

Teenage and Young Adults: Going home after transplant

**Information for young people,
carers and their families**

Oak Centre for Children and Young People



NHS



**Teenage
and Young
Adults Team**

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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: The Royal Marsden Help Centre

Freephone: 0800 783 7176
Email: patientcentre@rmh.nhs.uk

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

www.royalmarsden.nhs.uk

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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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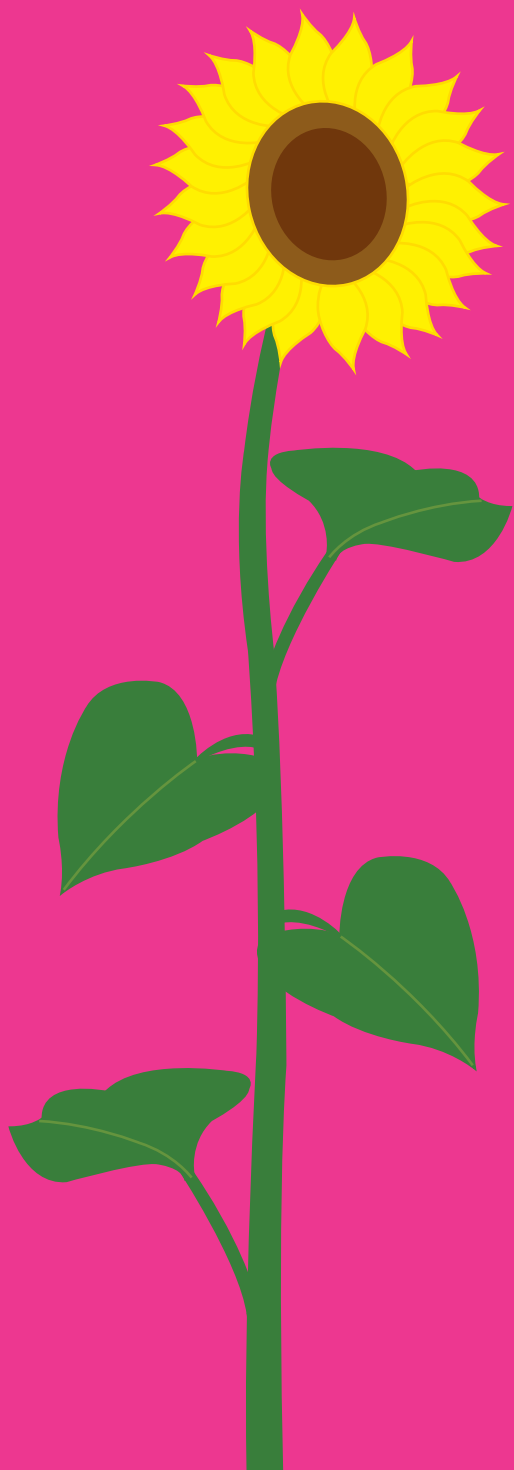
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Introduction

This leaflet gives you advice on what to expect over the next few months in your recovery post-transplant. Leaving hospital is often a time of mixed emotions such as excitement and apprehension. Everyone's experience is unique, but there are shared similarities. This leaflet aims to help to remove some of the uncertainty you may feel. It can take at least six months to a year to recover fully post-transplant. This can be frustrating at times, but be reassured that this is normal.

Before you go home, you will have a discharge talk with your transplant Clinical Nurse Specialist (CNS). This will give you an opportunity to ask any questions you have and also to identify any

extra support you or your family might need. Your CNS is your key worker and will be there to support you through these next steps.

It can be daunting being discharged following a long period of time in hospital, but please remember we are here to support you. There is also a lot of new information to take on regarding your aftercare, so if you would find it useful to have a written record of any of your treatment plan or medications, please let us know.

Immediate follow up

After discharge, you will have a follow up appointment once or twice a week in The Oak Centre for Children and Young People outpatients' department.

Clinic is held on a Tuesday afternoon. If follow up bloods are needed later in the week, this will be on the teenage day care unit. Here, you'll be reviewed by either one of the Teenage and Young Adult Advanced Nurse Practitioners or a doctor.



Clinic day

Before clinic:

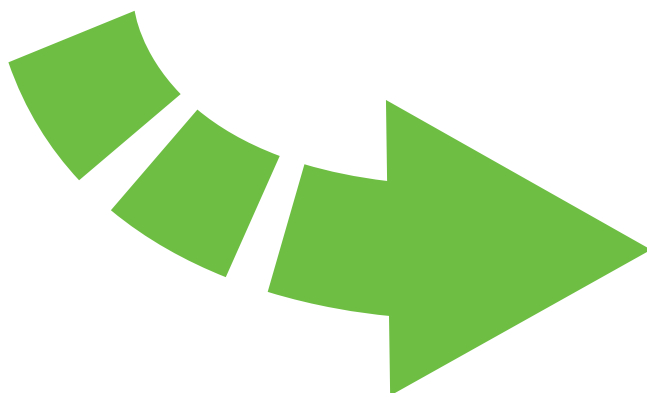
- Before coming to clinic, please make a note of any medications which you are running low on. At your appointment, you can ask the doctor to prescribe these for you. In order to avoid long pharmacy waits, you can ask for your medications one week before you run out, and then collect them the following week when you next attend clinic.
- You can take all your usual medication before you come to hospital, except your immunosuppressant (Ciclosporin, Mycophenolate or Tacrolimus) as we need to closely monitor your levels through a blood test. Please bring it with you to hospital so that you can take it immediately after having your bloods taken, as it is important that you do not miss a dose.

On arrival at clinic:

- We will ask you to attend one hour before your clinic appointment to have your bloods taken, as the doctor will need these results before seeing you. Whilst you have a central line in, this will need to be flushed and the dressing will need to be changed at least once a week. This will be done at the same time as you have your bloods taken.
- If you have any symptoms of infection (such as a cough, cold or diarrhoea) when you attend clinic, please let the receptionist know on arrival, as we may need to isolate you.
- If you start to feel unwell whilst waiting, please let the receptionist know. Either your CNS or the haematology Advanced Nurse Practitioner (ANP) can then come and assess you.

During the appointment:

- In the early stages post-transplant, it is not unusual to require blood, platelets or IV fluids based on the results of your blood tests. If required, we will give these to you in the outpatients department, ideally on the same day.
- We will weigh you regularly, as people often struggle with eating post-discharge. In the Tuesday clinic, there will be a dietitian present. You can ask to see them for any dietary advice.



Infection

It will take several months for your new immune system to be effective. You will initially be taking immunosuppressants, which will also reduce your body's ability to fight off any infections. Although we will discharge you on various medications to help reduce the chance of developing certain infections, you will still be at risk. It is not unusual to develop an infection post-discharge and to need re-admitting to hospital.

This is a normal part of recovery post-transplant, therefore you should check your temperature daily and watch out for new symptoms:

- If your temperature is below 36°C or above 37.5°C you must immediately call your CNS (during working hours), or The Royal

Marsden Macmillan Hotline out of working hours (or if you are unable to get hold of your CNS). You will need to be seen urgently for bloods, medical review and will need to have antibiotics into your veins within one hour. If you live within one hour of The Royal Marsden and we have a bed available, we will advise you to come to us. If not, we will advise you to attend your local Accident and Emergency service (A&E). We will then call them to refer you and help ensure that you are seen promptly on arrival. Please also take your yellow chemotherapy alert card with you.

- Please call us if you have any other symptoms of feeling unwell, such as shivers, nausea and vomiting, increased diarrhoea, pain and skin rash.

- If you notice any signs that your haemoglobin might be low (shortness of breath, increased tiredness, palpitations) or your platelets are low (bruising, nose bleeds, purple pin-prick rash) please call the transplant CNS (or The Royal Marsden Macmillan Hotline out of hours). We will then arrange to check your bloods, as you may require a top up of platelets or red blood cells. This is not unusual in the initial phases post-transplant.

Useful tips:

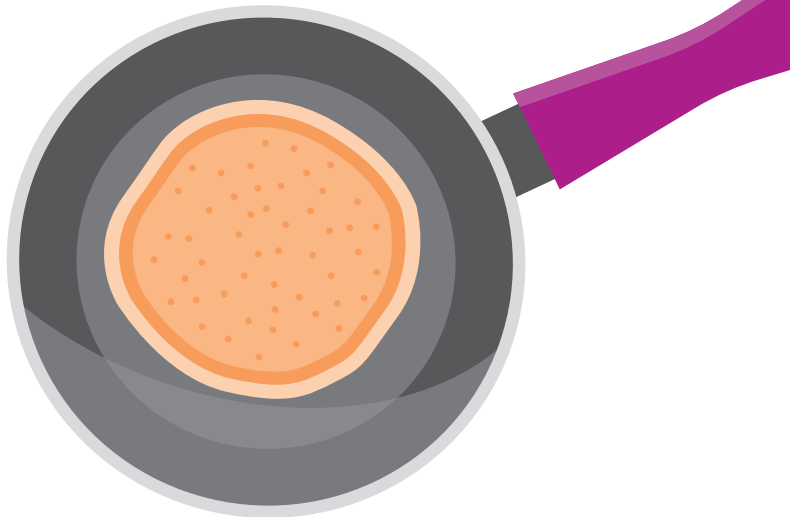
- If you feel unwell or have a high temperature, this is a warning sign from your body - do not take paracetamol as this will artificially lower your temperature
- Your immune system is not functioning fully yet so please do not ignore symptoms. Instead, act fast by calling the Transplant CNS (or The Royal Marsden Macmillan Hotline out of hours)
- Avoid contact with anyone with symptoms of infection, especially if your white counts are low or if you are neutropenic
- Please inform the transplant CNS if you unintentionally come into contact with anyone with chicken pox, measles or shingles, as we will probably need to give you some extra medication to protect you
- Whilst on immunosuppressants, avoid large crowds and public transport
- It is important to have a clean environment at home and good general hygiene. Wash your hands before and after eating, brush your teeth twice a day and wash daily, as micro-organisms on your own skin can cause problems
- Avoid getting body piercings for at least six to 12 months post-transplant and tattoos for two years post-transplant. Always check with your consultant first
- In the initial period post-transplant whilst you are still on immunosuppressants, avoid having any new pets. With existing pets, ensure you use good hand hygiene.

Food and drink



Good nutrition is very important, as it will help you to recover your strength, reduce the risk of picking up infections and also reduce long hospital admissions. However, people often find it difficult as they do not feel hungry, have no sense of taste, and their mouth may feel dry or they may be struggling with diarrhoea.

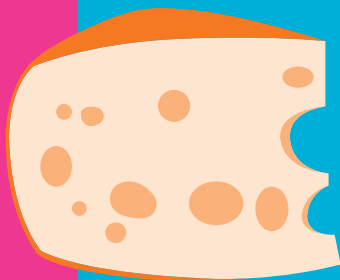
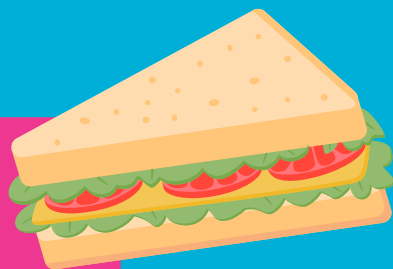
This will improve over time, but the next page has some useful tips to help you. When you come to clinic on a Tuesday, you can also ask to see the dietitian for any ongoing support or supplements that you might need.



Useful tips:

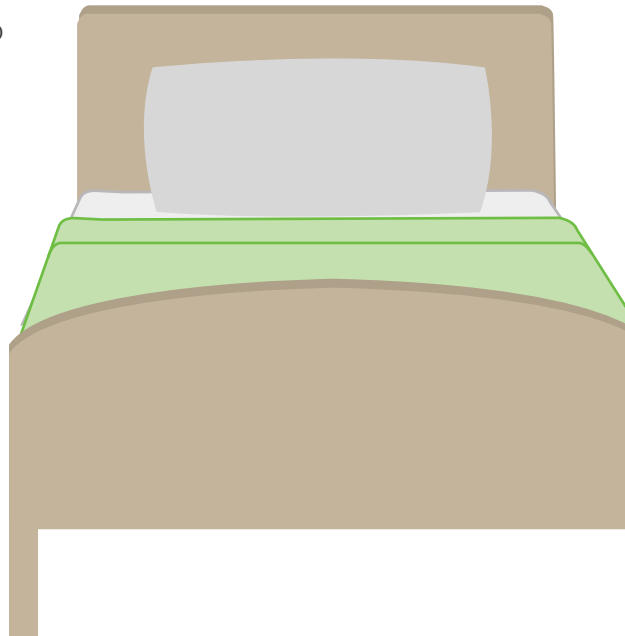
- Avoid large portions as these can be daunting, and instead aim for six smaller snacks per day
- Add extra calories to food by using full fat milk or adding cream, cheese and butter to dishes. This avoids adding extra volume which can be daunting
- Try nourishing drinks such as hot chocolate, milkshakes or smoothies
- Aim to drink 1.5 – 2 litres fluid daily, as the treatment you have had, and some of the medication you are now on are harmful to the kidneys, so it is important you keep them well hydrated. Please also note that if you have diarrhoea, you will need to drink more.
- Once you go home you do not need to be on the neutropenic diet, but there are still some foods you should avoid whilst on immunosuppressants. This includes shellfish, food from deli counters, soft cheeses and takeaways
- Ensure that food is within its use by date, and not left out of the fridge (if it is supposed to be refrigerated)

Most people find that if too much emphasis is put on eating and mealtimes, this extra pressure can make it harder to eat. Therefore, try to avoid this and normalise mealtimes. If you would like us to talk to you or any of your family to give some extra advice, please inform the transplant CNS.



Central line

We will aim to remove this as soon as possible after your transplant, but it is likely to need to remain in for the first three months. During this time, we will still monitor you closely, and you might need blood products or electrolyte replacements. Ensure that you avoid getting it wet and avoid swimming and any contact sports. Please also notify us immediately if you notice any redness or tenderness at the exit site.



Tiredness

This can often feel extreme and is very different to 'normal tiredness'. It will not be relieved by sleep and friends and family may not understand how you feel. As a result, people often find this overwhelming and frustrating, but this will start to improve over the next six to 12 months. This will vary for each individual but the next page has some useful tips to help you.

Useful tips:

- Try and keep a normal sleep and daytime routine
- Remember the **4 P's**:
Prioritise activities. **P**ace yourself throughout the day rather than trying to do too much at a time. **P**lan and organise. **P**ermission to rest if you need it during the day, and to ask for help
- Maintain a regular healthy diet
- Try to slowly build up your exercise tolerance, as your muscles will have weakened from a prolonged hospital stay. Start with small achievable goals such as a five minute walk and slowly build this up
- If you notice your tiredness suddenly getting worse with shortness of breath or palpitations, call the transplant CNS (or The Royal Marsden Macmillan Hotline out of hours) as your red blood cells may need topping up
- Speak to others about how you are feeling and ask your CNS if you feel it would be useful to see a physiotherapist or occupational therapist.

Graft Versus Host Disease (GVHD)



This is one of the main side effects post-transplant and below is a brief explanation of what to expect. If you would like any more details, then we recommend reading the Anthony Nolan booklet *Essential guide to GVHD* which can be downloaded from their webpage.

Although we will try to match you as closely as possible to your stem cell donor, there are always some minor mismatches and this is what causes GVHD. The graft (donor cells) recognise the host (you) as different and start to attack the cells.

This has the advantage of attacking any diseased (cancer) cells and helps to keep you in remission, but it also can attack other healthy cells such as those in your skin, gut and liver.

You should call your CNS or The Royal Marsden Macmillan Hotline if you experience a rash or increasing nausea and vomiting or diarrhoea, as these could be signs of GVHD. We will then advise you on the best management. It is important you let us know immediately, as it tends to be easier to treat GVHD the earlier you start treatment.

Useful tips:

- Skin GVHD is the most common site, so a good skin care routine is essential. Moisturise your skin two or three times daily with a non-perfumed emollient cream such as E45 or diprobase to help prevent your skin from becoming dry.
- Avoid direct sunlight for prolonged periods as this can trigger skin GVHD.
- If we give you steroid cream because you have started to develop skin GVHD, ensure you apply it as directed.
- Taking your immunosuppressants is essential, so if you are struggling with this or any side effects, let your CNS or doctor know.



Treatment is done with immunosuppressants, creams and sometimes starting steroids.

It is not possible to predict who will get GVHD, so it is important you let us know as soon as you notice any symptoms. It is also not a bad sign if you do not experience GVHD as some patients never do, and this does not mean that your transplant is not working.

Emotional impact

The impact of a transplant on you and your family, psychologically as well as physically, can be underestimated, especially as recovery can often feel frustratingly slow. This is normal and you are likely to experience a range of emotions going home, from excitement to fear and worry. Please talk to your CNS or doctor about how you are feeling, as we are here to support both you and your family. We also have access to a counselling service that we can refer you to.

Fertility and sexual activity

It is not uncommon to have lots of questions around fertility and sexual activity post-transplant, so we have provided information below. If you have any questions, please talk to your CNS or doctor. We can also refer you to a fertility expert at any point in your post-transplant recovery, if you feel this would be beneficial.

- It is safe to have sex after your transplant but you may not feel up to it initially. This is normal, so do things at your pace and when you feel ready.

- Some chemotherapy drugs can remain active in your body for several days and the effects can be passed on via sexual intercourse, however, this wears off quickly. Please be assured that this will not be a risk for anyone discharged following a transplant, as it will have been several weeks since you last had chemotherapy.
- There is a risk of infection if you are still on immunosuppressants or steroids, or have a new partner. We advise using condoms.
- Although as discussed with you pre-transplant, your fertility is likely to have been affected by your treatment, we advise precautions with the use of condoms to prevent unwanted pregnancy and STIs.
- We would not advise using the contraceptive pill for at least six months post-transplant, as this is likely to be ineffective in combination with the other medications that you will be taking.
- Sometimes people can experience problems with low libido (sex drive) or other sexual problems after a transplant. Your CNS will discuss this with you at a later stage, but if you want to talk about it before then, please ask.

Useful tips:

- The transplant not only affects you, but also your close family. We encourage them to talk to the CNS or doctors if they are struggling or have concerns, and we can help to get support for them.
- Your friends may be anxious and want to help, but may not know what to say. The best way to overcome this is to be open and honest with them.
- As long as you feel well enough and your friends and family have no infection risks, you can see them as soon as you are discharged. Keeping the connections with those that are important to you is essential to your recovery and to ‘getting back to normal’. It is tempting to overdo it, so the key is not to do too much too quickly.
- It is not unusual to feel a loss of confidence after a transplant and to have body image issues around hair loss, weight loss or weight gain, having a Hickman line and frustrations that you cannot do the same things as others. Making friends when you feel like this can seem a challenge, but remember that many people have similar uncertainties, even without having had the experience of an illness. There are lots of good organisations which can help to boost your confidence and can offer fun activities.
- It is normal to feel daunted post-transplant, so we encourage you to talk to those within your social support network and to contact your CNS. There are also groups locally and online that we can signpost you to.
- You may have frustrations around getting back your independence after treatment, and your parents and close family are likely to have their own fears and worries. Please contact your CNS if you have concerns, and they can support you during the recovery process.



Education and financial concerns

– Having treatment for cancer and undergoing a transplant will have caused disruption to education (for those still at school or in college). Most schools and careers advisors should be supportive, but if you wish for us to contact them or write letters of support, please let us know. Returning to school/college can be an anxious time, so your CNS can liaise with your teachers to help ease the transition, and discuss any adaptations you might need. Generally we recommend that you do not return to school/college until after you are off any immunosuppressants, as you will be increasingly vulnerable to infection during this time period.

Most people also find that they do not have the energy levels in the first three to six months post-transplant in order to attend school or college.

– For those of you in work, you can expect to be unable to work for at least three to six months post-transplant, which can cause a significant financial impact. If you require a ‘sick certificate’ for work, please let your CNS know so we can arrange this for you. We also have a welfare rights advisor that we can refer you to, who can help advise on benefits and grants. You might also be eligible to a Macmillan or Anthony Nolan grant, so please speak to your CNS who can then make an application on your behalf.

Useful tips:

- When thinking about going back to education or work, we recommend starting work initially with reduced hours which we can discuss with you
- Apply for benefits early on as the application process can be lengthy
- Anthony Nolan have a *Going back to work* booklet (for you) and a separate booklet *Information for Employers* (for your workplace). These can be useful as they tell you about what your rights are, and tells your employer about what to expect and how they can provide appropriate support
- Turn2Us offers advice on financial support and benefits www.turn2us.org.uk
- The Prince's Trust is a youth charity that helps young people aged 11-30 with education, jobs and training www.princes-trust.org.uk.





Common fears and questions

How do I know if my cancer is coming back?

- When you come to clinic, we will check a sample of your blood (chimerism) which will tell us the proportion of your blood that is donor cells and the proportion that is still yours. The aim is for it to be 100% donor. We will check for this every one to three months.
- Depending on your underlying type of cancer, at three months post-transplant we will do a repeat PET-CT scan and/or bone marrow aspirate to check for any signs of any underlying cancer.
- If you notice any new symptoms or are concerned, talk to your CNS who can support you.

Will things ever get back to normal?

- Recovery after a transplant can take several months (usually three to six months but varies for each individual) which may feel frustrating and slow at times.
- Be prepared for set-backs; this is a normal part of recovery and not a sign that the transplant has not worked.
- As you get stronger throughout your recovery, we will start to reduce the amount of medication you are on, along with the frequency of your clinic appointments.
- Please talk to your CNS about any frustrations and fears you have - they will be able to support you and signpost you to

organisations and groups for further support.

Do I need to have all of my childhood vaccinations repeated?

- Yes, you will need to have some of these repeated as your immune system has changed significantly. This will generally be six months post-transplant and we will inform both you and your GP.
- You will also need to have the annual flu vaccine via your GP.
- It is important that you have no live vaccines for at least two years post-transplant or whilst you have any active GVHD. Vaccines are one of two types: 'live' or 'inactive' and your GP will know the difference.

Can I travel abroad?

- Yes, but we advise not to travel in the first three to six months post-transplant whilst you are still on immunosuppressants. You will be at an increased risk of infection, so we will need to monitor you closely during this period.
- If you do want to go abroad, please discuss with your

consultant first to ensure it is safe to do so, and we can also provide you with a covering letter for medical staff in case you should need to be admitted to hospital whilst abroad.

- It is essential you have travel insurance and that the insurance company is aware that you have had a stem cell transplant. Some insurance companies can be expensive - Macmillan has a useful list of reasonably priced travel insurance companies to use via their website www.macmillan.org.uk

Will I need to be re-admitted to hospital?

You will need to be re-admitted if you have the following:

- Infection
- Reactivation of certain viruses (CMV), Herpes Zoster (shingles/chicken pox) or Adenovirus and GVHD: nausea and vomiting, diarrhoea, weight loss
- Respiratory complications, chest infections.

Common drugs that you are likely to be discharged on:

- Immunosuppressants (Ciclosporin, Mycophenolate, Tacrolimus); to help to reduce any GVHD
- Anti-fungal (usually Posaconazole); to help reduce the chance of you developing any fungal infections
- Anti-viral (usually Aciclovir); to help reduce the chance of you developing any viral infections
- Antibiotic (usually Penicillin V); to help reduce the chance of you developing any bacterial infections. You will normally be on this for life.
- Antibiotic to help prevent against PCP (Pneumocystis pneumonia), a type of pneumonia; this is given initially post-transplant via a monthly Pentamidine nebuliser when you attend clinic, and then once your counts have recovered further, as a tablet called Co-Trimoxazole (Septrin).
- Lansoprazole; to help prevent reflux/heart burn.

What about other young people with cancer?

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. On the unit, we have a range of social developmental activities including a weekly brunch, music sessions and other creative activities. If you have a particular hobby, interest or idea, please tell us.

You can find out about events with other young people through the [tya_royalmarsden](#) instagram page, or the TYA lead nurse or youth support coordinator. We also have a peer support buddy scheme where you can be matched with someone else who has been through treatment - if you are interested in this please let your CNS know.

General health advice

Sunburn: you will be at increased risk of sunburn, especially if you have had TBI (total body irradiation) or experienced any GVHD, so ensure that you avoid prolonged exposure to direct sunlight. Always use sun cream that has a UVA 5 star rating as this will help to protect you against skin cancer.

Smoking: this can cause many long term health complications (lung cancer, clogging up your arteries and an increased risk of heart disease). If you would like any help on quitting smoking, please let us know.

Exercise and a healthy diet: this will help to increase your strength and to reduce the risk of health problems.

Secondary cancers: having had treatment for cancer and a stem cell transplant, you will be at an increased risk of secondary cancers compared to others. When you attend clinic, we will check various tumour markers each year. For females, we will ask your GP to arrange for regular mammograms and cervical smear tests.

Late effects: approximately one year post-transplant, we will talk to you about regular checks you should be having to look after your general health. This will include attending dentist and optician appointments every six months, as both GVHD and the treatment you have had can impact on your dental and eye health.

Support and further information

Contact us

Please call **The Royal Marsden switchboard** on 0207 352 8171 and ask for the CNS on ext 4489 or ext 4219

Alternatively, please call:

**The Royal Marsden
Macmillan Hotline:**
020 8915 6899

You can ring the hotline 24 hours a day, 7 days a week.

Call us straight away if you are feeling unwell or are worried about the side effects of cancer treatments.

This service provides specialist advice and support to all patients at The Royal Marsden, as well as to their

carers, and both hospital and community-based doctors and nurses caring for patients at The Royal Marsden.

Recommended support and patient information

Anthony Nolan provides dedicated support for patients and family members after a stem cell transplant including an online forum, blogs and podcast.

*[www.anthonynolan.org/
patients-and-families](http://www.anthonynolan.org/patients-and-families)*

Blood Cancer UK provides patient information, advice for young adults and access to local support groups.

www.bloodcancer.org.uk



Maggie's is 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.

www.maggies.org

*Maggies.royalmarsden@
maggiescentres.org*

020 3982 3141

The Teenage Cancer Trust

has a specialist service for teenagers and young adults, and also run an annual conference (Find your sense of tumour) with networking opportunities and educational workshops.

www.teenagecancertrust.org

Teens unite run regular fun-filled activities for 13-24 year olds with cancer and provide ongoing support.

www.teensunite.org

The Ellen MacArthur Cancer Trust runs fully funded sailing trips for 8-24 year olds who have cancer. Sailing is used to support, empower and inspire young people.

www.

ellenmacarthurcancertrust.org

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 programs to support living well through and beyond cancer.

www.trekstock.com

Young Lives vs Cancer

Their 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, career opportunities, and the chance to influence our work to make lives better for young people with cancer.

www.

younglivesvscancer.org.uk

0300 330 0803



NOTES

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