

Your clinic notebook after an Allogenic Bone Marrow Transplant

Information for patients



Leeds Cancer
Centre

Your details

ALLERGIES:

Date of transplant:/...../.....

Apply Sticker

Name:

Address:

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Post code:

Home phone number:

Mobile phone number:

NHS No:

Date of birth:/...../.....

Next of Kin: Relationship:

Contact details:

GP Name:

GP telephone no:

GP practice address:

Staff and clinic details

Nurse specialists:

Jan Sampson 0113 206 8864

Suzanne Liebersbach 0113 206 7892

If unwell and need immediate advice

Contact St James Switchboard: **0113 243 3144** and ask for the 'oncology bleep holder' who will arrange an assessment.

Ward 89 Bone Marrow Transplant Ward

Bexley Wing, St James's Hospital, LS9 7TF

Ward 89 0113 206 9189

Ward 88 0113 206 9188

Outpatient appointment enquires:

0113 206 8130 **Monday and Friday clinics**

Email: leedsth-tr.haematologyonline@nhs.net

Day unit 0113 206 9187

Ambulatory Care 0113 206 8271

Going home after your transplant

Preparing to go home after your transplant

Now that you have had your transplant and you are almost ready to be discharged from the ward you should be thinking about how to get the best out of your clinic visits. Here are some tips! Remember the ward is available 24/7 to answer any queries no matter what time of day.

- Take a look at the **Next Seven Steps** booklet, this can be referred to for all transplant related issues alongside discussion with the clinical team. We strongly advise you share the booklet with family and close friends so that they can understand how best to help you make a full recovery.
- If you have a temperature of 37.5°C or over then check it again in one hour.
- If the first temperature OR the repeat temperature is 38°C or more then you should phone Ward 89 immediately on (0113 206 9189 or 0113 206 9289). You may take Paracetamol only when there is a temperature of 38°C (if you usually tolerate this drug).

If you are experiencing problems or are unsure about anything please phone the ward or your nurse specialist.

You should NOT delay if you have new symptoms such as:

- a rash that is new or getting worse
- diarrhoea, nausea or vomiting
- temperature greater than 38°C
- generally feeling unwell.

Your medication

- Make a list of all the treatment that you take including tablets, liquids, inhalers, and creams. Some patients keep a list of their treatment on a piece of paper stored in a wallet or purse while other patients prefer to keep a list on a mobile phone. When changes are made to your treatment please update your list – the doctor/nurse seeing you in clinic will be happy to help you.
- Most of you will be taking Ciclosporin, Tacrolimus or Sirolimus, these drugs help to protect you from graft versus host complications. It is important that we measure the levels of Ciclosporin/Tacrolimus/Sirolimus in your blood at each clinic visit as we use the results to decide on your dose for the following week. Please **DO NOT** take Ciclosporin/Tacrolimus/Sirolimus on the morning of your clinic visit. The morning dose is completely missed. Do take the evening dose as usual. **IF YOU FORGET** then please tell us as the start of your appointment since the blood result will be inaccurate and the test should be repeated as soon as possible.
 - **Do not** have grapefruit or its juice as this will affect how your Tacrolimus and Ciclosporin is absorbed.
 - **Do not** take non-steroidal anti-inflammatories (pain killers, e.g Ibuprofen, diclofenac, Naproxen) while your platelet count is low.
 - **Do not** take any un-prescribed medication (including supplements/herbal remedies) before checking with the doctor.

- At each clinic visit please remember to bring your medications list and this clinic note book. This will help to avoid the problem of running out of tablets in between hospital visits
- Please make sure you are available to take any medication change by phone. Please make sure we have your mobile number if this is your main phone contact
- Dossett boxes are available from Boots, you will need a larger size Dossett box to hold the amount of tablets required. It would be wise to restock the Dossett box on a Tuesday or Wednesday following the clinic appointment to accommodate any changes They can be useful for your relatives to help you to remember to take your tablets. It also may help if they are sometimes prepared for you, especially if your relatives work.
- Your list of treatments may include medicines that were originally prescribed by your GP e.g., blood pressure tablets. As far as possible you should continue to get these medicines from your GP but you should always keep the clinic doctor up to date. In the long term you will get most or all of your medication from your GP, but in the early stages after a transplant we use drugs that are not always available outside of the hospital.

General information

- Pay particular attention to symptoms relating to your appetite, diet, weight, skin, mouth, eyes, and bowels. Some symptoms may become a chronic problem and treatment may take several weeks to become completely effective. Please keep a diary of your symptoms e.g., how many loose

motions per day. This will help the medical team assess how severe your symptoms are and how they are responding to therapy and whether you need a new therapy.

- Unless you are advised to restrict your fluids then you should aim to drink 2-3 litres fluid a day (150 mls = 1 average sized teacup, 1000 mls = 1 litre and 20 cups would be equal to about 3 litres). It can help if you drink a small amount every hour, to help you achieve this target. Some patients find it helpful to have a reusable water/drinks bottle so they can easily monitor their own fluid intake throughout the day.
- Follow the '*Food safety advice for Immunocompromised patients*', until our team advise you otherwise – discuss this with the clinic doctor at each visit. Usually, you can stop the diet when your immunosuppressant's (steroids and Cyclosporin) have been discontinued. It is likely that your immune system will take longer than this to recover. It is difficult to put an exact time for all patients to follow so please discuss with us at clinic.
- **Alcohol: AVOID** – many drugs that you take may interact with alcohol.
- Try to take a short walk every day – even if it is only round your garden or to the bottom of your road. Fatigue is extremely common and small tasks can be overwhelming. It can often be underestimated how exhausted you can feel and the monotony of the first three months. Fatigue can often last longer than anticipated, after three months when the medication is weaning symptoms can improve but for some patients may take longer.

- Avoid crowded places such as the pub or supermarket.
- Avoid people with infection particularly children.
- **Travel abroad: PLEASE DO NOT** travel abroad without discussing this with the clinic doctor. In general, we advise against foreign travel during the first year after transplant and while you are on drugs that affect the immune system.
- It may be useful to make up the spare room. Many patients can have disrupted sleep patterns after transplant. This will mean you can watch TV or read a book without feeling guilty about disturbing your partner.
- **Driving:** Please avoid driving, tiredness is a very common symptom after a transplant and even if you can drive you should think about bringing somebody with you to clinic to drive you home should you feel too tired.
- **Transport:** If you need transport, we will provide you with the telephone numbers to book this. This should be done at least 48 hours in advance.
 - If you are admitted please remember or ask family/ friend to cancel any transport.
 - Requests for an escort will only be granted for medical reasons.
 - If you are admitted from clinic transport for your escort to get home will not be provided.
- Sun cream Factor 30-50 should be worn daily between April and October at home and abroad.
- Vaccinations start at six months after transplant. Some vaccinations may start after 100 days, such as Flu.

- If you are immunocompromised members living in your household will be eligible for the flu jab to ring fence the member of the household with a lowered immune system.
- Repeat Breathing tests (pulmonary function tests), heart scan and bone density scan are done routinely at one year after transplant.

Waiting times in clinic can sometimes be longer than planned, especially if other patients are ill and need extra time. It may help if you use the time to:

- Write down any questions you want to put to the team
- Check your list of treatments and whether you need a new prescription
- Finish that novel you've been reading!

We can introduce you to other transplant patients – this can help pass the time but also provide you with a useful network of support and advice.

You may find the websites below useful and may wish to share them with your family and friends. It may help them get a better understanding of what is happening to you.

www.anthonynolan.org






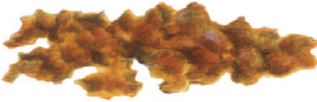

www.bloodwise.org.uk

Usual medication after bone marrow transplant

Drug	What it's for	Extra comments
Cyclosporin Tacrolimus Sirolimus Mycophenolate mofetil (MMF)	Immuno-suppressant Prevention of graft vs host disease	Do not take on morning of clinic days MMF usually stops at day + 35
Aciclovir	Prevents viral infections such as cold-sores and shingles	Continues for up to 1 year and whilst on immunosuppression
Itraconazole Posaconazole Voriconazole Ambisome (intravenous)	Prevents fungal infections such as thrush and fungal chest infections	Continues whilst on Immunosuppression
Letermovir	Prevention of CMV infection	Checked via weekly blood test Continues whilst on immunosuppression
Lansoprazole Famotidine	Prevention of acid indigestion	Usually stops by day +100 Continues if taking steroids

Drug	What it's for	Extra comments
Magnesium Glycerophosphate Magnesium aspartate	Replenish magnesium stores in the body	Usually stops by day +100 Most patients will need supplementation
Cotrimoxazole	Prevents an infection called PCP	Continues for up to 1 year and whilst on immunosuppression
Metoclopramide Ondansetron Levomopromazine Cyclizine	Anti- sickness	Continues usually until day 100
Folic acid	Vitamin for red blood cells	Stops around day 100
Cholecalciferol	Vitamin D	Continues up to six months
Ursodeoxycholic acid	Protects against a complication called VOD that affects the liver	Stops at day 100

THE BRISTOL STOOL FORM SCALE

<i>Type 1</i>		Separate hard lumps, like nuts (hard to pass)
<i>Type 2</i>		Sausage-shaped but lumpy
<i>Type 3</i>		Like a sausage but with cracks on its surface
<i>Type 4</i>		Like a sausage or snake, smooth and soft
<i>Type 5</i>		Soft blobs with clear-cut edges (passed easily)
<i>Type 6</i>		Fluffy pieces with ragged edges, a mushy stool
<i>Type 7</i>		Watery, no solid pieces ENTIRELY LIQUID

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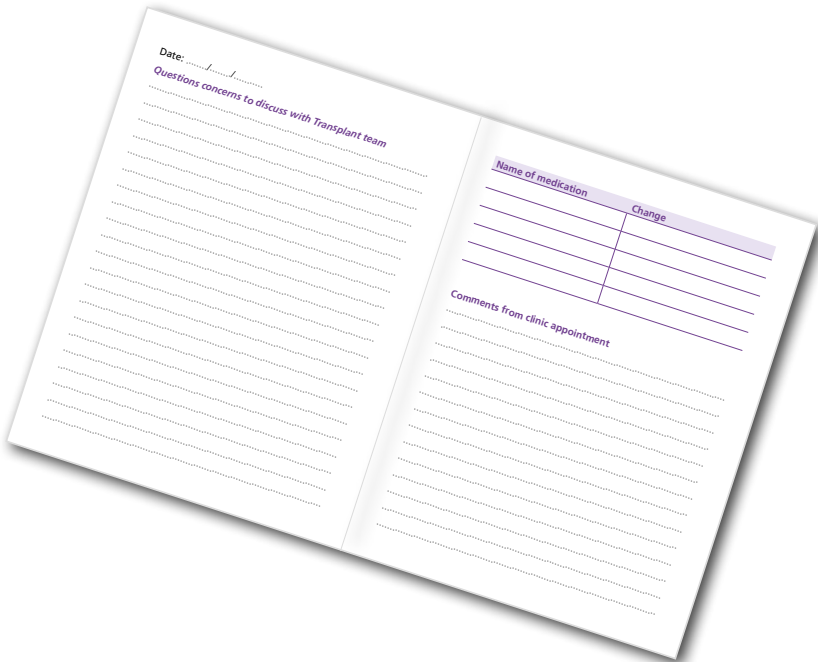
How to apply steroid cream

An FTU is the amount of medication needed to squeeze a line from the tip of an adult finger to the first crease of the finger.

The recommended dosage in terms of FTUs will depend on what part of the body is being treated. This is because the skin is thinner in certain parts of the body and more sensitive to the effects of corticosteroids.

Area of skin	FTU each dose (adults)
A hand and fingers	1 FTU
Front of chest and abdomen	7 FTU
Back and buttocks	7 FTU
Face and neck	2.5 FTU
Entire arm and hand	4 FTU
Entire leg and foot	8 FTU

Your diary pages to complete



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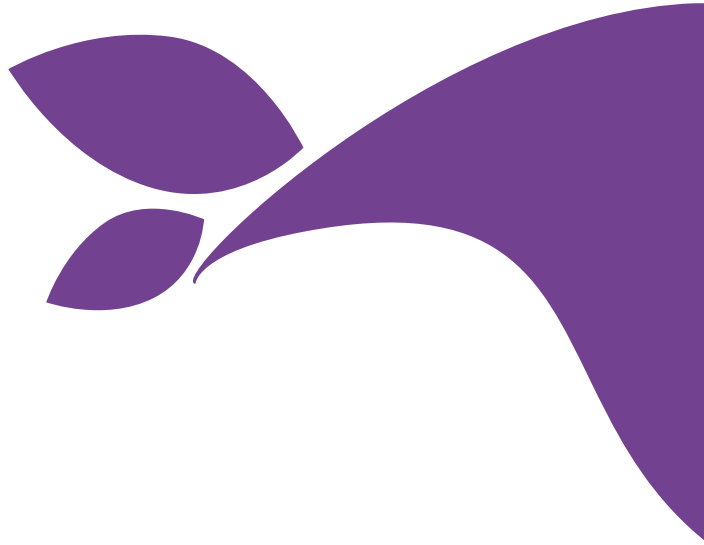
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What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



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