they are doing (when safe to do so) and run to the bed where the alarm has been raised.” J

Staying overnight

Every CYP’s space has a bed for **one** parent or carer over the age of 16 years to stay. For safety reasons, siblings are not permitted to stay

overnight unless there are exceptional circumstances and it has been agreed by the Ward Sister in advance.

The nursing staff need access to your CYP overnight. It is important that they sleep in their own bed and **not** in the parent bed, so they can be monitored and cared for easily. Food and drinks from the ward kitchen are only provided for patients and breastfeeding parents.

Showers and washing facilities for parents and carers are available opposite cubicle 13 and additionally, next to the quiet room. The bathrooms in the cubicles and bays are **only** for the patients – this is in line with infection prevention and control policies.

Laundry

There are washing machines, tumble driers and ironing facilities available, free of charge on McElwain Ward. Washing baskets are provided to carry your clothes to and from your bed space. Please return the basket to

the laundry room for other families to use.

“You will need to supply your own washing powder/softener. The laundry room can be found next to the sluice, by the nurses’ station.” J

Sluice

The sluice room or dirty utility, is where all the patient’s urine, stool, or vomit output should be taken to be measured and disposed of. Please label your CYP’s bedpans or urine bottles and put them in the sluice, so that staff can measure them and take any samples needed for tests.

“You can collect empty bedpans/urine bottles/sick bowls from the sluice. If your child is in their own room then you leave the bedpans on the shelf in the bathroom and the nurses or HCA will process them there.” J

Internet/Wi-Fi and telephones

Free Wi-Fi is available on the ward, and the signal is strong enough for basic usage. The mobile phone signal is poor, so there is a telephone

opposite the laundry room to make outgoing calls only. This telephone is provided free of charge and is shared by all families on the ward. Press 9 to make an outside call.

“Internet can be accessed via the RM Portal, you only need to click on the terms and conditions, don’t worry about putting the rest of the information it asks for. The Wi-Fi access resets at midnight so you will need to re-click on the terms and conditions every day.” J

Outside space

The Courtyard and The Glade Garden provide outdoor spaces that can be enjoyed by all families. There are published guidelines and criteria to use the garden/ outdoor space; please discuss with your CYP’s nurse.

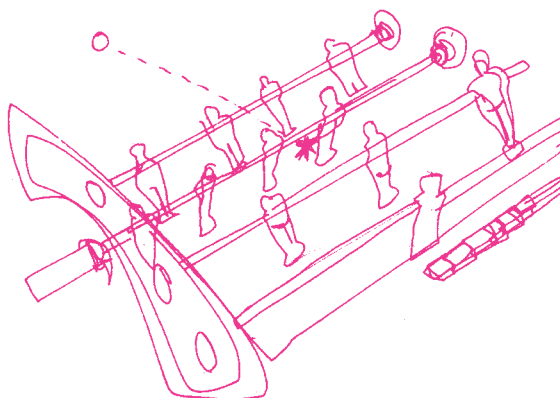
“It can be really great to get out for some fresh air, both for you and your child; it just helps you feel better.” J

Peace and quiet

There are two parents’ sitting rooms on the OCCYP that are designed to be peaceful. The larger Pandora Room and the smaller Quiet Room. These are shared spaces for parents, but can be used for families to sit together, or for meetings between families and the medical and nursing team.

Smoking

The Royal Marsden is a non smoking site and it is not permitted to smoke anywhere on Trust property. We ask that people who wish to smoke walk completely off Trust property to the road away from the hospital.



Other parents/carers on the unit

We encourage you to make connections with other families on the ward for your benefit as well as your CYP's. Other avenues of support available, if needed, include psychological support services, CLIC Sargent and key workers.

“Chatting to other parents can be lovely, but sometimes daunting if they are in different stages of treatment. Hold onto the fact that no one is in the exact same situation with regards to their child's cancer, so comparisons are unhelpful. However, finding support through chatting to other parents who know what it feels like to have a child diagnosed with cancer can be really valuable.” J

Safety and security

The safety of your CYP is of paramount importance to us – please cooperate to keep them as safe as possible.

Every CYP admitted to the ward will be given an identification wristband.

It is very important that they wear this to reduce the risk of serious consequences if medication and blood product errors occur.

If you are going to leave your CYP unsupervised, please make a member of staff aware.

The OCCYP has restricted access and entry can be gained using the intercom system at the entrances. Please do not allow other people access to the department when you are passing through the open door.

Please be careful with your personal belongings and keep them to a minimum; hospitals are public spaces and we cannot make the OCCYP 100% secure. We will ask you to sign a property disclaimer on admission.

The Royal Marsden has a zero tolerance policy for aggressive, abusive or threatening behaviour and anyone deemed to be showing signs of unacceptable behaviour will be dealt with appropriately.

We strive to provide your CYP and family with the best care possible and want to work collaboratively with you to achieve that.

“If you are staying for a while then you can ask to have a swipe card in exchange for a £10 deposit. This allows you easier access in and out of the ward. This is particularly helpful at weekends and nights when you otherwise need to rely on a member of staff to open the door for you. The swipe card is updated weekly for you by a member of staff and you need to return it when you go home so other families can benefit.” J

Facilities

The Sutton site of The Royal Marsden has a cash point and a small hospital shop (open Monday to Friday, 10am – 4pm).

Ward team

This includes:

- Nurses
- Health care support workers
- Doctors
- Ward receptionist
- Catering host/hostess
- Ward housekeepers
- ISS domestic staff
- Therapists
- Play specialistists.

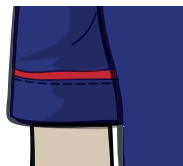
Nurses

There are nurses working on the McElwain Ward 24 hours a day, 7 days a week.

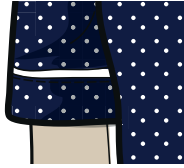
The day shift is from 8am until 8.30pm. The night shift is from 8pm until 8.30am.

You can identify the nursing team members by their uniform:

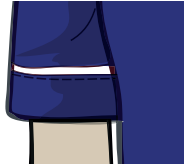
- Matron (navy blue uniform with red piping)



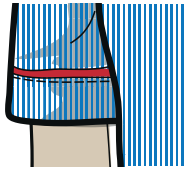
- Ward Sister (navy blue and white spotted uniform)



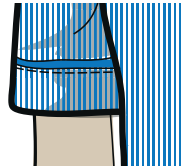
- Clinical Nurse Educator (navy blue uniform with white piping)



- Senior Staff Nurse (navy blue striped uniform with red piping)



- Staff Nurse (navy blue striped uniform with navy blue piping)



“The nurses that you will see are the lovely nurses that look after the patients on the ward, the different uniforms tell you how senior they are.” J

More information on some of the roles within the team are outlined below:

Health Care Support Workers

Health Care Support Workers, (previously known as Health Care Assistants) work with the nurses to support them with daily tasks, such as carrying out observations of temperature, blood pressure, and monitoring input/output. They always work under the supervision of nurses and report to them.

“A HCA supports the nurses on the ward, they cannot administer medication or undertake any procedures, but can support daily care and monitoring of patients.” J

Housekeeper

The ward housekeeper works Monday to Friday, 8am – 4pm. They are responsible for the maintenance of the ward and the stock levels, including the parent kitchen.

Physiotherapy, Occupational Therapy, SALT, Psychology

There is a physiotherapist, occupational therapist, speech and language therapist (SALT) and therapy assistants that work on the ward to ensure your CYP receives any additional support with their mobility, speech and any weak areas. There is also a team of psychologists that work with all our families who require extra support, or just someone to talk to outside of the ward.

“The psychology service is invaluable for your child and for yourselves as parents/ carers.” J

Doctors

At all times at least one doctor is working on McElwain Ward and one consultant is on call 24 hours a day, 7 days a week. During the day, teams of doctors work across the unit.

“There are a number of junior doctors who work on the ward and are involved in the day to

day care of your child. Most of these doctors rotate every 6 months so don't be surprised if you return that faces may have changed. The junior doctors are supported by the Consultant Oncologists who are permanent staff.” J

Advanced Nurse Practitioners (ANP)

These are registered nurses who are very experienced in their field and have undertaken further training and education to develop skills, knowledge and practice in children's nursing and children's cancer care.

Clinical Nurse Specialists (CNS)

These are registered nurses who act as the patients 'key worker' throughout their treatment pathway. This experienced and knowledgeable nurse will co-ordinate patient care and be a key point of contact.

“Your allocated CNS will work closely with your child's consultant. They will meet with you and liaise with the local

hospital. The CNS's are very experienced nurses who are a great source of knowledge." J

CLIC Sargent

This is a charity which provides social workers to children and young people with cancer, and their families. If you give consent, the ward staff can refer you to CLIC Sargent and you will be allocated a member of the team.

"They have staff based at The Royal Marsden and are available to provide practical, emotional and financial support. Their office is located in the corridor between the ward and main reception, just ask a member of staff for directions." J

Dietitians

Dietitians work closely with the nursing and medical team to ensure your CYP's is receiving optimal nutrition whilst going through treatment.

"There are a team of lovely dietitians who support childrens' nutritional intake while they are on the ward.

They are also available to provide support following discharge and ensure the local dietitians know about any needs your child may have". J

Play specialists

They work Monday to Friday 8am to 5pm. Through therapeutic play they can prepare or provide your CYP with coping strategies during procedures or scans, either in departments, the play room or at the bedside.

A patient and play specialist
in the Oak Centre for Children
and Young People



Getting to The Royal Marsden, Sutton

**Address: Downs Road,
Sutton, Surrey SM2 5PT**

020 8642 6011

Travel by train

Sutton Station: served by trains running from London Victoria, London Bridge, London Blackfriars, London Kings Cross, Clapham Junction and Horsham. The hospital is about a mile and a half from Sutton station and is an uphill walk. The journey takes about ten minutes by bus or taxi.

Belmont Station: served by trains on the London Victoria to Epsom Downs line. Belmont station is a quarter of a mile from the hospital.

Bus

Numbers 80, 280, 420 and S1 run along Brighton Road, Downs Road and Cotswold Road. They connect with Morden underground station (Northern Line), and Sutton, Tooting, Redhill and Banstead train stations. Bus numbers S3 and S4 stop in the hospital grounds. They run every 30 minutes (peak hours only, no Sunday service) and both pass through Sutton town centre and stop at the train station.

Parking

There is limited car parking space available for patients and visitors at our Sutton hospital. Parking is on a pay on foot basis.

There are parking permits available at a reduced cost. Please see www.royalmarsden.nhs.uk/contact-us/how-get-royal-marsden/sutton for more information or go to the car park kiosk on site.

Sutton has a large town centre with shops, supermarkets and restaurants.

The nearest village is Banstead which has a post office, supermarkets, restaurants and a pharmacy. There is no public transport from the hospital to Banstead, however if you have a car, it is a 10 minute drive.

There is a large Tesco supermarket on the A217 which is about a 15 minute drive away.



St George's University Hospitals



Who is treated at St George's?

CYPs will be referred to St George's for neurosurgery as the first part of their treatment, when they are newly discovered to have a brain tumour. They will then be referred to The Royal Marsden for further care after surgery.

Planned care

CYPs under the care of The Royal Marsden may need to be treated at St George's for planned procedures, for example, hearing tests, specialist hormone tests, planned surgery or when they are newly diagnosed. All care is carefully co-ordinated between the two hospitals.

This will be explained by the team treating your CYP.

Unplanned care

It may be necessary to transfer your CYP to St George's from The Royal Marsden for specialist care. The reasons for this will be discussed with you by the medical and nursing team. Transport to St George's may be via a car or an ambulance depending on what is appropriate for your CYP. A nurse may accompany you.

High dependency or intensive care

Sometimes CYPs require an emergency transfer from The Royal Marsden for high dependency or intensive care.

The South Thames Retrieval Service will come to OCCYP and transfer you and your CYP to a high dependency unit or paediatric intensive care unit at a different hospital, in a specialist ambulance. CYPs are normally transferred to St George's but occasionally CYPs will be transferred to a different hospital in London, if there are no available beds at St George's.

You will be able to stay with your CYP during the transfer and at St George's.

Who will look after my CYP at St George's?

St George's has a specialist oncology team made up of a speciality doctor and nurse practitioners. The Lead Clinician (doctor) and Lead Nurse (matron) for children at The Royal Marsden work closely with medical, nursing and management colleagues at St George's.

Both hospitals use the same treatment plans, policies and protocols for treating patients.

- **Consultants and senior doctors** from The Royal Marsden work at both hospitals.
- **Nurse Practitioners** – These are registered nurses who are very experienced in their field and who have undertaken further training and education to develop skills, knowledge and practice in children's nursing and children's cancer care.
- **Clinical Nurse Specialist (CNS)** – CNS's are the key workers for children and families being treated for cancer at St George's; they are the main point of contact, manage patients' pathways and link to the CNS at The Royal Marsden.
- **Ward Sister** – Their main responsibility is to oversee patient care on a ward.
- **Ward Nurse** – The nurses caring for children with cancer at St George's receive the same education and training as nurses working at The Royal Marsden.

Where will my CYP be cared for at St George's?

The wards where CYPs with cancer are cared for at St George's are:

- **Pinckney Ward** – 15 beds, mostly in cubicles for specialist services such as Oncology, Haematology and Infectious Diseases. This is the main place of care for children and young people with cancer.
- **Nicholls Ward** – 25 beds for children who need surgery and or neurological care.
- **Jungle Ward** – 12 beds for children having treatments or procedures as day cases.
- **High Dependency and Paediatric Intensive Care Unit (PICU)** – 10 beds for critically ill children.

Accommodation

There is a range of overnight accommodation on each of these wards as well as rooms in Ronald McDonald House, which is within the hospital grounds and adjacent to the main car park. The parents' area on the first floor is for families whose CYP is in

PICU. There is a sitting room, kitchen and toilet facilities.

Visiting

Parents may visit at any time during their CYP's stay. Other family and friends can visit up until 8pm. We ask that bedside visitors are limited to two people per bed.

Food and drink

Within St George's there is a canteen on the first floor which parents may use. There is also an M&S food shop and café on the ground floor of the Lanesborough Wing, and multiple coffee shops situated around the hospital. There is a small kitchen on Pinckney ward with tea and coffee-making equipment, a fridge, microwave and cooking facilities.

Shops and banks

There is a newsagent which sells newspapers, a small selection of toiletries, stationery and confectionery. There is a florist next to the main entrance of the hospital and a Natwest bank on the ground floor of the medical school.

Getting to St George's

**Address: Blackshaw Road,
Tooting, London
SW17 0QT**

020 8672 1255

By tube

Tooting Broadway – Northern Line (10 minutes' walk). You should enter the hospital via Hoyle Road (off Tooting High Street) through a gate in Effort Street.

By bus

Buses numbers 44, 57, 77, 131, 155, 219, 269, 270, 280, 493 and G1 all stop a short walk from St George's.

For further information about buses, trains and tubes, please call London Travel Information on 020 7222 1234 (24 hours) or visit their website at www.tfl.gov.uk.

By car

There are two car parks with entrances on Blackshaw Road. The charges are paid on exit and are available from www.stgeorges.nhs.uk/patients-and-visitors/car-parking-charges/

Please ask ward staff for a permit to reduce your parking cost.

Making comments



All the staff working at the OCCYP do so because they have an interest in and enjoy working with children and young people. We are always looking for ways to improve our service, so please let us know if you have any ideas; you are very welcome to speak to any member of the team too. Please complete the family and friends test before you leave – your feedback is valuable to us.

If you are dissatisfied

If there are any aspects of your experience that you are dissatisfied with, please discuss initially with the Ward Sister or the nurse in charge or Matron who is based on McElwain ward.

Written concerns

If you would prefer to register your concerns in writing

please address them to:

The Patient Advice and Liaison Service (PALS)

Post: The Royal Marsden NHS Foundation Trust, Fulham Road, London SW3 6JJ

Tel: 0800 783 7176

Complaints and Improvements Department

Post: St George's University Hospitals, Blackshaw Road, Tooting, London SW17 0QT

Tel: 020 8725 3492

Compliments

We would be delighted to hear from you. Please feel free to send any letters of praise to the Ward Sister.

By acting on your comments, suggestions and concerns we hope we can work with you to improve our services for future patients.

Wall art in the Teenage and Young Adult Unit of the Oak Centre for Children and Young People





Radiotherapy and
Chemotherapy Services
F538021 & F538022

CUSTOMER
SERVICE
EXCELLENCE

