

The ROYAL MARSDEN
NHS Foundation Trust

Information for families being cared for by the Neuro- Oncology Team at The Royal Marsden



NHS

**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.



Name	
Diagnosis	
Consultant	
Clinical Nurse Specialist	
Treatment plan	
Central line	

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Emergency guidelines

This is a guide to the cancer related signs and symptoms which your child may experience that require immediate action. Please remember this is only a guide. Other signs and symptoms not mentioned here should be discussed with your local team or The Royal Marsden 24-hour telephone advice line **020 8915 6248**.

Signs and symptoms which require immediate action	Action/contacts
<p>Raised intracranial pressure – there is a risk for all children receiving treatment for a brain tumour of developing increased pressure within the brain. Symptoms include one or more of the following:</p> <ul style="list-style-type: none">– Sudden onset or severe headaches– Feeling disorientated, excessively tired or less alert/responsive– Persistent headaches occurring on most days, usually accompanied by vomiting and often waking the child at night or occurring when your child wakes– Sudden changes in vision, eg blurred vision, new squint.	<p>Urgent medical attention. Attend your Shared Care Hospital or the nearest A&E (Accident and Emergency).</p>

Contact details on pages 38–41

Signs and symptoms which require immediate action	Action/contacts
<p>Spinal cord compression</p> <p>You/your child may experience new onset of back pain without an explanation (eg a fall, trauma), altered sensation, or weakness in any of your/their limbs and/or a loss of bladder and bowel control.</p>	<p>Urgent medical attention is needed.</p> <p>Contact your local hospital or the 24-hour advice line at The Royal Marsden as soon as possible.</p>
<p>Seizures/major convulsive seizures</p> <ul style="list-style-type: none"> – Please be aware that seizures can vary significantly – Your child may cry out, stiffen and fall to the ground. Their arms and legs may jerk and they may go blue in the face. <p>If convulsive seizure lasts for more than 5 minutes;</p> <p>Or, if one seizure follows another without your child recovering in between;</p> <p>Or, your child hurts themselves during a fall.</p>	<p>Protect your child from injury. Remove objects that may cause harm. Cushion their head. Position them on their side in the recovery position as soon as the seizure passes.</p> <p>Call 999 for an ambulance and get immediate help.</p> <p>Do not try to stop the movements. Talk to your child gently and guide them away from danger.</p>

The Royal Marsden 24-hour advice line: 020 8915 6248

Signs and symptoms which require immediate action	Action/contacts
<p>Focal seizures</p> <ul style="list-style-type: none"> – Jerking movements, odd sensations, feeling afraid, anxious, or dazed and confused – Visual changes – Persistent headache (in absence of any additional signs of raised intracranial pressure) – Changes mobility eg falling over, imbalance – Any new weakness in your child’s arms or legs – Any change in your child’s continence eg wetting the bed – Personality changes – Changes in speech. 	<p>Call The Royal Marsden 24-hour advice line.</p>
<p>Temperature/unwell – this may be sepsis and can be life threatening. It can lead to cold hands and feet/mottled skin/shivering.</p> <p>Please be aware of the nonverbal signs/behaviour such as sleepiness and lethargy or you may feel your child is just ‘not right’. It is very important you get your child assessed early.</p>	<p>Contact your local hospital. If your child is or could be neutropenic (Neutrophil cells less than 0.5) treat as an emergency and follow the guidelines on pages 39–40 in the family held record folder.</p> <p>Or call your local hospital or The Royal Marsden 24-hour advice line.</p> <p>Avoid giving paracetamol.</p>

The Royal Marsden 24-hour advice line: 020 8915 6248

Contact details on pages 38–41



What is shared care?

The Royal Marsden, Sutton, together with St George's Hospital, Tooting, is the primary treatment centre (PTC) for your child. Not all patients will attend St George's Hospital, but this may sometimes be necessary for more specialised cancer services.

Your 'Shared Care' is a hospital and community nursing team that will be close to your home. Not all hospitals are shared care centres; your clinical team will advise you of your closest. These are teams that we work closely with and have regular contact. You may hear your Shared Care Hospital being referred to as your 'POSCU' – this stands

for Paediatric Oncology Shared Care Unit (also known as Paediatric Oncology Shared Care Hospital). **If your child becomes unwell, you must attend your Shared Care Hospital.**

Your Shared Care Team will be able to administer some chemotherapy (depending on the chemotherapy protocol), check blood counts, change dressings, dispense medications, and give supportive care such as blood products and antibiotics. Some of this care may be able to be given in your home.

Your child will have a designated Clinical Nurse Specialist and Consultant at your Shared Care Hospital.

What to do if your child becomes unwell



febrile neutropenia / Neutropenic sepsis

Some chemotherapy drugs can reduce the production of white blood cells by the bone marrow. This lowers your child's immunity and makes them more prone to infection. This is often referred to as neutropenia. If a child's neutrophil count is 0.5, or below, they are 'neutropenic'. The risk of infection varies depending on the type of treatment your child is having, how low the blood counts are and the length of time they are low. If a child develops a temperature above 38°C

whilst they are neutropenic, this is referred to as febrile neutropenia. When your child is neutropenic, they are at an increased risk of infection.

Your child will need to have intravenous antibiotics (delivered through a vein) for the treatment of febrile neutropenia.



High temperature/ feeling unwell

If your child develops a temperature of 38°C or above, telephone your Shared Care Hospital and **take them there immediately.**

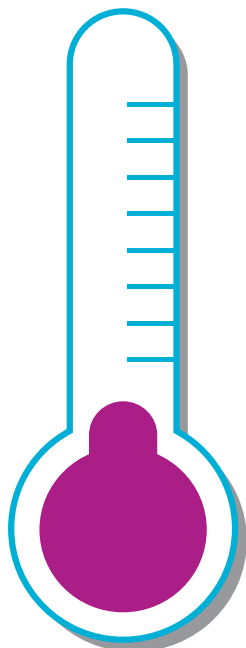
Do not give paracetamol (Calpol) or ibuprofen.

If your child is 'not right' or not behaving in their 'normal' way, with or without a temperature above 38°C **do not wait.** Telephone your Shared Care Hospital and take them there immediately.

If your child is generally unwell with diarrhoea or vomiting, telephone your Shared Care Hospital who will review your child and decide whether they require treatment.

Be aware that steroids can hide a high temperature. If your child is taking steroids and appears generally unwell, with or without a temperature above 38°C, telephone your Shared Care Hospital for advice.

If your child's temperature is below 35°C, you should telephone your Shared Care Hospital and take them there immediately.



Dietary supplements and medications at home

Despite research into cancer and dietary supplements, there is not enough evidence to prove that they can help treat cancer or stop it coming back. Although herbs and plants may be natural, this does not mean that they are safe – they may cause side effects or interact with your child's prescribed medications. In addition, as these products are not regulated and tested in the same way as medicines, they may contain other harmful substances from the extraction or production process.

The Royal Marsden recommends that supplements are **not** taken

during chemotherapy, radiotherapy, and other treatments for cancer.

Exceptions to this are:

- Vitamins or minerals prescribed to treat a known deficiency or as a supportive medication for some cancer treatments.

A link to the *Cancer and dietary supplements* booklet can be found below:

www.patientinfolibrary.royalmarsden.nhs.uk/cancer-and-dietary-supplements

Children on treatment should not be given ibuprofen as this can diminish their platelets and increase their risk of bleeding.

Paracetamol may be given if your child has mild pain but is otherwise well. Your child's temperature will need to be checked prior to giving any paracetamol – it should be below 37°C and they should have neutrophils above 0.5. If you have any questions, please contact your Shared Care Team.

Paracetamol can be repeated every 4–6 hours with a maximum of 4 doses in a 24 hour period, for a maximum of 3 days. If your child's symptoms persist, please contact your Shared Care Hospital.

Your child may be prescribed morphine for moderate pain after a clinical review. Morphine is a controlled drug and should be stored in an area that is not accessible to children.



Chickenpox, shingles and measles



Chickenpox and shingles are caused by the varicella zoster virus (VZV) and are a contagious virus. Measles is caused by a virus found in the nose and throat of an infected child or adult. When someone with measles coughs, sneezes or talks, infectious droplets spray into the air, where other people can breathe them in. The infectious droplets can hang in the air for about an hour. Chickenpox is infectious 48 hours before the first spot appears. The rash generally breaks out 10–21 days after exposure and remains contagious until all lesions have scabbed over.

Symptoms of measles include flu-like symptoms, such as fever, runny nose, watery eyes and tiredness.

Symptoms of chickenpox include flu-like symptoms, such as fever, runny nose, watery eyes and tiredness. Your child may have an itchy rash, characterised by small red spots, raised red areas or fluid filled blisters that break out and scab. The rash usually starts in the stomach, chest, back or scalp and new spots will develop for up to 3–5 days or sometimes longer.

Shingles is a reactivation of the varicella-zoster virus, the same virus that causes chickenpox.

Shingles results in clusters of burning, itching blisters, typically on one side of the chest or back but may affect the face and more rarely, the eye.

Chickenpox and shingles are caught from direct contact with a person affected with either chickenpox or shingles. Direct contact is defined as being in physical contact with an affected person for 15 minutes or longer. This could be from shaking hands or hugging someone, for example. Someone who does not have chickenpox or shingles cannot pass it on.

Treatment is available both to reduce the risk of catching chickenpox, shingles and

measles, and to treat the infection if it arises. Children on treatment or within six months of treatment completion who develop chickenpox, shingles or measles should receive prompt treatment with Aciclovir. This is usually given intravenously at first but may be changed to oral medication after five days.

If your child has a close contact with someone who develops chickenpox, shingles or measles, telephone your Shared Care Hospital. This is still required if your child has previously had chickenpox as treatment can weaken their immune response.

Immunisations



The treatment your child receives can reduce their immunity to some viruses that they may have already been vaccinated against.

Your child can not have any live vaccinations whilst on treatment. They will receive booster vaccines of any immunisations they have had 6–12 months after they have finished treatment. This will be via your GP.

Please speak to your medical team if your child is due to have any vaccinations.

We recommend that siblings and close family members are fully vaccinated.

Flu and Covid-19 vaccination

We recommend that patients and their family members receive the Covid-19 vaccination when they are eligible. The guidelines often change so please contact your medical team to discuss this.

We recommend that all children and their immediate family members receive the influenza (flu) immunisation every autumn during chemotherapy treatment, and up to six months after treatment is completed.

It is important that children on treatment are given the inactive version of the vaccination via injection under the skin. The intranasal (live) vaccination is **not** suitable for patients.

Close contacts of children receiving chemotherapy can receive the nasal (live) vaccination (via a spray into each nostril), including siblings.

If your child has received a bone marrow transplant, close contacts should **not** receive the nasal (live) vaccination. Instead, they should have the inactive version of the vaccination via an injection under the skin.

Patients should not receive the vaccination when they are neutropenic or in the 48 hours before intravenous chemotherapy is given. Immunisations can be arranged via your GP.

For more information, please visit the Children's Cancer and Leukaemia Group via www.cclg.org.uk

Effects of chemotherapy and radiotherapy on blood cells in the bone marrow

The drugs and radiotherapy given for treatment will lower blood cell counts and suppress the bone marrow. The effects of this are shown in the table below:

Blood count	Normal level	Low level	Symptoms/effects of low level	Treatment for low level
Red blood cell count (Hb)	Varies with age, but around 110–130	70 or lower (except during radiotherapy) A low Hb count is also known as anaemia	<ul style="list-style-type: none"> – Tiredness and lack of energy – Pallor – Breathlessness – Feeling cold – Dizziness/headaches – Poor feeding/lack of appetite 	Blood transfusion

table continued

Blood count	Normal level	Low level	Symptoms/effects of low level	Treatment for low level
White blood cell count (WBC)	5–10		Increased risk of infection	No treatment
Neutrophil count (N)	1.5–6	0.5 or lower This is known as neutropenia	Increased risk of bacterial infections	When your child is neutropenic and has a temperature above 38°C, they will need antibiotics
Platelet count	150–400	30 or lower For patients due to have a lumbar puncture : 40 or lower For patients undergoing spinal irradiation : 50 or lower A low platelet count is also known as thrombocytopenia	<ul style="list-style-type: none"> – Bruises more easily – Bleeding gums or nose bleeds – Small bleeds under the skin (petechiae) 	Platelet transfusion Children due a lumbar puncture will be transfused if platelets are below 40

Central venous access device (CVAD) care



Your child may have a central venous access device inserted to receive their treatment or supportive care. Your child may have a Port-a-Cath, Hickman line or PICC line depending on their treatment protocol and preference. These can be used for administration of drugs as well as for taking blood samples.

We advise that you check the area of the CVAD **daily**.

If your child has a **Port-a-Cath**:

- Check that the site is not red or swollen
- Check that there is no pus or blood at the site
- If accessed, check that clamps are secure
- Check that there is a bung on the end of the line (your nursing team can show you this).

When your child's port is **not** accessed:

- They can have a bath or go swimming as normal
- The port should be flushed monthly.

If your child has a **PICC line**:

- Check that the line is secure, and that the dressing has not become loose or wet
- Check that there is no redness, swelling or oozing around the site
- Check that bungs are secure (your nursing team can show you this).

If your child has a **Hickman line**:

- Check that the line is secure, and that the dressing has not become loose or wet
- Check that there is no redness, swelling or oozing around the site
- Check that bungs are secure (your nursing team can show you this)
- Check that the line is looped under the dressing.

All central venous access devices should be dressed with a clear dressing so that the site can be seen. Dressings, bungs and port needles need to be changed every 7 days.

If you have any concerns about your child's central venous access device, please contact your Community Nursing Team or Shared Care Hospital.

For more information, please visit the Children's Cancer and Leukaemia Group via www.cclg.org.uk/CSOIR/Central-lines

Pre-procedure and fasting guidelines



Generally, most children will require a blood test 48 hours before a procedure or general anaesthetic. This can be arranged via your Shared Care Hospital or Community Nursing Team.

If your child needs to have a general anaesthetic or sedation, special preparation is necessary for the procedure to be performed safely. This involves not eating and drinking before the anaesthetic or sedation.

General anaesthetic

- No food or milk **six hours** before the general anaesthetic time
- Clear fluids such as water or diluted squash are allowed up to **one hour** before the general anaesthetic time but **not** milk or juice

- No chewing gum **six hours** before the general anaesthetic time.

We will contact you the day before the procedure with the specific fasting times for your child.

Food consumed before general anaesthetic should only be a light meal or snack. Gum should not be chewed prior to the anaesthetic time as this may result in the procedure being cancelled.

There may be additional requirements for food and drink intake for children and young people needing a scan; please follow any instructions given.



Treatment related side effects

There are some common side effects of treatment that your child may experience. They may not get any or all of them, but you should be aware that they can happen. Different treatments have different side effects, and your medical team will provide you with this information.

The most common side effects include:

Nausea and vomiting:

Your child can be given anti-sickness medication to help manage this. Try to encourage them to drink plenty of water and eat small amounts of food often. If your

child is vomiting for more than 24 hours and cannot eat or drink, please contact your Shared Care Hospital.

Hair loss and changes to body image: Some treatments will cause your child to lose some or all their hair, they may gain/lose weight and other skin and physical changes may occur. Our Psychological Support Team can help you and your child manage the emotional impact of this (see contact details on page 40). Some children may wish to get a wig; this can be organised through the Little Princess Trust via www.littleprincesses.org.uk

Diarrhoea and constipation:

Your child's normal bowel habits may change; try to ensure they drink plenty of water. We recommend using a barrier cream to stop skin breakdown if they have diarrhoea. Laxatives may be used if your child has constipation. Please contact your Shared Care Hospital if your child has severe diarrhoea or constipation.

Mucositis/sore mouth:

Some children may get a sore mouth or mouth ulcers. It is important to keep your child's mouth clean by brushing their teeth twice a day and drinking plenty of water. Younger children who cannot express their pain may stop eating, drool or have a husky voice. Please contact your medical team for advice regarding pain relief if your child has a sore mouth.

Poor appetite: Your child's appetite may change, and they may require support with nutrition. Please contact our Dietetic Team if you are concerned about your child's appetite. Encourage your child to eat little and

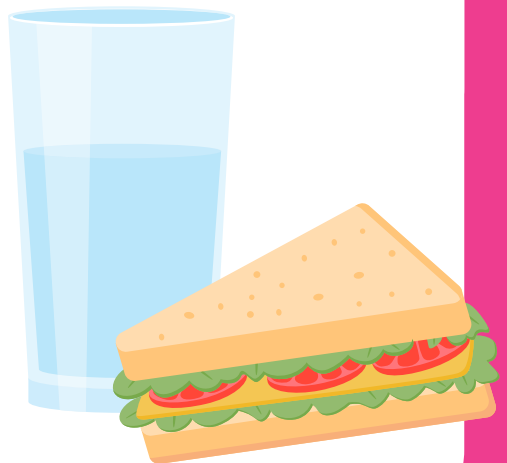
often and drink plenty of water. Your child's taste may change; they may not like foods they used to or may enjoy some new flavours. Some children may require a nasal gastric tube to help with their nutrition. More information about helping your child to eat well can be found here

www.cclg.org.uk/publications/All-publications/Helping-your-child-to-eat-well-during-cancer-treatment/HELPEAT

Please visit

www.macmillan.org.uk/cancer-information-and-support

for further treatment related side effects and how to manage them.



Support at The Royal Marsden



There are many services available to support you and your child through their cancer diagnosis and treatment. Contact details for the teams below are listed on pages 40–41.

Research Nursing Team:

Some children may receive treatment as part of a clinical trial. If your child can be part of a clinical trial, the research team will provide you with the necessary information.

The Children and Young People's Outreach and Symptom Care Nurse

Specialists: The CYPOONS work alongside a consultant paediatrician to provide

specialist symptom advice and support to families. They aim to help improve your child's quality of life during and after chemotherapy, surgery and radiotherapy treatment if their symptoms are becoming complex.

Psychological Support

Team: The team is available to support all members of the family at diagnosis and throughout treatment.

Young Lives vs Cancer:

They offer information, access to practical and financial help as well as therapeutic support to individuals, couples or the whole family.

Physiotherapist: They help children and young people who have weakness and difficulties in moving around.

Occupational Therapist: They help children who have difficulty completing everyday tasks such as moving around, accessing the toilet or feeding themselves, or any other activities of daily living.

Dietitian: They are available to support with any feeding or nutrition difficulties your child is experiencing and offer teaching and advice.

School Room and Teachers: Our school room and teachers can support with the educational needs of your child during treatment. They can help with home tuition and keep in contact with your child's school.

Play Specialists: They are available in the hospital and use play as a therapeutic tool.

Maggie's Centre: The Maggie's Centre at The Royal Marsden (Sutton) is open for inpatients, outpatients and their families to visit. Patients are welcome to come and use the space, and the Maggie's team is available to provide support to any visitors who would like to talk. Inpatient visits will need to be agreed by both the patient's hospital team and the Maggie's team prior to the visit.

The Brain Tumour Charity: The charity provides detailed information on side effects and offers support specifically for children, young adults and families. Please visit www.thebraintumourcharity.org

For more detailed information please visit The Royal Marsden website www.royalmarsden.nhs.uk/your-care/children-and-young-people



Teenagers and young adults (TYA)

The Teenage Cancer Trust Unit (TCTU) at The Royal Marsden, Sutton is a purpose-built unit for teenagers and young adults aged 16–24 years. It has both inpatient and day care areas.

Patients are supported by a specialist TYA multidisciplinary team. The team is made up of doctors, nurses, youth support workers, teachers, social workers, psychologists, physiotherapists, dietitians, occupational therapists, speech and language therapists and a chaplain.

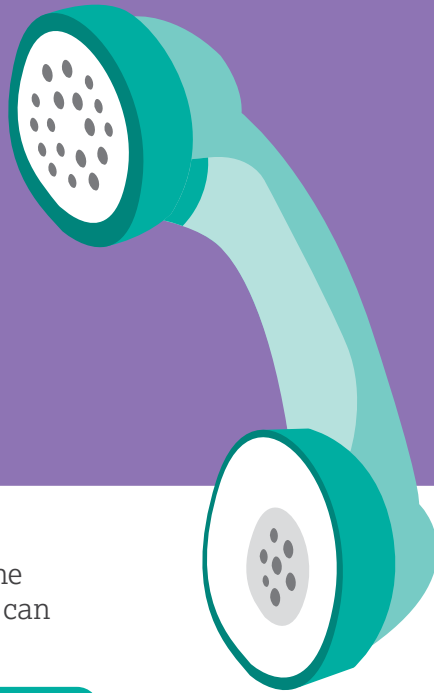
Youth supporter workers in the TCTU are also part of the wider team. They can

help with anything non-medical that will help you deal with cancer. To speak to a TCTU youth support worker, please contact your Clinical Nurse Specialist.

Teenage and Young Adult Holistic Clinic

The TYA holistic clinic is for patients aged 16–24 years being seen at The Royal Marsden.

The TYA MDT (multidisciplinary team) is there to support patients with not only their medical needs, but their needs as young people. This includes support with education, work, relationships, fertility concerns, physical activity, and psychosocial wellbeing.



To find out more about the support the TYA service can provide, please contact:

TYA Advanced Nurse Practitioner

Tel 020 8642 6011
ext. 4484

Email teenageandyoungadult.anp@nhs.net

TYA Lead Nurse

Tel 07741 295 751 or
020 8915 6550

For more information,
please visit
[www.royalmarsden.nhs.uk/
your-care/children-and-young-
people/patients-aged-16-24-
teenagers-and-young-adults](http://www.royalmarsden.nhs.uk/your-care/children-and-young-people/patients-aged-16-24-teenagers-and-young-adults)

Fertility referrals



Often following a cancer diagnosis patients have questions concerning how treatment will affect their fertility. Advice can be given taking account of individual needs. We have links with expert fertility centres which offer an array of services we can refer you to, should you wish. These include fertility counselling, egg harvesting, sperm banking, hormone replacement therapy and many more. It's important to note that not all anti-cancer therapy affects fertility.

Please ask your Consultant or contact your Clinical Nurse Specialist for information regarding fertility.

Life at home



Looking after yourself: It is important that you don't forget yourself whilst caring for your child. Take regular breaks and try to keep up with some of your normal daily activities. There are parent support groups available. Please contact the Psychological Support Team or the Young Lives vs Cancer Team for more information. Alternatively, please visit www.cclg.org.uk/online-community

Parents of The Royal Marsden have set up a Facebook group to support each other. This is called *Parent support group of The Royal Marsden Hospital*.

Siblings: Siblings are likely to be affected by their sibling receiving a cancer diagnosis. The Psychological Support Team is available to help all

members of the family. For information on how you can help siblings, please visit www.cclg.org.uk/Brothers-and-sisters

Grandparents and wider family: The whole family is likely to be affected by your child's diagnosis of cancer. For more information to support grandparents, please visit www.cclg.org.uk/Grandparents

Diet: Your child should be encouraged to eat a healthy diet and not consume foods that have a high risk of causing food poisoning, such as soft egg, shellfish, raw meat and fish, soft cheese, and pâté. Food should be cooked thoroughly, and leftovers should not be reheated. Wash fruit and salad before preparation and avoid takeaways and buffet foods.

Oral syringes: Syringes can be washed out with warm soapy water and reused until they begin to show signs of wear. Syringes used for medications can be disposed of in normal bins. If they have been used for chemotherapy, they should be placed in a carrier bag and then placed in a normal bin.

Medicines: When coming to the hospital, please bring all of your child's medications with you. For repeat prescription medication requests from The Royal Marsden, please email cypprescriptionrequest@rmh.nhs.uk

at least 5 working days before your supply runs out. Your GP may be able to prescribe some prescriptions. For questions regarding your child's medications, please contact our Pharmacy Team.



Nappies and bodily fluids:

If your child is receiving chemotherapy, we advise that you wear rubber gloves to change their nappy. If you need to come into contact with any of your child's bodily fluids, wear gloves and wash your hands afterwards. Your child will be excreting chemotherapy in their urine, faeces and vomit for up to 7 days.

Holidays: It may be safe to go on holiday whilst receiving treatment in the UK and abroad. Please discuss this with your medical team before making any bookings and give at least two weeks' notice. If you are going away, your Shared Care Hospital will make all the necessary arrangements with hospitals that will be local to you during your stay, and write you letters of support, should you need them. You will need travel insurance if travelling abroad. Young Lives vs Cancer has a list of insurance companies that are available and charities that provide holiday accommodation to families.

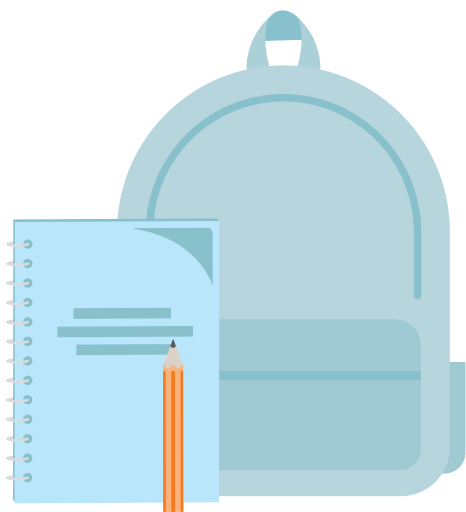
Transport: It is safe for your child to travel on public transport whilst on treatment, even when neutropenic. We do advise that you avoid peak times. If you require transport to your appointments, please contact our Transport Team (contact details on page 41).

Building work: If you are planning any building work, please discuss this with your child's medical team as it can increase the risk of your child developing a fungal infection.

School/nursery: During most cancer treatments, your child can continue their usual activities including

school attendance. Children receiving certain treatment plans are advised to be more cautious about contact with other children when neutropenic. Your medical team will advise you if this is the case. Your community nursing team will arrange a visit to the school prior to your child attending to make the necessary arrangements. For more information, please visit www.cclg.org.uk/Information-for-schools

A useful guide for teachers about supporting children with cancer at school: www.cclg.org.uk/Publications/All-publications/Welcome-back!/WLCMBACK/I-have-a-friend-who-has-cancer/IHAVEAFR/Supporting-your-pupil-after-a-cancer-diagnosis/SUPPUPIL

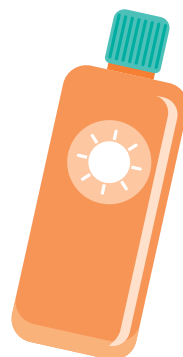
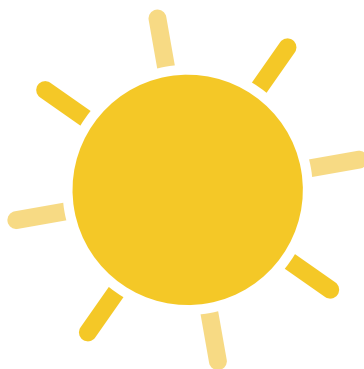


Pets: We encourage children to wash their hands after touching pets, but they do not need to stay away from them. Pets should be vaccinated and treated for worms. Children should avoid contact with litter trays and pet's faeces. We do not recommend bringing a new pet into the family whilst a child is on treatment. For more information, please visit www.cclg.org.uk/write/MediaUploads/Publications/PDFs/Handling_Animals_and_Pets_2021_Web.pdf

Swimming: If your child has PICC line or Hickman line they cannot go swimming. If they have a Port-a-Cath they can go swimming if the needle is not in place.

Sun protection: Children on treatment and children who have completed treatment should be fully protected from the sun as their skin may burn more easily than normal. Always use sunblock and ensure they wear a sun hat.

Socialising: It is important that you and your child continue to socialise with friends and family. If good hygiene is encouraged for everyone, and the people you are socialising with are not infectious or unwell, you should continue to socialise. This information may differ for children who have received a bone marrow transplant. Please discuss this with your medical team.



Further support

There are various charities and support services available

to help you, your child, and your family through the treatment of cancer.

Information is available from your Young Lives vs Cancer Support Worker and from the Children's Cancer and Leukaemia Group (CCLG) via www.cclg.org.uk/useful-links

For organisations who can grant wishes, please visit www.togetherforshortlives.org.uk/get-support/supporting-you/family-resources/grants-and-wishes/



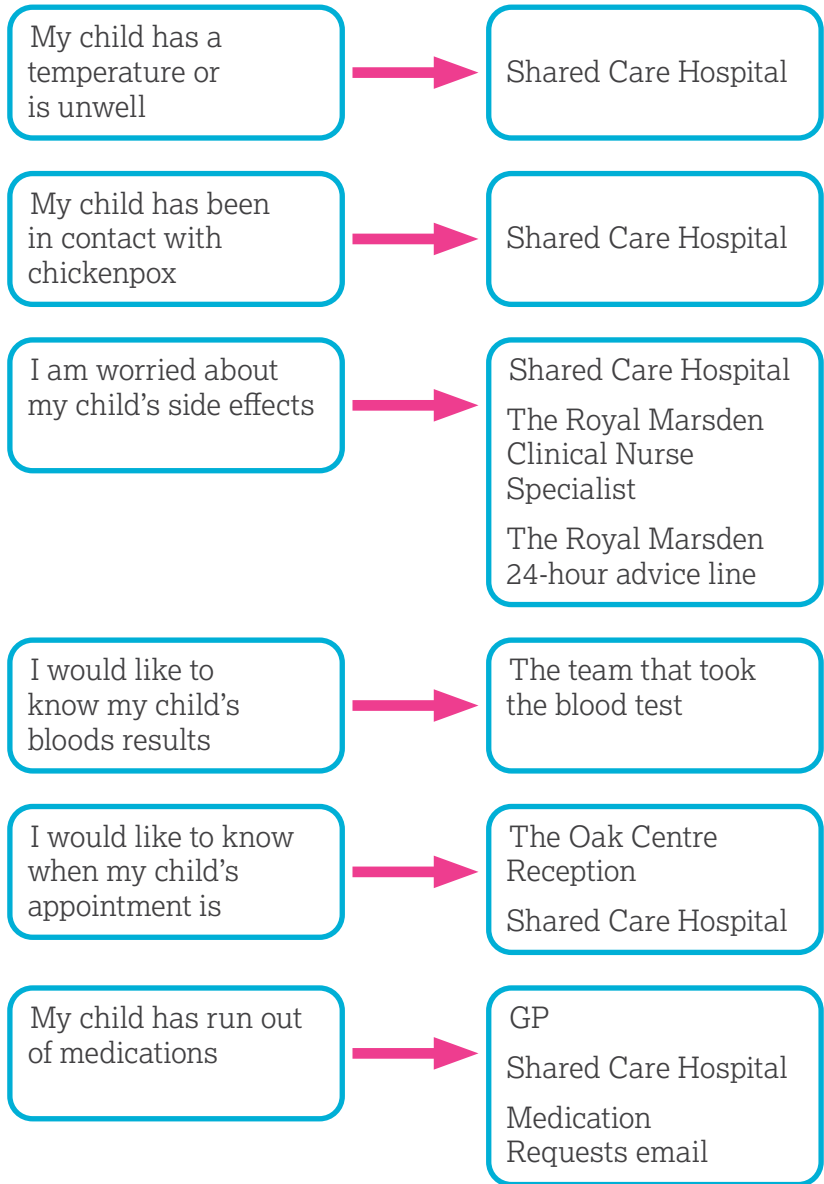
Keeping track

Some families find it useful to record their child's blood results and some aspects of their treatment.

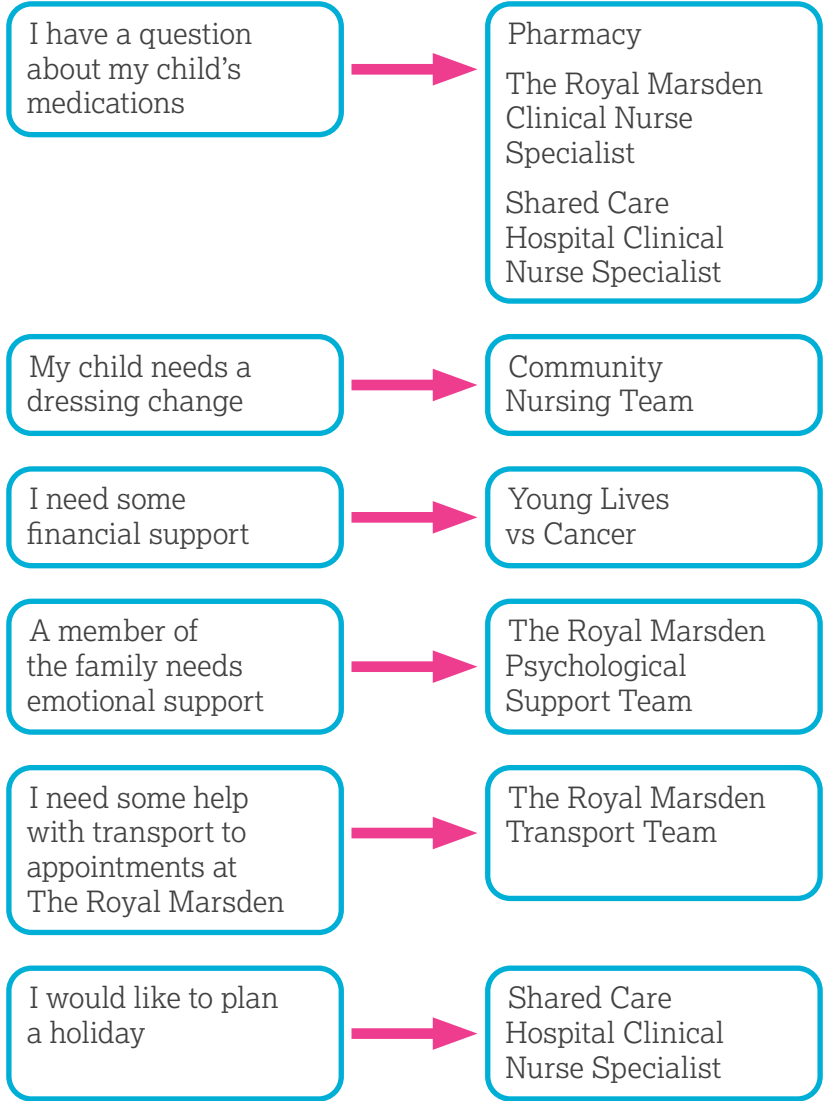
It is not mandatory, but we encourage you to record some of the following details either on a chart or in a notebook:

- Full blood count
- U&Es (Urea and Electrolytes)
- Weekly oral chemotherapy dosing
- Height and weight when taken in hospital
- Lumbar puncture dates
- Scan dates
- Unplanned hospital admissions
- Dressing changes
- Start of cycle dates.

Who should I contact?



Continued on next page



Contact details on pages 40–41

Contact details – The Royal Marsden

Name	Email address	Phone number
The Royal Marsden 24-hour advice line		020 8915 6248
Clinical Nurse Specialists	rmh-tr.neuroCYP@nhs.net	020 8661 3805
McElwain Ward		020 8661 3611
Teenage Cancer Trust		020 8915 6254
Children's Day Unit		020 8661 3601
The Oak Centre Reception / Appointments		020 8661 3551 020 8661 3662
Pharmacy		020 8661 1400
Research Team	paediatric.researchnurses@nhs.net	020 8661 3468
Oncology Outreach Team (CYPOONS)	patch.team@nhs.net	020 8661 3625
Dietitian		020 8661 1134 020 8661 4093 020 8661 4264
Physiotherapist		020 8661 1082
Occupational Therapist	Occupational TherapySutton@rmh.nhs.uk	020 8661 3090
Play Specialist		020 8642 6011 ext 1425 / 4031
Psychological Support Team	pyapss@rmh.nhs.uk	020 8661 3676

Young Lives vs Cancer	rmh.sharedinbox@ younglivesvs cancer.org.uk	020 8661 3880 030 0330 0803
School Room/ Teachers	schoolroom@ rmh.nhs.uk	020 8661 3614
Hospital Transport		020 8661 3804
Medication Requests	cypprescription request@ rmh.nhs.uk	
Maggie's Centre	Maggies. royalmarsden@ maggiescentres.org	020 3982 3141

Contact details – Your child's Shared Care Hospital

Name	Email address	Phone number
Hospital		
Clinical Nurse Specialist		
Inpatient Ward		
Day Unit		
Community Nursing Team		

Would you like to help improve children's specialist oncology services?



We welcome you to join our parent group to help improve how we deliver care to children under 16 and their families.

We would like to hear from parents whose child is currently receiving treatment or has completed treatment in the last two years. The group meets virtually four times a year on a weekday evening.

You will receive a gift voucher for each meeting attended as a thank you for your time.

For more information contact cyp.ppi@rmh.nhs.uk



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