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Na żądanie te informacje mogą zostać udostępnione w innych formatach, takich jak zapis większą czcionką lub łatwą do czytania, a także w innych językach. Aby uzyskać więcej informacji, porozmawiaj ze swoim zespołem specjalistów.

Macluumaadkaan waxaa loo heli karaa qaab kale, sida ugu akhrinta ugu fudud, ama far waa weyn, waxana laga yabaa in lagu heli luuqaado Kale, haddii la codsado. Wixii macluumaad dheeraad ah, kala hadal kooxda xarunta caafimaadka.

Bu bilgi, kolay okunurluk veya büyük baskılar gibi alternatif biçimlerde sunulabilir, ve talep üzerine Alternatif Dillerde sunulabilir. Daha fazla bilgi için klinik ekibinizle irtibata geçin.

یہ معلومات متبادل فارمیٹس میں دستیاب کی جا سکتی ہیں، جیسا کہ پڑھنے میں آسان یا بڑا پرنٹ اور درخواست پر متبادل زبانوں میں بھی دستیاب ہو سکتی ہیں۔ مزید معلومات کے لیے، اپنی کلینکل ٹیم سے بات کریں۔

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Please contact us if you need general information or advice about Trust services: www.bartshealth.nhs.uk/pals

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All our patient information leaflets are reviewed every three years.

Patient information

Your ongoing recovery at home after your Autologous stem cell transplant

A guide for patients with Lymphoma
Lymphoma Team, Department of Haemato-Oncology

Introduction

This booklet contains useful information about your on-going recovery following your treatment with High Dose Chemotherapy and an autologous stem cell transplant once you have been discharged from hospital.

It is likely that you have been given a lot of information throughout your transplant process. Sometimes it is difficult to remember this or to know when and how to process all you have been told.

For some, having a stem cell transplant can lead to a lot of changes and transitions. It can affect your life in many ways in the short term.

This next step, going home, is a big step forward to recovery and one which you have most likely been looking forward to. However, we understand that it can also be quite overwhelming. It is important that you know you are not alone and that we will be monitoring your recovery closely via our day unit and outpatient clinics in the months to come.



We also encourage you to contact us should you have health related concerns, require any medical assistance or need support or practical advice.

Outlined here is some important information for you to be aware of which will hopefully make the transition from hospital to home as smooth as possible.

Please refer to page 11 of this booklet for a directory of useful contacts.

Risk of infection

Even though you are well enough to go home, you are still at risk of infection. Following an autologous transplant, it usually takes up to three months for your immune system to fully recover.

It is not common to require re-admission into hospital for a temperature or infection following an autologous stem cell transplant but there are things you can do to reduce the risk further.

Maintaining the same precautions that were discussed with you in hospital may help minimise the risk of infection:

- Maintain good hand washing with soap and water
- Continuing strict regular mouth care
- Avoiding people with colds, flu or known viral infections: e.g. children and adults with measles, shingles or chicken pox.
- Avoiding heavy crowds where possible
- Minimising contact with animals. Wash your hands thoroughly after handling pets and ensure pets themselves are in good health.
- Ensure food is prepared and washed well.

We advise you check your temperature at least once a day when you are at home. **If you have a temperature above 38 °C you need to contact us immediately, even if you are feeling well.**

USEFUL CONTACTS

7A (South) Day Unit

Tel: 020 3465 6780 / 6789 / 6786 /55357

Monday to Friday: 9am–8pm; Weekends: 9am–5pm

5C Ward

Tel: 020 3465 5508

5D Ward

Tel: 020 3465 6777

HAEMATO-ONCOLOGY EMERGENCY HOTLINE: 07909 002671

This is a mobile phone manned by a member of the team 24 hours a day for urgent out of hours medical matters

Clinical Nurse Specialists (CNS) Lymphoma and Stem Cell Transplant

Your CNS's remain your key workers throughout your post-transplant phase. Please feel free to contact us during normal working hours **Monday to Friday 09am–5pm.**

Please note that we may not always be immediately free to talk, but will get back to you as soon as is possible

Carolyn Brown (Mon to Thurs)

Tel: 07917 613545

carolynbrown1@nhs.net

Sunita Khanal (Tues to Fri)

Tel:07909 672953

Sunita.khanal@nhs.net

Day 100 Assessment and further follow up.

Once your counts are recovered and you are on the correct medications the CNS's will book a Clinic appointment for you to be seen by the Consultant for clinical review. At this appointment we will request for day 100 outcome investigations to be performed. These might be in the form of a PET scan (or sometimes CT, or MRI scans and possibly bone marrow tests etc.

Patients who were referred to St Bartholomew's Hospital for their transplant will be given the option to be discharged back to their referring Hospital for their follow up, or to remain at Bart's for follow up, or to continue with both hospitals. Patients who have received all their treatment at St Bartholomew's Hospital will continue to be followed up here. This will initially be every three months and then become longer depending on your clinical situation.

You and the GP receive a summary letter following each clinic appointment.

Immunisations

The stem cell transplant can result in loss of some or all of the prior immunity you had as a result of childhood vaccinations against conditions such as diphtheria, tetanus, measles, mumps, rubella, meningitis and so on. Therefore it is important to repeat these.

Approximately three months after your stem cell transplant, we will send both you and your GP a request letter and copy of the vaccination schedule advised.

Please call your GP and book in to have these vaccinations as soon as the letter arrives. We request that your GP confirms to us when you have completed the re-vaccination schedule

If you do not receive the schedule, please let us know and we will issue one to you.

You should contact us if you experience any signs and symptoms of an infection; including a cold, runny nose, cough or feeling generally unwell.

It is important to act promptly when experiencing fever as in the majority of cases, a simple course of tablets at home will resolve the issue. However, left untreated infections can require readmission and in a small number of cases become life-threatening.

Risk of bleeding

It is quite common and expected to require occasional blood or platelet 'top up' transfusions once you have been discharged home.

Your need for transfusion support will be assessed according to the results of your blood tests when you attend the day unit for nurse led follow up. Transfusions **will** be administered on the same day.

If you have any new bleeding, bruising or persistent nosebleeds please contact us immediately as you may require a platelet transfusion. This is quick to organise.

If you experience palpitations, dizziness or shortness of breath, please contact us immediately as you may require a blood transfusion.

Fatigue

Even though your blood count levels are at a safe level for you to be discharged, you should remember that this is still a recovery period for your body.

Fatigue is a complex but common symptom of Lymphoma treatment which affects most patients at some point. It is even more common during the initial post-transplant recovery phase. Fatigue is characterized by extreme lethargy or exhaustion which differs from everyday tiredness. It can be overwhelming, is not a result of exertion and may not be relieved by rest or sleep. Fatigue can affect you on all levels including emotionally and psychologically in addition to the physical effects described above.

Challenging fatigue is key to managing and overcoming it. Thus, despite feeling tired, it is important to keep active. Routines such as waking early to shower and dress, gentle exercise such as taking short walks outside and a regular bed time will help enormously and are extremely important for your body's recovery. Maintaining activity will enable you to gradually build up strength and recover a general sense of wellbeing.

Continuing to do the exercises recommended to you during your stay by the physiotherapists, (making use of the stretchy latex 'Thera-Band') is a very simple way of combating fatigue. Increasing your understanding of what fatigue is and how to challenge it will be of huge benefit to you and those around you.

Post-transplant fatigue should improve and affect you less and less. It is not uncommon for it to continue to affect you for up to one year, but should become less frequent, for example become monthly. For further information please refer to the Macmillan or lymphoma action websites. Your CNS can guide you if you are unsure.

Central venous access device ("Hickman" or "PICC" line)

You will most likely go home with your line still in place as it is common at this stage to require regular blood tests and transfusions.

Whilst your line remains in place, it needs to be flushed, cleaned and redressed weekly on the day unit when you attend checkups. At home, continue to look after your line as you did in hospital. Cover it whilst in the shower and take care not to accidentally tug the tubing. It is best to keep it well secured and covered up at all times to minimise the risks.

You will need to monitor your PICC line daily at home. If you experience any pain, redness or ooze around the insertion site, please contact us immediately. Likewise, if you develop a persistent heavy aching sensation in the relevant arm, or arm swelling, please contact us as these can be signs of infection or a blood clot.

Other medicines

Any medicines which you routinely take for other conditions will continue as provided by your GP, unless we advise otherwise.

Outpatient follow-up post Autologous Stem Cell Transplant-Nurse led post-transplant clinic

You will need to be reviewed at Bart's quite regularly when you first go home. **This is an important aspect of transplant care.** Your referring hospital has contracted us to manage your care until Day 100 post-transplant as they are not a transplant center.

After discharge, your recovery will be monitored by the Lymphoma Clinical Nurse Specialists. Visits take place on 7A (South) Day Unit, 7th Floor, King George V Wing at St Barts. When you attend you will have a blood test from which your general recovery and health is assessed. This will also tell us if you need any blood product support such as a platelet transfusion, or the need for a growth factor injection to boost your neutrophil count.

The CNS's will assess your overall health including your physical, emotional and psychological wellbeing, coping and fatigue. If there are any concerns raised or assessed which require medical attention, we will ask the day unit doctor to see you also.

Sometimes you may require further tests such as x-rays, scans or additional blood tests. These are a normal part of recovery and enable us to monitor your progress and condition closely.

Similarly, if we feel you would benefit from a consultation with another health professional, e.g. a dietician or physiotherapist, we will arrange this also.

The schedule and frequency of visits to the nurse led clinic varies for each patient according to your pattern of recovery and is largely based on your most recent set of blood results and presenting needs. The CNS will direct when this next appointment will be. The frequency of visits will reduce with time. We will only ask you to come as often as is necessary to ensure your safe recovery.

* live bacteria used in making yogurts are not harmful. So yogurt described as 'live' is safe during neutropenia. However the bacteria used in bio or probiotic foods cannot be guaranteed as safe during neutropenia.

Outpatient medication post Autologous Stem Cell Transplant

You may find you are discharged home with a lot of medications. These will be explained to you by the ward nurse who issues you with them. Many will be required in the very short term only:

E.g. G-CSF injections, anti-sickness tablets.

However, the following two important medications are routinely given on a long term basis to all patients to protect against infection:

ACICLOVIR 400mg tablet (anti-viral)

Twice daily for **12 MONTHS** starting immediately

CO-TRIMOXAZOLE FORTÉ 960mg tablet (anti-biotic)

Once daily on Mondays, Wednesdays and Fridays **ONLY for 6 MONTHS** starting once your platelet count recovers to above '50'. We will let you know when this should start.

Please let us know if you have any allergies to this medication as you will be prescribed an alternative.

PLEASE NOTE: It is very important that you take these two medications continuously for the length of time stated above.

You will need to let us know when you are running low of these in order that we can supply more!

We can write to your GP and ask them to supply these medications to you on a repeat prescription, this should prevent you from having to travel to Barts for repeat prescriptions. Please can you let us know if you have any issues trying to get prescriptions from your GP.

If you notice any damage to the tubing, such as a split, please also let us know as this poses an infection risk.

Having a PICC line in place will not restrict you from doing most of the activities you wish to do. However, please note, it is not advisable to swim whilst you still have a PICC. Swimming is fine once the PICC is removed and the site of the PICC has healed.

Once your platelet count reaches 50, it is most likely that we will remove the PICC. This is a simple procedure which takes just a few moments on the day unit. There is no need for local anaesthesia as was used to insert the PICC. This is a painless procedure performed by a nurse.

Nutrition

A well balanced, healthy diet is recommended in order to maintain your immune system. Now that you are home, you may find your personal choices help boost your appetite.

You may have found it difficult to eat post-transplant. This can be due to a number of reasons which have a negative impact upon appetite. These include nausea and vomiting, diarrhoea, mucositis (sore mouth) and taste changes due to medication. Hopefully now, many of these issues will have significantly decreased or diminished.

However, it is usual for there to be a transition period whilst you build up to a normal appetite and food intake for you. The following list on page 7 provides practical tips to help:

- Try managing small, frequent meals and nutritious snacks as opposed to large plates.
- If you have any ongoing nausea, take anti-nausea medications at least 30 minutes before a meal.
- Try to drink at least 2 to 3 litres of fluids a day. This will prevent dehydration, keep your mouth moist and minimise kidney problems.

- If you are struggling to drink, you can boost your fluid intake by trying jellies, ice lollies, soups and smoothies, all of which have a high fluid content whilst providing some calories also.

Following a stem cell transplant, you are at greater risk of infection from bacteria or fungus in foods. This is mainly due to the reduced number of neutrophils in your blood (neutropenia). Under normal circumstances, neutrophils would fight the risk of infection posed from a food source.

The main way you can reduce your risk is to observe standard food hygiene rules. Check packaging is intact and use by dates when shopping, ensure food is stored correctly, wash your hands before preparing food, avoid cross contamination of food by changing and washing chopping boards (raw and cooked) , ensure clean work surfaces, cook food properly and avoid re-heating food where possible. **NEVER re-heat cooked rice.**

Detailed on the next page are the updated consensus recommendations on dietary advice for patients with neutropenia from the sub group of the British Dietetic Association Oncology Group (2012).

The table outlines recommendations for people with a neutrophil count below '2.0'. This may/may not apply to you for a few weeks. We will assess your neutrophil count at every visit.

Note: Stricter advice exists for patients with a neutrophil count below '0.5'. This is unlikely to apply to you so to avoid confusion, we will provide this information only if it becomes relevant.

More information can be found in the Bloodwise booklet "Dietary advice for Haematology patients with neutropenia". This can be found on the Bloodwise website or your CNS can give you a copy if requested.

Food safety advice for a neutrophil count below $2.0 \times 10^9/\text{litre}$

Avoid	Alternatives
All unpasteurised dairy products e.g., milk sold on local farms	Any pasteurized milk, soya milk, Jersey milk, UHT milk
Soft cheeses made with unpasteurized milk e.g., feta, parmesan Homemade/ deli paneer and labnah Mould-ripened e.g., camembert, brie, goat's cheese Blue veined cheese e.g., Danish Blue and Stilton	Processed cheese e.g., Dairylea, Kraft, Philadelphia, mesh and halloumi Pasteurised parmesan and mozzarella. Paneer made with pasteurized milk Vacuum-packed pasteurized and hard cheeses e.g., Cheddar and Edam
Raw or lightly cooked shellfish	Well-cooked shellfish e.g., prawn curry
Raw/undercooked meat, poultry, or fish e.g., meat which is still pink, sushi, oysters and caviar Smoked meats e.g., salami Avoid smoked salmon unless eaten directly from a freshly opened packet	Well cooked meat, poultry, and fish; tinned meat and fish. Vacuum-packed cold meats such as turkey and ham stored below 3°C and eaten following the manufacturer's instructions. Vacuum packed fish eaten straight from a new packet (including smoked salmon).
Raw eggs or undercooked eggs e.g., homemade mayonnaise, homemade ice cream, ice cream from vans /soft serve ice cream dispensers, mousse, egg-nog, meringue and hollandaise and béarnaise sauce	Hard boiled eggs, shop bought mayonnaise, ice cream and other products made with pasteurized egg.
Probiotic or 'bio' foods, drinks or supplements e.g., Yakult, Actimel, ProViva Yogurt which is described on the label as bio or probiotic*	Any yogurt that does not describe itself as bio or probiotic including live plain, Greek and fruit yogurts
Meat paté, vegetable paté	Pasteurised paté and paste in tins or jars that do not need to be refrigerated