



A Guide to Discharge Post High Dose Chemotherapy and Autologous Stem Cell Transplant

Going home after an autologous stem cell transplant can be a time for celebration but equally you may be feeling anxious. You have been closely monitored by many healthcare professionals throughout your in patient stay. It is common to have worries and concerns as your discharge date draws nearer.

The transplant team will assess you and identify when you are ready for discharge. It is important you take part in the planning of your care in order to prepare you and your family for this transition.

The Stem Cell Transplant Clinical Nurse Specialist will work with you before discharge to inform you of the precautions you need to take. You will also be able to discuss your needs and concerns using the holistic needs assessment tool.

Your family and friends may also have questions about your pending discharge. The Stem Cell Transplant Clinical Nurse Specialist is happy to offer advice (with your consent) about caring for you at home during your recovery period. This can be done over the telephone if they are not able to attend the hospital.

This information aims to aid you in returning home post your autologous transplant.

It is important you have the telephone numbers required available at home should you need to contact us.

Phone Numbers

Stem Cell Transplant Clinical Nurse Specialist Mon, Tues, Wed, Fri – 09:00-17:00	01793 605962
Haematology Clinical Nurse Specialists Mon- Fri 9:00-17:00	01793 604341
Triage Line Mon to Fri 9am – 5:30pm Out of Hours	01793 604348 01793 604400



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Going Home

Leaving hospital and going home can be an anxious time. You will also need to take precautions to reduce your risk of infection and improve your health and wellbeing. This can be a stressful time for some patients and it is important you try and manage this stress effectively.

Follow Up Appointments

On discharge from hospital you will be given follow up appointments. Please ensure you are aware of these scheduled appointments before leaving the ward.

The outpatient appointments will take place in Osprey Unit on the 3rd Floor. These follow up visits will be to assess:

- Recovery of your full blood count
- Monitor your liver and kidney function
- Assess how you are physically improving
- Access, redress and flush your Central venous access device (Hickman/Picc) if required.

The frequency of these appointments will depend on your own personal recovery.

It is common to have appointments several times a week initially, however, these visits will gradually reduce as you improve overall.

In the beginning we suggest you bring someone with you to clinic appointments as you may be feeling tired and weak.

It may be useful to write down any questions you may wish to discuss at these appointments.

Please also bring a list of your current medication including the supply amount you have left at home.

CVC/PICC Line Care

You will probably be discharged with your CVC/Picc line in-situ. Your line can be accessed for blood samples to be taken or any further treatment required.

Please ensure you have weekly appointments for line care either with Day Therapy or at the IV Therapy Centre (by prior arrangement only) when your outpatient appointments become less frequent.



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Arrangements will be made for your line to be removed once you no longer require frequent blood testing, blood products and following your Transplant Consultants instructions.

Should you have any concerns or questions between your clinic visits please call the Stem Cell Transplant Clinical Nurse Specialist.

WHAT TO LOOK OUT FOR AT HOME

Infection

It usually takes 3-12 months for your immune system to fully recover from your autologous transplant. You are at increased risk of infection during this time. Your bloods will be monitored to see how well your immune system is recovering.

It is important you are aware of the signs and symptoms to look out for.

Please call the 24 Hour Triage line if you have:

- Temperature 37.5 degrees Celsius or above
- Feel Shivery or Flu-Like
- Coughing, sneezing, runny nose, shortness of breath or chest discomfort
- Any redness, swelling or pain to your throat, eyes, ears, skin, abdomen or joints
- Blisters similar to cold sores around your mouth or anywhere else
- Rashes
- Blurred vision or other visual changes
- Frequency in passing urine or a stinging and burning sensation
- Feel generally unwell
- Problems with you CVC/Picc line including, pain, redness or swelling.

Triage Line numbers
Day Therapy Mon to Fri 9:00 – 5:30pm 01793 604348
Dove Unit Out of Hours 01793 604400

Reducing Risk of Infection – there are some things you can do to reduce your risk of infection once discharged.

Mouth Care

- Continue to brush your teeth with a soft toothbrush.
- If wearing dentures you must keep them clean soaking them in denture cleaner daily.



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- A dry mouth is a common side effect after your transplant it is important to avoid commercial mouthwashes and continue using your mouthwashes as prescribed on discharge. These symptoms can last 3-4 months or longer after your transplant.
- Continuing to drink plenty of fluids can also help keep your mouth moist.

Personal Hygiene

- It is important you are washing your hands regularly especially prior to eating and after using the toilet.
- If you have any pets you must wash your hands after having any contact with them.
- Shower or bathe daily frequently and use moisturiser for your skin.
- If wearing contact lenses make sure these have been thoroughly cleaned. Do not reuse cleaning solution.

Diet

- It is important you continue to follow the food safety guidance provided to you by the dietician whilst you were in hospital until your immune system has fully recovered.
- You will have a reduced appetite on discharge which should gradually improve.
- It is important to eat a balanced diet to aid in your recovery. We advise you try meals/snack little and often to start with until your appetite is improving.
- If you are having difficulty with eating the dietician will be able to offer advice on supplements. Please contact the Stem Cell Transplant Clinical Nurse Specialist who will arrange contact with the dietician.

Family & Visitors

- Close physical contact should be avoided with anyone who has signs and symptoms of being unwell including coughs, colds, diarrhoea or vomiting.
- You can have visitors but we would advise small numbers initially and ensure they are also well.
- You are more susceptible to viruses as your immune system remains low. This can include viruses you may have had in the past such as shingles or chicken pox.
- Should you come into contact with chickenpox, shingles, measles or German measles please call the triage line.



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GENERAL INFORMATION

Vaccinations

Your childhood immunisation will need to be given again once your immune system has fully recovered.

This schedule usually starts at 6 months to 1 year post your transplant and your GP Surgery will be informed.

Once you have received your vaccination schedule we recommend you contact your GP surgery to arrange an appointment.

It is important you do not have any live vaccines until 2 years after your transplant.

Daily Activities

The time it takes people to recover post stem cell transplant varies individually. Most people find it takes approximately 3-12 months. The time after your transplant is vital in aiding your recovery.

The cells in your mouth, stomach, intestines, hair and muscles will gradually regrow. Approximately 3 months after your transplant your hair will start to grow more quickly.

Daily tasks will feel more strenuous and difficult initially but this will improve over time.

Fatigue

Going home you will feel extremely tired and weak and less well than you did before your admission to hospital. You may find small tasks are exhausting initially but this exhaustion will improve over time.

It may take several months for you to regain your strength and to be able to take part in the activities you enjoyed before your transplant.

As you become stronger gradual gentle exercise can help improve your energy levels and have a positive impact on your psychological wellbeing.

Exercise

Most people find it takes some time to regain their strength. Each day you could try 5-10 minutes of gentle exercise around the house or a short walk outside. This can be steadily increased at your own pace.



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It is recommended you avoid busy public places in the first few months after discharge whilst your immune system is recovering.

Giving yourself goals to achieve daily may help you build up your energy and stamina. However, initially it is still very common you may need to take a nap.

A regular exercise plan once you are beginning to feel stronger in your recovery may be beneficial. Swindon Borough Council runs a structured exercise programme called 'Steps to Health' which may be beneficial. Your Stem Cell Transplant CNS can provide you with further information and refer you if you are interested in this programme.

Once you start to feel stronger you can resume your hobbies as you feel able.

Drinking Alcohol & Using Tobacco

Your organs need time to recover after your transplant. Alcohol can harm your liver and also you're recovering bone marrow. We advise you do not drink alcohol until your Transplant Consultant advises you it is safe to do so.

Smoking can cause long term health complications. It can lead to a serious lung infection post stem cell transplant as well as increasing your risks of a secondary cancer. If you require help with stopping smoking, please call:

01793 465513 or email: livewell@swindon.gov.uk or livewellswindon@nhs.net

Returning To Work

The earliest you can return to work is approximately 3 months from the time of your transplant.

While some people may feel ready to return straight away for others this process can take much longer.

Making the transition back to your usual lifestyle and work can be a difficult for a number of reasons.

Sometimes people feel anxious about returning to work due to appearance changes, lack of concentration, attention and memory issues.

A gradual phased return to work would be appropriate and this can be supported with a fit note provided by your Transplant Consultant.



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You can talk to your transplant team about returning to work. We can provide support and offer you ways to ease your transition.

Sexual Activity

You will feel tired after your stem cell transplant and not ready to resume sexual physical activity immediately. These feelings are common, however, if you have concerns about this please discuss with your Stem Cell Transplant Clinical Nurse Specialist.

Your platelet count and white blood cells may remain low for some time post your stem cell transplant. Therefore you are at risk of bleeding and infection. Please inform your transplant team should you have any symptoms post intercourse.

Sun Safety & Travelling

Your skin is at an increased risk of sun damage post chemotherapy and a Stem Cell Transplant. Therefore it is recommended you avoid this as much as possible by following these safety tips:

- Protect your skin with clothing including a hat, t-shirt and sunglasses
- Spend time in the shade between 11am and 3pm when sunny.
- Use a high protection sunscreen of at least SPF 30 which is also high UVA protection.
- Apply sunscreen generously and frequently re-apply when in the sun
- For the first 3 months after your transplant avoid travelling outside your local area.
- If you do travel away from home in the first 3 months OR you plan to travel abroad in the first 2 years following your transplant please discuss further with the Transplant team.

Ongoing Support

Your Transplant team will provide you with ongoing support post discharge home.

Should you have any concerns or questions please contact your Stem Cell Transplant Clinical Nurse Specialist.



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Useful contact numbers:

Macmillan Cancer Support

Tel: 0808 808 00 00

www.macmillan.org.uk

Local Macmillan Advice Worker Sue Williams & John Bristow

Tel: 01793 496154

Cancer Research UK www.cancerhelp.org.uk

CLIC Sargent Social Worker

Tel: 01793 646145

(Patients 18-25 age group) www.clicsargent.org.uk

Leukaemia Research Fund

Tel: 020 7405 0101

www.lrf.org.uk

Lymphoma Association

Tel: 0808 808 5555

www.lymphomas.org.uk

International Myeloma Foundation

Tel: 0800 980 3332 www.myeloma.org.uk

UK National Electronic

Library for Health

www.nelh.nhs.uk

LIFT Counseling Services

Tel: 01793 836836

<http://lift.awp.nhs.uk/swindonandwilts>

This information sheet is available to order in other languages and formats. If you would like a copy, please contact us on 01793 604031 or email gwh.pals@nhs.net

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