Autologous Stem Cell Transplants
Important Information

There is a lot of information in this pamphlet so if you do not read it all, the following points are the basic minimum you need to know for your safety. Please keep this page somewhere obvious so that you or your carer can refer to it if you are uncertain or unwell.

• Keep your Alert Card handy at all times.
• Keep your mouth clean, use a soft toothbrush and avoid brushing the gums.
• Eat only fresh food which has been refrigerated or frozen appropriately and defrosted in the fridge or microwave.
• Rinse fruit, vegetables and salads before preparation.
• Avoid takeaways, sushi, soft cheeses, leftovers.
• Avoid crowds and prevent sick people from visiting you.
• Avoid injuries especially from gardening and pets.
• Avoid constipation and report this early if it occurs.
• Maintain a good fluid intake of about 2 litres per day.
• If you have diarrhoea or vomiting report these symptoms early.
• Learn how to take your temperature 4 times a day.
• Wash your hands before eating and after being in public places.

If any of the following occur, contact the Haematology Day Unit, who may be able to accommodate you during work hours, or the after-hours haematologist on call to will arrange treatment at the RHH Emergency department.

• A temperature of 38 degrees or more.
• Shivers and shakes or feeling abnormally hot or cold.
• Any dizziness, fainting or collapse.
• Any bleeding.
• Persistent diarrhoea.
• Vomiting for more than a few hours which prevents you from drinking.

Important Phone Numbers:

Outpatient Oncology 6166 8238
Oncology Triage Nurse (9:00am to 4:00pm) 0429 009 217
RHH switchboard 6166 8308 for the Haematologist on call
This pamphlet is intended to provide you with an outline of what is involved with an autologous bone marrow transplant. Your individual circumstances may differ slightly from the information contained here. It is specifically written for those patients who choose to have their transplant as an outpatient rather than being admitted to hospital, but the information is useful for all transplant patients. It is not intended to replace a discussion with your doctor and nurse.

Prior to reading this pamphlet you may have already completed your blood stem cell collection either as a Peripheral Blood Stem Cell Harvest or as a Bone Marrow Harvest and have those cells stored here at the Royal Hobart Hospital.

Your own haematologist may also be a transplant doctor at the Royal Hobart Hospital, if this is the case, he/she will supervise your care here. If not, your haematologist will refer you to one of the consultants here for the duration of your transplant and you will return to the care of your referring doctor when you have recovered.

Your transplant doctor will assess you before the transplant and will be responsible for your care. You will also be asked to sign a consent form.

The Royal Hobart Hospital has been designated as the bone marrow transplant hospital in Tasmania so that all Tasmanian bone marrow transplant patients are cared for by a specialist team of doctors, nurses and allied health professionals.

Your transplant doctor will decide when it is safe for you to return home. You may be in Hobart for at least 2 to 3 weeks.

The Tasmanian bone marrow transplant team understand the difficulties encountered by patients who need to travel long distances and stay away from home. Every attempt will be made to streamline this aspect of your care. You are entitled to travel and accommodation subsidies which your local transport officer will arrange suitable accommodation available within a short drive of the RHH and assistance with parking which is provided by a Hobart based charity The David Collins Leukaemia Foundation. If this flat is not available the Leukaemia Foundation of Australia, will provide you with suitable accommodation.

The Cancer Council, the Leukaemia Foundation of Australia, other charities and the social workers at the RHH are also able to assist in other ways.

Please communicate any concerns you may have with the nursing staff at your referring hospital or the Bone Marrow Transplant Coordinator in Hobart.
Bone marrow transplantation is a very specific area of medicine. The terminology regarding stem cell transplants can be confusing, so it is useful to explain these terms.

**Allogeneic:** Stem cells are collected from a donor and infused into another person – the patient. Donors can be related to the recipient or can be anonymous volunteer donors.

**Autologous:** The word ‘autologous’ means that the stem cell donor is the patient. Autologous stem cells are collected, cryopreserved (meaning to keep frozen) and reinfused at a later date as a ‘rescue’ treatment after high dose chemotherapy.

**Blood Stem Cells:** can be collected from the bone marrow (under an anaesthetic), blood stream (peripheral blood) or umbilical cord.

**Bone Marrow Transplant:** A general term which relates to intravenous (IV) administration of the blood stem cells collected previously.

**Conditioning Therapy:** is given prior to the transplant to treat disease. It is higher than standard doses chemotherapy you may have already received. It also reduces the number of cells in the marrow. This creates space or ‘conditions’ the bone marrow so the new stem cells re-establish and grow.

**Engraftment:** or the ‘recovery’ phase. This is the period of time in which your bone marrow is recovering from the high dose chemotherapy and the new stem cells become established and mature into normal adult blood cells. This period can vary but usually take 10 to 14 days.

**Peripheral Blood Stem Cell Transplant:** Indicates that blood stem cells collected from the patient’s circulating blood, were used in the transplant.

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**Formation of Blood Stem Cells**

The bone marrow produces all of our blood cells, including:

- the red blood cells which carry oxygen
- the white blood cells which fight infections, and
- the platelets which form blood clots.

All these blood cells start their life as a stem cell or ‘baby’ cell. A stem cell has the ability to mature into these different blood cells. The mature blood cells live for a limited time in the blood stream so the bone marrow is constantly working to produce new cells. Natural chemicals called growth factors send messages to the bone marrow which control the rate of production of stem cells according to the body’s needs.

The administration of chemotherapy and injections of growth factor can dramatically alter the production of stem cells in the bone marrow.

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**Why have an Autologous Transplant?**

An autologous transplant can be used to treat a number of blood or cancer disorders. The intravenous (IV) infusion of autologous blood stem cells allows you to receive high doses of chemotherapy. Chemotherapy is given prior to the transplant to rid your body of any remaining malignant cells. Chemotherapy cannot distinguish between normal and diseased cells and generally attacks and destroys cells while they in the process of multiplying. Because our bone marrow is continually producing millions of cells it is most vulnerable to the chemotherapy. Your own blood stem cells are reinfused at least twenty four hours after the chemotherapy in order to replenish or ‘rescue’ the bone marrow. You may also be given injections of a growth factor (G-CSF) in order to further stimulate the growth of the stem cells into normal mature blood cells.
Planning the Transplant

The transplantation process involves a large team of medical professionals, but you are the most important, central person. Outpatient care requires commitment from health professionals, yourself and your carer. The key to successfully managing your outpatient transplant is communication. Your daily visits are an opportunity for you to discuss any issues at all with the medical team. Please feel that both you and your carer can express any worries or frustrations with us. We may be able to help specific problems and it often helps just to talk things over. Please ask any health professional to clarify any information at any time during this process. It is important that you are comfortable with the information you receive.

Once a decision has been made to consider a transplant you will be contacted by the Bone Marrow Transplant Coordinator at the Royal Hobart Hospital for pre-assessment. We welcome relatives or close friends to attend with you and if you have a particular person who will be your carer they must attend this session with you.

The timing and details of the transplant will be discussed and these can vary according to personal circumstances. The conditioning chemotherapy and transplant can be planned for you to attend the Royal as either an inpatient on 9A or outpatient on the Day Chemotherapy Unit 8A at RHH. You will be under close supervision until your stem cells have engrafted and you have recovered. In order to attend as an outpatient you need a carer to stay with you for 24 hours/day, who is able to transport you to and from the hospital as required and can maintain a clean home environment and cook and care for you. This is not meant to sound daunting and the majority of our patients cope very well outside of the hospital. You will receive plenty of advice and support from the staff at the Royal and may feel that you can recover well in a more homely environment. If you become ill at any time you will be admitted to the Oncology Inpatient ward.

If outpatient care is not possible you can be admitted for part of or the entire period of the transplant process. Patients who live more than 40 minutes travel time from the hospital will be provided with suitable accommodation for themselves and their carer.

At the pre-assessment the BMT coordinator will speak to you about your personal circumstances and your general state of health. She will educate you and your carer or family member regarding the transplant. You may be referred for assessment by other members of your transplant team such as the Social Worker and dietitian and your doctor may request some screening investigations.

You will be provided with information regarding the type and side effects of the conditioning chemotherapy that you will receive. The chemotherapy protocol can consist of one or more days of treatment and can vary according to the disease and individual.

Financial and social issues may become important at this time and please feel free to talk to our social worker who will be able to provide you with appropriate information and referrals.

Emotional support can be provided to you and/or your family by our psychologist. Please feel free to ask any members the medical or nursing staff to arrange an appointment for you.

It is important to look after your teeth prior to the transplant as dental or gum problems could become a site for infection. We may ask you to visit your own dentist for an assessment before your transplant. If you do not have a regular dentist we can arrange a review for you here at the Royal. The BMT Coordinator will discuss this with you at the pre-assessment.
Central Venous Access Device

The stem cells are reinfused intravenously, like a blood transfusion. You may already have a long term device of a type which may or may not be suitable and this will be discussed at your pre-assessment. Otherwise the most suitable intravenous device for your circumstances will be discussed with you and arrangements made.

The Transplant

Whether you are admitted or are an outpatient a family member is welcome to sit with you.

Intravenous fluids will be given through your venous access device and premedications, similar to those used for chemotherapy. There will be a nurse and hospital scientist at your bedside and the resident doctor will be on the unit during the reinfusion. The stem cell scientist will bring the cells into your room in a trolley containing a water bath. Your identity will be checked, the cells will be defrosted at the bedside, connected to your IV line and infused over about 20 minutes. Most patients tolerate the reinfusion well and everything goes smoothly. Rarely the thick cells may only move slowly through your IV line and the nurse may need to flush them to keep them running.

The DMSO mixed with the cells is a sulphur-based substance and has the potential to cause allergic reactions or nausea. If you feel nauseated, flushed, develop shortness of breath or back pain, tell your nurse immediately.

You may experience an unpleasant garlic-type or sweet corn taste as the stem cells are being reinfused. This is the DMSO and we advise that you bring a packet of mints to suck during the reinfusion to mask this taste. The odour of the DMSO will exude through your skin pores for the next 24 to 48 hours and in some cases is quite noticeable, but not unpleasant. You may need to explain this to any visitors.

Daily Review

Following the transplant, if you are an outpatient, you will need to visit the hospital daily while your new blood stem cells engraft. If you are admitted the medical and nursing staff will review you daily. The engraftment phase is the time between the chemotherapy having stopped blood production in the marrow and the stem cells becoming fully mature. Because the blood stem cells are autologous your body will recognise them as normal and encourage their growth. Daily injections of G-CSF also promote this process.

This is the period of time when you are most vulnerable to the side effects of the chemotherapy and potential complications from bone marrow suppression. Your white blood cells (neutrophils) will recover first, by about day 10. Your red blood cells and platelets may take a few days longer to recover. Each day following the transplant you will have blood tests and be reviewed by a nurse and resident doctor. They will assess you for symptoms related to the transplant and review the blood tests which will show how your blood is changing and show if your blood chemistry or other organs are being affected. You will need to be reviewed daily until your doctor tells you that your bone marrow has recovered, you may still need fairly frequent visits, but these will gradually be reduced.
Transplant Side Effects

Different chemotherapy protocols are prescribed for different diseases so these can vary, but there are general side effects which are relevant to them all. These will be discussed at your pre-assessment, otherwise the following provides a general idea.

Managing Transplant Side Effects

Hair Loss
The chemotherapy may cause your hair to fall out. This is temporary but can be distressing. You can be provided with a wig or other head coverings at the hospital. Please ask for a referral if this has not been provided for you already.

Nausea and Vomiting
Most chemotherapy protocols do cause nausea and possibly vomiting however effective medications are given to reduce the risk of severe nausea occurring. Your taste may be altered so it is advisable to avoid spicy, acidic foods which may contribute to nausea or irritate your stomach.

Managing Nausea and Vomiting
• It is better to prevent nausea and vomiting than to try to relieve it once it has begun.
• Take your preventive medication when you wake up, even if you feel well, swallow whole, with water.
• Unless you are feeling completely well and are eating normally you also need to take your relieving medication regularly according to the instructions on the box.
• You need to be drinking about 8 cups or 2 litres of fluid a day to prevent dehydration. If you do begin vomiting and are not able to keep enough fluid down you may need to come into hospital.
• Please describe to your doctor and nurse how you feel and how much you are eating and drinking. We may treat or prevent dehydration by giving you intravenous fluids while you attend the outpatient unit and/or change your medications. Severe vomiting would require hospital admission.

Bowel Changes
You can develop diarrhoea as a side effect of the chemotherapy or if you pick up an infection. Occasionally, you could become constipated. Once again it is important to deal with this early.

Managing Bowel Changes

Diarrhoea
• If you have diarrhoea and you are an outpatient it is important to keep drinking fluids even if you cannot manage food so that you don’t become dehydrated.
• Each time you pass a loose stool you must drink a cup of fluid.
• Please mention any diarrhoea to your medical team as soon as it occurs.

Constipation
• Constipation can be extremely uncomfortable or painful, make nausea worse or cause bleeding from the bowel particularly if you have haemorrhoids.
• It is important to mention this symptom early to your nurse or doctor who can give you medications to treat the constipation.
• It is important to not tear the bowel mucosa as this could lead to you developing a fever. Avoid inserting haemorrhoid creams or enemas during the engraftment phase.
Mucositis
The fine skin lining the mouth, throat and gut can become inflamed following the chemotherapy. This can vary from mild to occasionally severe cases. During your daily review your mouth will be assessed and you will be questioned to assess if you have any pain or difficulty swallowing.

Managing Mucositis
• We recommend that you use a soft, clean toothbrush, brushing your teeth with gentle circular strokes twice/day while avoiding the gums.
• The effect of keeping your mouth clean and moist is more important than using a particular mouthwash product, so please use commercial mouthwashes only provided by the hospital as others may contain alcohol. Alternately you can rinse your mouth out with warm water mixed with a teaspoon of salt or bicarbonate soda. You need to rinse your mouth out after each meal and before bed.
• If you have dentures please ensure that they don’t apply pressure to your gums and ensure that they are free of any debris after meals. It is important to keep them very clean so soak them in a dental antiseptic solution while they are out. It is best to leave your dentures out as much as possible except for meals and visitors.
• Avoid hot food and drinks and acidic, crunchy or sharp textured foods which may sting or cut your mouth.
• Frequent sips of water, sucking ice, chewing sugarless gum or sucking soft sugarless lollies may all help.
• If you do develop mucositis your medical team will provide you with more mouthwashes and pain relief.
• Severe mucositis could lead to your being admitted to hospital for pain relief and nutritional support.

Nutrition
The effects of nausea, diarrhoea, mucositis or altered taste can lead to poor nutrition and weight loss. Your medical team will be assessing you for these effects on a daily basis. A referral to the dietitian can easily be arranged and nursing staff can supply you with nutritional supplements.

Maintaining Good Nutrition
• You will probably only be able to manage bland foods once you have started the transplant process or tasty foods which you are already accustomed to.
• It is a good idea to freeze small amounts of your favourite foods such as soups or nutritious puddings beforehand.
• You probably won’t be able to sit down to 3 large meals a day and may find it easier to snack on small amounts of high calorie/ high protein food.
• If you have mucositis you may be able to only eat soft or pureed foods.
• Include plenty of protein, such as meat, chicken, fish, eggs, dairy products.
• Include carbohydrates for energy such as bread, rice, pasta.
• Include fruit and vegetables, fruit may be more palatable lightly stewed and extra calories can be added with custards, jellies, ice cream etc.
• You can add meat, pasta, and rice to soups to provide more calories without greatly increasing the volume. Soups then also still appear appetising if they need to be pureed.
Safe Food Handling
- It is best to use fresh foods or those which you have fresh frozen.
- Defrost foods in the microwave or fridge rather than leaving out on a bench.
- Store perishables in the fridge and non perishables in clean containers.
- Wash hands prior to handling and use clean utensils and work surfaces.
- Protein containing foods such as meat, chicken, eggs need to be cooked thoroughly.
- Fruit and vegetables, especially salad vegetables need to be rinsed before use.
- Avoid reheated meals, leftovers, takeaways, especially chicken and sushi.
- Avoid soft cheeses.

Fatigue
The combined effects of chemotherapy, low blood counts and poor nutrition may cause you to feel extremely fatigued.

Managing Fatigue
- You may need to rest frequently and may find activities such as showering or the daily trip to the hospital to be extremely taxing.
- Your carer can assist you by providing your meals and a quiet restful environment.
- Try to pace yourself and rest frequently so that you save some energy for activities you enjoy.
- A short walk in the fresh air may also help if you can manage it.
- If it is at all possible, sitting in a pleasant shady spot outside or in a room with a view where you can see flowers, trees, sky or a water feature may lift your spirits and energise you.
- Try not to sleep for long periods during the day so that your sleep patterns do not become altered.
- If you have trouble sleeping at night please discuss this with your medical team.

Neutropenia
The neutrophils are a type of white blood cell which destroy bacteria and are absent during the engraftment phase. Developing an infection during this phase can be life threatening and requires prompt treatment.

Avoiding Infections
- Check your temperature every 4 hours during the day and use your ‘Alert card’ if you have a temperature of 38 degrees or above.
- Protect the lining of the mouth as previously mentioned.
- The skin is our first line of defence against invading organisms so it is important to avoid injuries especially from dirty sources such as scratches from gardening or pets.
- Advise family and friends that they should not visit you if they are sick.
- Avoid crowded public places.
- Maintain good food hygiene.
Blood and Platelet Transfusions

Your daily blood tests will show whether you require transfusions of red blood cells to reverse anaemia or platelets to prevent or treat bleeding.

Signs and symptoms of anaemia include pale looking skin, fatigue, shortness of breath on exertion and dizziness. Please inform your medical team on your daily visits if you experience any of these.

A low platelet count may cause spontaneous bleeding such as a nose bleed or bruising. Small purple dots on the skin could also be tiny bruises and if you have any of these please show your doctor or nurse. If your platelet count drops to a very low level or you have any bleeding we will give you a transfusion of platelets during your daily review. However if you develop any bleeding at all in between visits you must attend the Emergency Department and contact the oncologist on call.

Avoiding Bleeding

• Clean your teeth gently.
• Avoid injuries with sharp objects.
• Use an electric shaver.
• Inform your medical team if you develop constipation.

Fertility

High dose chemotherapy can affect your fertility, damage reproductive cells and harm a developing foetus. It is important to avoid pregnancy during this process. Please discuss any issues with your doctor or nurse.

Emotional issues

Your mood may be affected and you may feel quite ‘down’ or anxious during this time which is a normal response. Severe illness has an enormous impact upon an individual and their family and can strain family relationships and finances. Physical symptoms such as nausea, anaemia and fatigue may contribute to a person’s emotional response to the transplant. While your blood counts are at their lowest is usually the time that most people also feel at their lowest emotionally. At any time during the transplant process including after recovery you can speak to your medical team about how you or a member of your family may be feeling. You can also be referred to our psychologist and social worker who are readily available to assist you.

As you start to recover physically you may also recover emotionally. Many patients who undergo an autologous transplant do indeed ‘bounce back’ and quickly recover and return to their normal lifestyle within weeks. Some patients are troubled with ongoing physical problems such as fatigue which may take several months to resolve. Some people experience ongoing depression, worry or anxiety about the future, harbour fear of the disease returning, or have work or relationship difficulties. In this case it is wise to seek professional help through your hospital or General Practitioner.
Returning Home
If you live outside of the southern region you will be advised by your transplant doctor when it is safe for you to return home. Your local specialist will then take over your care again.

The Royal Hobart Hospital maintains a confidential data base on all our transplant patients so that we can use this data to continually improve the standard of care. We will ask you to attend two follow up appointments with your specialist to assess your recovery and record this data on day 30 and day 100 post-transplant. Otherwise your own consultant will look after you in the long term. Your doctor may recommend a revaccination schedule, including an annual influenza vaccination.

Some patients encounter practical or emotional difficulties returning to their normal lifestyle following a long period of intensive medical care. Some individuals relish the return to normal while others can encounter a sense of being left adrift when all the hospital visits are suddenly over. If you need to, you can seek assistance from your medical team and there are some community organisations such as The Leukaemia Foundation and Cancer Council Support groups may also be of assistance.

Useful Telephone Numbers

Statewide BMT Coordinator
Gill Sheldon-Collins
Telephone: 03 6166 8078
Mobile: 0418 136 192

8A Day Chemotherapy Unit RHH
Telephone: 03 6166 8708
Oncology Triage Nurse (9:00am - 4:00pm)
0429 009 217

1A Oncology Clinics RHH
Telephone: 03 6166 6655

LGH WP Holman Clinic
Telephone: 1300 667 674

Addresses

HOBART
Day Chemotherapy Unit
8th Floor A Block
Royal Hobart Hospital
48 Liverpool Street
Hobart TAS 7000

LAUNCESTON
WP Holman Clinic
Launceston General Hospital
1st Floor
Charles Street
Launceston TAS 7250

Useful Internet Addresses

Cancer Council of Tasmania
www.cancertas.org.au

Cancer Institute of NSW
www.cancerinstitute.org.au

Cancer Council of Australia
www.cancer.org.au

Australian Organisation for Young People Living with Cancer
www.canteen.org.au

Leukaemia Foundation of Australia
www.leukaemia.org.au

Lymphoma Australia
www.lymphoma.org.au

Myeloma Foundation of Australia
www.myeloma.org.au

MacMillan Cancer Support
www.macmillan.org.uk (UK information site)
Statewide BMT Coordinator
Gill Sheldon-Collins
Telephone: 03 6166 8078

HOBART
Day Chemotherapy Unit
8th Floor A Block
Royal Hobart Hospital
48 Liverpool Street,
Hobart TAS 7000
Telephone: 03 6166 8708

LAUNCESTON
WP Holman Clinic
1st Floor
Launceston General Hospital
Charles Street
Launceston TAS 7250
Telephone: 1300 667 674
03 6777 6150

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