AUTOLOGOUS
BONE MARROW TRANSPLANT

A PATIENT'S GUIDE

Autologous Bone Marrow Transplant: A Patient's Guide
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Introduction

Dear Reader,

As a bone marrow transplant (BMT) patient there is a lot of new information to absorb, and a lot of terminology associated with BMT, some of which is confronting and confusing. For those of you who have not required previous treatment, or have only had a little, much of the information will be new, and sometimes scary. This book aims to put the information that you receive from your doctor into easy to understand language and allow you to read at your own pace.

The book has been written for patients, and their families, with the help of patients who have undergone BMT and members of the team who care for patients undergoing BMT – doctors, nurses, social workers and dieticians – to help other patients and their families understand the process.

Arrow Bone Marrow Transplant Foundation is delighted to support the publication of this book, as it provides an outstanding reference for any patient or carer undergoing a bone marrow transplant and is an important part of our patient support program.

Arrow Bone Marrow Transplant Foundation is a charitable organisation focused on improving the quality of life for all people needing a bone marrow transplant. We do this by providing financial assistance and information to patients, their families and carers; as well as supporting the educational and professional development needs of nurses and other healthcare professionals working in the transplant field; and investing in medical research that improves bone marrow transplant patient outcomes.

We hope you find this booklet to be a valuable resource. For more information about Arrow and how we can assist you through your journey of treatment, or how to donate, please see the last page of this book or visit www.arrow.org.au.

Yours sincerely,

RKoller

Richelle Koller
Chief Executive Officer
Arrow Bone Marrow Transplant Foundation

Foreword

This book provides information to help you understand the bone marrow transplant (BMT) process and to help you cope. It is important to remember that this guide is not meant to take the place of discussions you should have with your BMT team – it is to help you to understand those discussions.

The term BMT is a general term used to cover all types of transplants using haematopoietic stem cells – peripheral blood stem cell transplant (PBSCT), haematopoietic stem cell transplant (HSCT) and bone marrow transplant.

Patients have a wide range of information needs – some will want to know more than others. For those who just want the key points, chapter 1 is written as a stand-alone chapter, covering the basics of the BMT process. For those who want to know more, later chapters provide detailed information about the process introduced in chapter 1.

This book covers many important aspects of the BMT process, including collecting stem cells, how a transplant happens and what occurs afterwards, complications and side effects, and how a transplant can affect people's lives in the long term.

We have written this book using lay language and have tried to avoid technical jargon as much as possible. However, it is important to include a variety of medical and scientific concepts that have direct relevance to BMT. Some of these may prove to be distressing or disturbing if you are considering having a transplant, so it's important to talk through these issues with your BMT team.

The material covered in this book is by necessity general in nature and does not apply to each patient or treatment hospital. The circumstances of each person being considered for a transplant vary widely, depending on age, the type and stage of the underlying blood disease being treated, and what treatment has been given previously. All these factors have an important influence on how the transplant is done and the risks and chances of success. These issues are not covered in any detail in this book, so you must go through these possible risks and benefits with your transplant doctor.

It is important to remember that autologous BMT is a relatively safe procedure. This book covers all the possible risks and complications of the procedure, but this does not mean you will get all or any of them. Your doctor will talk to you about your exact risk and expected complications, which may depend on your overall health before the transplant.

If you decide to have a transplant, you are entitled to ask for a copy of the treatment protocol that will be used to guide therapy during your hospital stay and after discharge.

Contents

A Blood & Marrow Transplant & Cellular Therapies Network NSW initiative

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A collaborative effort of the
BMT+CT Network NSW

Blood & Marrow Transplant
& Cellular Therapies Network

arrow
THE BONE MARROW
TRANSPLANT FOUNDATION

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Arrow Bone Marrow Transplant Foundation

CHAPTER 1

The Basics of Bone Marrow Transplants

Bone marrow transplant (BMT) was first used with good results in 1968. Since then, it has been used for patients with blood diseases such as leukaemia, lymphoma and multiple myeloma, as well as for some patients with immune diseases and, occasionally, solid tumours.

What is bone marrow?

Bone marrow is the soft, spongy part in the centre of your bones where blood cells are produced. The bone marrow contains stem cells, which are early-stage cells that produce other cells. Each tissue in the body contains stem cells that renew and replace that tissue when needed due to damage or wear and tear. Haematopoietic (blood) stem cells generate all blood cells in the human body, including red cells, white cells and platelets.

What is a BMT?

BMT is a general term used to cover all types of transplants using blood stem cells whatever the source – peripheral blood stem cell transplant (PBSCT), haematopoietic stem cell transplant (HSCT) and bone marrow transplant.

A BMT is a treatment option for some people who have life-threatening blood or immune system disorders.

It allows doctors to use high doses of chemotherapy and radiotherapy to increase the chance of a cure in diseases such as lymphoma and leukaemia or to control the disease in multiple myeloma. A BMT replaces bone marrow stem cells in people whose bone marrow has been destroyed by large doses of chemotherapy or radiotherapy.

The healthy stem cells are put into your body intravenously, and then find their way into your bones to become healthy marrow. The transplant of healthy stem cells rescues you from your chemotherapy, and/or radiotherapy, by enabling your bone marrow to start making new red and white blood cells and platelets.

Types of BMT

Autologous transplant

An autologous transplant, or reinfusion, uses your own stem cells and is the focus of the book.

This type of transplant can be done if the disease:

- responds to chemotherapy
- is in remission, or
- does not involve the bone marrow (e.g. Hodgkin's or non-Hodgkin's lymphoma, multiple myeloma or acute myeloid leukaemia)

Before an autologous transplant, stem cells are collected from the patient's blood or occasionally bone marrow, frozen and stored, and then given back after high-dose chemotherapy or radiotherapy.

Allogeneic transplant

This type of transplant uses stem cells donated by another person (a donor), either a family member or unrelated donor.

This book does not describe allogeneic BMT in detail. For more information about allogeneic transplants, see the BMT&CT Network NSW publication, *Allogeneic Bone Marrow Transplant: A Patient's Guide.*

Preparing for a BMT

The BMT team

An expert team of doctors, nurses and other support staff will care for you. The team can quickly identify and treat any problems or side effects. BMT programs also give patients and their families emotional and psychological support before, during and after the transplant.

For a BMT to work well, you must be healthy enough to cope with the procedure. When deciding if you should have a BMT, your doctor will consider your age, general physical condition and the type and stage of your disease.

The work up

Before a BMT, a number of tests are carried out to ensure you are healthy enough for the treatment. You will also have tests of heart, lung and kidney function before and after the BMT so your doctor can check whether these organs are still working as well after the transplant. The pre-BMT tests (also called "the work up") are usually done before you are in hospital, but may be done after you are admitted.

You will need to have a dental check-up and all necessary work done before the BMT. If you or your dentist are unsure, please check with your BMT team before any work is started.

Making informed decisions

Gathering information

When you are considering a BMT, you will be given a lot of information about the process. Some people do in-depth research and think through every detail, while others just want enough information for the next day or stage. Some people only want to know enough to be informed, and choose not to read or listen to anything negative so they can stay motivated and focused.

A BMT is a complicated procedure, so it is vital you are informed and that you clearly understand what the BMT means for you. This requires good communication with your BMT doctor and the rest of the team.

Mostly you will have your BMT at the hospital where you had your disease treated, so you may already know the treatment team.

When the BMT team first discusses the possibility with you, you will receive a lot of information about the proposed BMT, its side effects and possible complications. To help you absorb this information, it can help to take notes during the consultation or record the discussion. Many people like to have a relative or friend go with them, to take part in the discussion, take notes or just listen.

If you don't understand what you've been told, don't be afraid to ask questions or to ask for the information to be repeated as often as you need. Questions are a good sign that you are working in partnership with your medical team. It is very important to be involved in your care and to express your concerns before, during and after a BMT. Your role is crucial, particularly in telling the team about how you are feeling and any symptoms you are having.

In the days before the BMT, you will need to sign a number of consent forms for the treatment or clinical research.

Finally, remember that not everyone will want to go ahead with a BMT. After thinking about all the possible risks and benefits, some people decide it is not for them. In this case, you need to tell your doctors and talk to them about other treatments. Your doctor will still give you the best other treatment options available.

How is a BMT done?

Collecting bone marrow stem cells

There are two ways of collecting stem cells for autologous BMT – from your blood or your bone marrow. Your BMT doctor will discuss both procedures with you, as it is not always possible to predict how your stem cells can be collected. Most patients have their stem cells collected over one or several days using an apheresis machine, which is similar to a kidney dialysis machine. This process is known as a peripheral blood stem cell harvest. During the harvest, the stem cells are separated from the other cells in the blood and collected in a bag on or in the apheresis machine. The rest of the blood is returned to you.

Harvesting of your stem cells occurs:

- After the administration of chemotherapy followed by the injection of a synthetic version of a naturally occurring growth factor (G-CSF) for about 10-14 days. This then stimulates the bone marrow to send the stem cells out into the bloodstream so that they can be collected during a limited time period – often 10-14 days after the chemotherapy.
- After the administration of G-CSF alone for about 4-5 days.

If the collection of stem cells from your blood is not successful, your BMT doctor may decide to collect them from your bone marrow, after discussion with you. This is known as a bone marrow harvest. This type of harvest is done in the operating theatre under general anaesthetic.

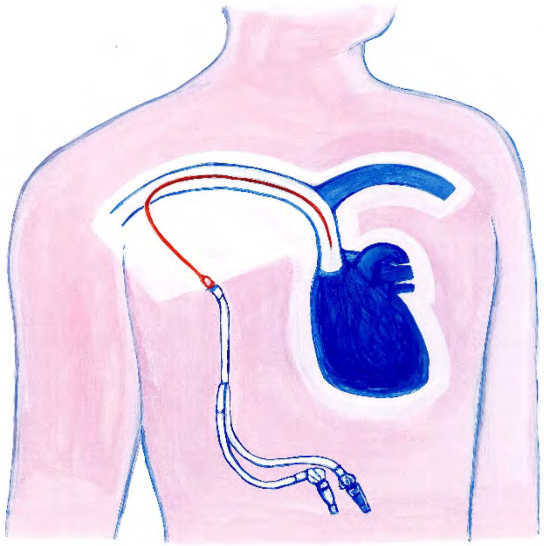
Whichever way your stem cells are collected, they are tested to make sure there are enough cells to do a BMT and that they are free of infection. The cells are then frozen, using a special drug (DMSO) to protect them, until the transplant.

The central line

If you don't already have one, a central venous catheter may be inserted under the skin of your chest, or through the crook of your arm, into a vein. It is also called a central line, Hickman catheter or PICC (peripherally inserted central catheter) depending on the type of line.

Some patients who have good veins and are considered to be at low risk of complications may have a temporary cannula put into the hand or arm as required. Your team will discuss your options with you.

A central line is a long, hollow tube that usually has two or three passages (called lumens) to allow for a number of uses. It is made of silicone or hard plastic. Your central line will stay in place during the BMT and may be used to collect blood samples and to give you all the medications and fluids you need. Central lines are mostly inserted into a large vein that runs beneath your collar bone or into a vein in the crook of your arm with the tip sitting near the entry into your heart. Some of the central line remains outside your body for easy access. A clamp keeps the tube closed when it is not being used. The central line may be put in when you are in the operating theatre, in the x-ray department or on the ward.



An example of a central line in position – a Hickman catheter.

Conditioning treatment

You will have several days of chemotherapy and/or radiotherapy, which destroy bone marrow and cancerous cells and make room for the healthy stem cells. This is called the conditioning or preparative regimen.

You may also hear the phrase ‘countdown to transplant’, because this treatment is expressed in your medical notes in terms of the number of days until the transplant. For example, day-5 (minus 5) means that you are five days away from the transplant day, which is called day 0. The type and number of days of chemotherapy and/or radiotherapy vary according to the disease being treated, your physical condition and the protocol or preferred treatment plan of the hospital where the BMT is being done.

Often the dose of chemotherapy and/or radiotherapy given to patients during conditioning is much stronger than doses given to patients with the same disease who are not having a BMT. You may become weak, irritable and nauseous. Anti-nausea medications will help during this period. Don’t be alarmed if your blood results go down at this time, as this is what the chemotherapy or radiotherapy is supposed to do, that is, empty your bone marrow before your transplant.

The transplant

The transplant will take place a day or two after the chemotherapy and/or radiotherapy. The transplant is not a surgical procedure. It takes place in your hospital room, not an operating room.

Before the transplant, you may be given medication to prevent a reaction to DMSO, the preservative used to protect the frozen cells. The DMSO can cause an unpleasant taste in the mouth and sometimes cause a sensation of scratching on the throat, so it may be useful to suck mint sweets throughout the infusion.

The healthy bone marrow stem cells are infused through your central line, in much the same way that any blood product is given.

Many patients describe the actual transplant as an anticlimax, as it is all over so quickly – usually between 30 minutes and an hour.

You will be checked frequently for signs of fever, chills, hives and chest pains while the bone marrow is being infused.

The DMSO results in you giving off a distinctive smell for a couple of days. You may not be aware of the smell yourself, but visitors may comment on the "fishy" or "sweet corn" smell in the room.

When the transplant is completed, the days of waiting begin.

The bone marrow begins to grow (engraftment)

Engraftment means new cell growth. It takes place after your bone marrow transplant when there is a sustained rise in new blood cell production. As a general guide, engraftment is said to have happened once the white blood cell count rises above 0.5 x 10 9 /L and the platelet count to above 20 x 103 /L without transfusion.

The 10 days to three weeks after the transplant, before engraftment, are the most critical. The high-dose chemotherapy and/or radiotherapy given to you during conditioning has destroyed your bone marrow, crippling your immune or defence system, and leaving your body with no natural defences against infection.

As you wait for the transplanted bone marrow to migrate to the cavities of the large bones, engraft and begin producing normal blood cells, you will be very susceptible to infection and excessive bleeding.

While many infections start from within the body, your BMT team will take a number of precautions to minimise your exposure to viruses and bacteria in your environment. These will vary from centre to centre. Visitors and hospital personnel will wash their hands with an antiseptic and may wear protective gowns, gloves and/or masks while in your room.

Any visitors or relatives will be asked not to visit if they are unwell e.g. if they have a sore throat, runny nose, a cold/flu or upset stomach. Fresh fruits, vegetables, plants and cut flowers, which often carry fungi and bacteria that pose a risk of infection, may not be allowed in your room.

Blood samples will be taken daily to monitor engraftment and organ function.

When the transplanted bone marrow engrafts and begins producing normal blood cells, you will gradually be taken off the antibiotics, and blood and platelet transfusions will generally no longer be required.

Some hospitals have an early-discharge program where eligible patients are discharged within a day or two of transplant. If this is available at your hospital, it will be discussed with you. A team follows up early-discharge patients at the day ward of their hospital, at the patient's home or a combination of both.

Some hospitals offer delayed admission for transplant. This means conditioning treatment and transplant are done as an outpatient. Admission is then arranged when your white cell counts become low.

Once the bone marrow is producing a sufficient number of healthy red blood cells, white blood cells and platelets, you will be discharged from the hospital, provided no other complications have developed. BMT patients typically spend 2-4 weeks in hospital.

How you may feel physically during the transplant

A BMT is a physically, emotionally and psychologically taxing procedure for you and your family. Seek as much help as you need to cope – toughing it out on your own is not usually the best way to cope with the transplant experience.

At times, you may feel very sick and weak during the transplant. Walking, sitting up in bed for long periods of time, reading books, talking on the phone, visiting with friends or even watching TV may require more energy than you have. Complications, such as infection and bleeding, can develop after a bone marrow transplant. Pain is usually controlled with medication, which may include the use of intravenous morphine or other narcotic drugs. In addition, mouth and throat sores can develop that make eating and swallowing uncomfortable and difficult. Temporary mental confusion sometimes occurs, due mostly to either fever or drugs. This can be frightening but it is temporary. The medical and nursing staff will help you and your carers deal with these problems.

Dealing with emotional and psychological concerns

Being diagnosed with a life-threatening illness can be a traumatic experience. It is common to feel overwhelmed by the amount of information you receive and the need for urgent treatment. Each person feels differently and responds differently. People will find some aspects of the treatment process more stressful than others.

It is important you know that BMT is a team effort and that you are the central and most important person in this team. Understanding your treatment plan and clear communication are essential elements in maintaining your emotional and psychological well-being. People often say it is the unexpected symptom, complication and treatment that upsets or frightens them the most. A BMT already involves a degree of uncertainty. Poor communication can add unnecessary stress to this situation. Don't hesitate to clarify any aspect of the process.

People will vary in the amount of information they want about the transplant. Some will want to speak to others who have been through a BMT. Some will want to be well researched on all aspects of the transplant process. Others will only need to have minimal facts about their proposed treatment. Whichever category you fall into, it will be important for you to have all the information you need about your treatment before the transplant.

You may find that you feel isolated, with little control over your day-to-day activity, because of the precautions taken to guard against infection while your immune system is not working properly. You will be in a single room and the number of visitors you can have at one time is restricted.

Make your bed or room your own space with your personal effects. Try to stay as independent as you can and talk to your nurses about how you can participate in your care. Lack of privacy is another common issue for people having a BMT. Talk to your nurse about allocating times when you will be as undisturbed as possible. Waiting for the transplanted stem cells to engraft, for blood counts to return to safe levels or for side effects to disappear can be very frustrating and can lead to increased stress. Try to remain positive and be realistic in your goals. BMT is an individual process that cannot be predicted all of the time.

You may find that personal relationships with family and friends come under pressure during BMT. This is not uncommon. Relationships within families will change, and it is important to recognise what these changes will be. Talk to the BMT social worker if you need help.

Each family member or close friend will cope with your BMT in their own way and this may, at times, lead to misunderstandings or conflict. Just because a family member or friend is not visiting does not mean they don't care. They may just be taking some time out as their way of coping.

Psychological discomfort, like physical discomfort, is a normal symptom of the BMT experience. Social workers and psychologists/psychiatrists are also part of your BMT team, so call on them when you need help. There is no right or wrong way to manage all the challenges and stresses that BMT throws at you. There is only the method that works for you.

Going home

Recovering from a BMT continues for some months after you leave hospital. For the first few weeks you may be too weak to do much more than sleep, sit up and walk a bit around the house. You will need to visit the hospital or clinic regularly so your BMT team can monitor your progress and administer any medications and/or blood products needed.

It will take at least six months before you will be ready to return to work or your normal daily activities. You'll need lots of patience and determination to cope during this period. Some people find that reaching their 'new normal' takes longer than others.

Your new marrow is still in its infancy and is not yet able to protect you from some bacteria and viruses encountered in everyday life, so it is important to protect yourself from potential sources of infection. Enjoy the outdoors, dine alfresco, keep sick friends and relatives away, see movies and do the shopping at quiet times. You can get back to a normal life; you just have to take a little extra care.

Life after BMT

Life after transplant can be both exhilarating and stressful. On the one hand, it is exciting to be alive after being so close to death and many people find their quality of life has improved after transplant.

But there is always the worry that a relapse will occur. Also, innocent statements or events can sometimes conjure up unpleasant memories of the transplant experience long after recovery. It can take a long time to come to grips with these difficulties. Tell your BMT team about any difficulties you experience.

Frequently asked questions

What is a bone marrow transplant (BMT)?

A BMT is a standard treatment option for some people who have life-threatening blood or immune system diseases. It is the process of replacing unhealthy bone marrow cells (stem cells) with healthy bone marrow cells. The healthy bone marrow cells are re-infused intravenously after very strong chemotherapy and/or radiotherapy, which kills your unhealthy bone marrow cells. The re-infusion of healthy bone marrow cells essentially rescues you from your chemotherapy and/or radiation by enabling your bone marrow to start producing new red and white blood cells and platelets.

Are there different types of BMT?

Yes, there are two different types of BMT.

This book focuses on autologous bone marrow transplant, which uses your own blood stem cells.

An allogeneic BMT involves finding a donor whose tissue type is closely related to yours – the donor can be related or unrelated. Cord blood stem cells are increasingly used in allogeneic BMT. Allogeneic transplants are not discussed in this book.

What is the difference between a BMT and a peripheral blood stem cell transplant?

Both transplants aim to do the same thing – replace bone marrow stem cells in a person who has had their bone marrow destroyed by large doses of chemotherapy and or radiotherapy.

Bone marrow is the spongy substance found in the hollow of bones of the hips, legs and arms. It contains stem cells (also called CD34 positive cells), which produce all circulating blood cells; red blood cells, white blood cells and platelets.

When the stem cells are collected from circulating blood, the transplant is called a peripheral blood stem cell transplant. A transplant with stem cells collected from the marrow, usually from the hip bone area, is called a bone marrow transplant.

Will I need an operation to have a BMT?

No, the stem cells will simply be re-infused through your intravenous line in the same way you receive transfusions such as platelets or red blood cells (packed cells).

What is engraftment and when will it happen?

Engraftment means new cell growth, and takes place after your bone marrow transplant when there is a sustained rise in new blood cell production. This generally occurs within 10-14 days after your transplant, but for some patients it takes longer. The first obvious sign may be a rise in your white blood cell count above 0.5. This tells us that your new bone marrow cells are starting to produce new blood cells. Until this time, you are at high risk of infection and need to avoid possible sources of infection.

What are the possible side effects of a BMT?

The two main risks from the transplant process are an increased risk of infection and bleeding due to high doses of chemotherapy and/or radiation. Short-term effects may include nausea, vomiting, fatigue, mouth ulcers, weight loss, hair loss and skin reactions. Long-term effects include infertility and possible complications in the liver, kidneys, lungs, joints and/or heart, although these complications are relatively uncommon after an autologous BMT.

What are my chances of having a successful BMT?

This is very difficult to answer as so many individual issues come into play. The outcome of your transplant is highly influenced by your original disease, the stage of your disease and your general condition at the time of the transplant. There are many other variables, including how you have responded to treatment. The best person to discuss your possible transplant outcome is your transplant doctor. He/she can discuss your individual factors that influence your chances of success.

Resources

Leukaemia Foundation

Free call: 1800 620 420

www.leukaemia.org.au

The Leukaemia Foundation has a team of trained patient support staff, who are available for patient care, family counselling, friendly advice, practical help or just simply understanding and personal empathy when it's needed most.

Services offered to people living with leukaemia and related disorders, and their carers include:

Information, education and support

- a telephone service, which includes counselling, information and education about diseases, treatments and their effects
- information booklets, courses and group workshops for people living with these illnesses
- talks to schools, community groups and workplaces.

Practical and financial support

- accommodation and other housing arrangements close to hospitals; offering a home away from home for you and your family during treatment
- transport services in some areas
- financial support offered in special circumstances, ranging from paying for an airfare for treatment or a utility bill.

CanTeen

Free Call: 1800 226 833

www.canteen.org.au

CanTeen provides support for young people aged between 12 and 24 who either have cancer, or are the siblings or children of someone who has cancer.

They provide counselling and individual assistance as well as information and peer support programs.

In October 2014, CanTeen launched a world first online support platform for young people living with cancer. This groundbreaking website combines 7 day access to professional CanTeen counsellors with 24/7 access to youth specific information and a personalised online peer community.

The Cancer Council NSW

Cancer Helpline: 13 11 20

www.cancercouncil.com.au

The Cancer Council NSW is a charity that provides information and support to people with cancer and their carers. It runs a Cancer Helpline, a free and confidential telephone information and support service. The Helpline, which is staffed by oncology health professionals:

- can answer questions on how to cope with treatment and side effects
- send you written information
- put you in touch with services in your own area
- offers emotional support.

The Helpline is staffed during business hours, or leave a message after hours and the staff will return your call. Only local call costs from anywhere in NSW.

For information in a language other than English, call the Telephone Translation and Interpreting Service on 13 14 50.

Department of Human Services

https://www.servicesaustralia.gov.au/individuals/centrelink Centrelink

multilingual: 13 1202

Disability, sickness and carers: 13 2717

Family Assistance Office: 13 6150

Youth and student services: 13 2490

NSW Department of Housing

Tel: 1800 152 152

https://www.facs.nsw.gov.au/housing

The NSW Department of Housing can help with rent assistance.

Look Good Feel Better

Tel: 1800 650 960

www.lgfb.org.au

Free workshops for women, men and teen’s having chemotherapy or radiotherapy for cancer, which teach beauty techniques to maintain self-image during cancer treatment.

Web resources

Australia

BMT+CT Network NSW	www.aci.health.nsw.gov.au
Arrow Foundation	www.arrow.org.au
Cancer Council NSW	www.cancercouncil.com.au
Leukaemia Foundation	www.leukaemia.org.au
Look Good Feel Better	www.lgfb.org.au
Australian Bone Marrow Registry	www.abmdr.org.au

NSW Health Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS)
www.health.nsw.gov.au/transport/Pages/iptaas.aspx

International

BMT resources/self-help websites	www.bmtinfonet.org www.bethematch.org www.nbmtlink.org www.leukemia-lymphoma.org

CHAPTER 2

All About Blood Cells

Blood is made up of many different kinds of cells, each with a specific function. Most blood cells are formed in the bone marrow and are released into the bloodstream at various stages of maturity. The function of each of the blood cells and their normal ranges are shown in **Table 1**.

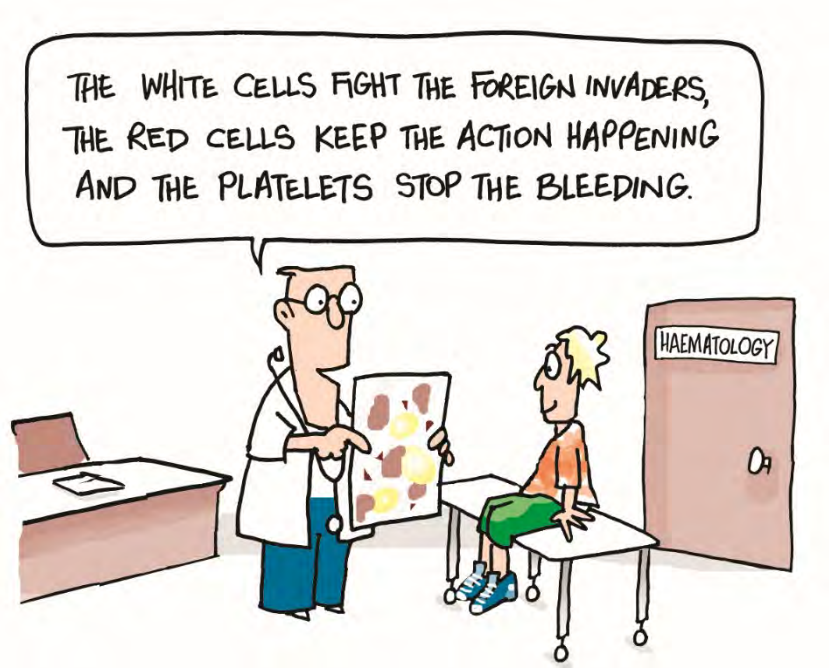


Table 1. Blood cell functions and blood tests

CELL TYPE	FUNCTION	BLOOD TESTS	NORMAL RANGE
Red blood cells, also called RBCs or erythrocytes	Contain a protein called haemoglobin, which carries oxygen from the lungs to all parts of the body and gives blood its red colour. Also pick up carbon dioxide and take it to the lungs to be breathed out.	Red blood cell count or RBC Haemoglobin or Hb: oxygen-carrying capacity	Males 4.5-6.0 Females 3.8-5.4 Males 131-180 Females 115-160
Platelets	Initiate blood clotting to stop bleeding	Platelet count	150 - 400
White blood cells, also called WBCs or leukocytes	Fight infection and protect the body against foreign organisms, including bacteria, viruses, parasites and fungi	White blood cell count or WBC Leukocyte differential count: proportions of the five main types of white blood cell	4.0-11.0 Neutrophils 60-70% Monocytes 3-8% Eosinophils 2-4% Basophils 0.5-1% Lymphocytes 20-25%
TYPES OF WHITE BLOOD CELLS:			
Neutrophils, also called neut or N	Ingest and destroy bacteria – first line of defence against infection	Absolute neutrophil count or ANC	2.0 - 8.0
Monocytes, also called mono	Ingest and destroy bacteria and fungi, and clean up cellular debris left behind after infection	Monocytes	0.1 - 0.8
Lymphocytes	Fight viral infections and help destroy other parasites, bacteria and fungi	Lymphocytes	1.0 - 4.0

Blood cell production

The body constantly makes new blood cells. In healthy adults, about 100 billion red cells and 400 million white cells are made each hour. The life span of mature blood cells is only a few days or months.

Almost all (95%) of the body's blood cells are made in the bone marrow; the rest are made in the spleen. While most blood cells made in the bone marrow are discharged directly into the bloodstream, one type of lymphocyte, T cells, first travel to the thymus gland (thus, the name T cells) where they develop further before being released into the bloodstream.

Stages of maturity

All mature blood cells come from very early stage cells in the bone marrow called pluripotent stem cells. This type of cell is able to make copies of itself. Pluripotent stem cells also make lymphoid and myeloid stem cells, which evolve into the different types of blood cells.

Like pluripotent stem cells, the myeloid and lymphoid stem cells can make copies of themselves as well as make early-stage blood cells. However, they are not able to make as many copies of themselves as pluripotent stem cells do, and they make fewer different types of offspring. The offspring of lymphoid stem cells can only turn into lymphocytes (T cells or B cells). The offspring of myeloid stem cells can only turn into red blood cells, platelets, or white blood cells other than lymphocytes.

The offspring of myeloid and lymphoid stem cells that can only turn into one type of mature cell are called committed progenitor cells. Cells that are almost mature are called precursor cells.

CHAPTER 3

Collecting bone marrow stem cells

There are two ways to collect stem cells for a transplant:

Peripheral blood stem cell (PBSC) harvest:

- where stem cells are collected from the circulating blood using a process called apheresis (next page)

Bone marrow harvest:

- where bone marrow is collected from bones, usually the hips, while the donor is under general anaesthetic.

Peripheral blood stem cells are the preferred source of stem cells for autologous BMT. It is not always possible to predict whether peripheral blood stem cells can be collected. Some patients may need to have stem cells harvested from their bone marrow. All possibilities will be discussed with you before the process of mobilisation is started (see below).

Peripheral blood stem cell mobilisation

Mobilisation occurs when the bone marrow increases production of stem cells, which then spill out into the circulating blood so they can be collected.

Your BMT doctor will decide on the best regimen to mobilise your peripheral blood stem cells. The regimen will depend on your diagnosis, previous chemotherapy and radiotherapy, and your general health.

What is G-CSF?

Granulocyte colony stimulating factor (G-CSF) is a synthetic version of a naturally occurring hormone. The hormone is not usually detectable in the body, but the immune system makes it in response to infection. Its natural action is to stimulate the growth of bone marrow stem cells, which can become white cells to fight infection. It also causes mobilisation of peripheral blood stem cells.

Mobilisation therapy

The choice of mobilisation regimens includes the following:
- G-CSF alone
- G-CSF plus chemotherapy
- G-CSF plus chemotherapy plus other agents

Most patients need G-CSF for 8-10 days to mobilise a sufficient number of stem cells. Depending on your diagnosis, you may have a course of combination chemotherapy and G- CSF injections. This treats the underlying disease and mobilises the stem cells into the circulating blood.

An example of a common regimen is cyclophosphamide chemotherapy plus G-CSF. You will be admitted to hospital for the cyclophosphamide chemotherapy (usually for one or two days). The G-CSF, which is given as an injection under the skin, can be given at home or in an outpatient clinic.

If you have already been treated with a lot of chemotherapy, your doctor may feel it is safest to mobilise your stem cells using G-CSF injections alone or in combination with another synthetic hormone such as stem cell factor, which is another injection under the skin. In this case the injections are given for four or five days rather than 8-10 days.

Side effects of G-CSF

If you haven’t had G-CSF before, you may notice side effects. These are mostly flu-like symptoms, such as aches and pains, fatigue and generally feeling a bit off.

Usually these symptoms are mild, but you may feel more unwell and need a simple pain- killer like paracetamol.

Some patients have more severe pain and may need stronger painkillers. Severe side effects are very rare.

The side effects of G-CSF usually go away within a few days of the drug being stopped.

Harvesting the stem cells – apheresis

As your blood counts recover, your blood will be monitored for the special marker on the bone marrow stem cells, known as CD34.

When your CD34 count reaches a certain level (usually 20, but your BMT doctor and the apheresis nurses will decide) your stem cells will be collected using an apheresis machine. Apheresis means skimming off stem cells from the blood to be used for BMT and then returning the remainder of the blood to you.

Most patients are able to have their stem cells harvested by apheresis. However, this won't be possible for some patients because of their particular disease, and the type and amount of past treatment.

Also, in some patients, the bone marrow stem cells don't mobilise and they may need to have a bone marrow harvest (see next page).

Peripheral blood stem cells being collected.

What happens during apheresis?

Usually, a cannula or needle is put into a large vein in each of your elbows and connected by tubes to the apheresis machine. The blood is taken from one arm and put through the machine. The white blood cell layer (where the stem cells reside) is separated from the rest of the blood, which is returned to you through the other arm. Sometimes it can be difficult to find veins suitable for the apheresis procedure. If this is the case, a central venous line will be placed into one of the large veins in your neck or groin.

This central line (called a vascath) is in place only for a short time and is removed when sufficient cells have been harvested.

The apheresis machine will process 10-20L of blood during the harvest, depending on your height, weight, blood results and hospital practices. At the end of the procedure the bag of stem cells (100-250mL) will be sent to the laboratory for processing and testing for stem cell numbers.

The collection process, or "harvesting", is usually done as an outpatient procedure and can take at least 4 hours.

Usually you can go home as soon as you feel ready. Before you leave you will be given instructions about what happens next.

Some patients need apheresis for 2-3 days to obtain enough stem cells for a BMT so it is important to take the G-CSF until you are told to stop.

Side effects of apheresis

Apheresis is a very safe procedure and is usually completed without incident, but there may be minor side effects.

- Pins and needles: Some people experience tingling (pins and needles) around their mouth or in their fingers or toes. This is due to a decrease in calcium levels in the blood, which is caused by the anticoagulant solution (citrate) that stops the blood clotting in the machine. It is easily fixed with a calcium replacement. Tell the apheresis operator as soon as you experience any tingling.
- Faintness: More rarely some people feel faint while on the machine due to low blood pressure. If this happens, the collection will temporarily be stopped until your blood pressure has increased.

Bone marrow harvest

Before your bone marrow harvest, you may be given G-CSF injections for 4-5 days to boost the number of CD34 cells in your marrow. Your doctor will discuss this with you.

What happens during bone marrow harvest?

Bone marrow harvests are performed in the operating theatre under general anaesthesia. They involve little risk (mostly associated with the general anaesthetic), but some discomfort.

While you are under anaesthesia, a needle is inserted into the cavity of your rear hip bone – or "iliac crest" – which contains a lot of bone marrow. Rarely marrow may need to be collected from the sternum or chest bone.

The bone marrow, which is a thick, red liquid, is extracted with a needle and syringe. Several skin punctures on each hip and multiple bone punctures are needed to extract the required amount of bone marrow. Usually there are no surgical incisions or stitches involved, just skin punctures where the needle was inserted.

The amount of bone marrow harvested depends on your height and weight, but usually about 1L of blood and marrow is harvested.

This may sound like a lot, but it is only about 2% of your bone marrow, and the body replaces it in four weeks. Rarely a second bone marrow harvest is needed because insufficient stem cells were collected in the first attempt.

Side effects of bone marrow harvest

- When the anaesthesia wears off, you will feel some discomfort at the harvest site. The pain has been described as similar to “being kicked by a horse,” but can usually be controlled with paracetamol.
- There may be some colourful bruising at the back of the hips the week after the harvest. Depending on your case, you may require a blood transfusion after the harvest and may need to stay in hospital overnight.

Processing and freezing stem cells

Whichever way your bone marrow stem cells are collected, they are transported to the processing laboratory as soon as possible. The processing laboratory may be in your hospital or a larger hospital in your region.

The stem cells are tested to ensure there are enough cells for the BMT and that they are free of infection. They are frozen, using a special drug (DMSO) to protect them during the freezing period until you are ready for your transplant.

If you are lucky enough to have had a large number of stem cells collected, your harvest may be divided into 2-3 lots to provide more flexibility for their use. This may allow the potential for more than one BMT. Your doctor will discuss this with you if it is an option.

Key points

- There are two ways to collect stem cells for a transplant:
  - **Peripheral blood stem cell (PBSC) harvest:** where stem cells are collected from the circulating blood using a process called apheresis.
  - **Bone marrow harvest:** where bone marrow is collected from bones, usually the hips, while the patient is under general anaesthetic.
- Peripheral blood stem cells are the preferred source of stem cells for autologous BMT.
- Mobilisation occurs when the bone marrow increases production of stem cells, which then spill out into the circulating blood so they can be collected.
- Granulocyte colony stimulating factor (G-CSF) is a synthetic version of a naturally occurring hormone. It stimulates the growth of bone marrow stem cells and mobilises peripheral blood stem cells.
- Most people need G-CSF for 8-10 days to release enough stem cells into the circulating blood.
- G-CSF usually causes only mild side effects, such as aches, fatigue and feeling unwell. Severe side effects are rare.
- Apheresis is the process of skimming off stem cells from the blood. It is a very safe procedure, but there may be minor side effects, such as pins and needles and faintness.
- Bone marrow harvests are performed in the operating theatre under general anaesthesia. They involve little risk (mostly associated with the general anaesthetic), but some discomfort, such as pain at the harvest site.
- Once collected, stem cells are tested and then frozen until you are ready for your transplant.

CHAPTER 4

Preparing for the Bone Marrow Transplant

The work up

Some routine medical tests will be done before you have the BMT, usually before you are admitted to hospital. These tests determine whether your body is fit enough to endure the physical stresses of a BMT. You may have some or all of the tests, depending on your disease type.

Your BMT doctor or transplant co-ordinator will give you more information about the tests, which are called the 'work up' and are summarised below.

Gated heart pool scan (GHPS or 'gate') and cardiac echo

Both the GHPS and cardiac echo are tests of your heart function. An assessment of your heart function is needed because some chemotherapy drugs can damage your heart. It is important to know how well your heart is functioning as you may be given large volumes of fluid during the BMT. If your heart is not functioning to full capacity, the amount of fluids you are given may need to be adjusted or you may need extra drugs to help your heart cope. The GHPS is done in the hospital's nuclear medicine department and the cardiac echo is performed in either the cardiology or ultrasound department.

Glomerular filtration rate (GFR)

This kidney function test measures how fast your kidneys filter and remove waste products. It is done in the hospital's nuclear medicine department, or by using calculations based on a 24-hour urine collection. It checks whether your kidney function is good enough to cope with the large number of drugs and the volume of fluids needed for your BMT. If you have kidney damage, the dose of some drugs may need to be reduced. Generally, it needs to be done on a different day from the GHPS.

Pulmonary function tests (PFT, RFT)/diffusing lung capacity (DLCO)

This series of tests measures the function of your lungs without the need to physically examine them. These tests, which also help to diagnose suspected lung disease, are performed in the respiratory department.

Lumbar puncture (LP)

Depending on your type of disease, you may have had lumbar punctures as part of your diagnosis and/or treatment. You will be informed if you need to have one as part of your work up. If you haven't had one previously, your doctor will discuss the procedure with you.

If you require a lumbar puncture, a needle is carefully inserted between the bones in your spine into the fluid that circulates around the spinal cord and your brain (cerebrospinal fluid or CSF). A small amount of CSF is taken out and tested for the blood disease you are being treated for. Some people need a dose of chemotherapy to be injected into the CSF at the same time as the sample is taken.

Chest X-ray

If you have not recently had a chest X-ray, you will have one to check for abnormalities in your lungs before the BMT.

Sinus X-ray

If there is any suspicion that you have had a sinus infection, you will need an X-ray of this area. It is important to tell your doctor if you think, or know, you have a chronic sinus problem, as it will need to be fixed before the BMT.

Computerised Tomography (CT or CAT) or Positron Emission Tomography (PET) scan

Depending on your type of disease and when you had your last scan, you may need another one to ensure you have no active disease or infection. If you haven't needed scans as part of your treatment plan, you probably won't need one before the BMT. The scans may examine all or part of your body.

Blood tests and bone marrow biopsy

You will also have a number of blood tests, many of which you have had before, to establish a baseline before the BMT. You may also need to have a bone marrow biopsy, depending on when you had your last one, to ensure you are in remission.

Dental care

The mouth, or oral cavity, is one of the major sources of bacteria that can cause infections during BMT, so it is important to have a dental checkup and have any problems fixed before the BMT. If your dentist is unsure about the treatment, please ask them to contact your doctor.

If you can't afford the dental treatment, talk to your doctor, BMT co-ordinator or social worker, as they may be able to organise alternatives to a private dentist.

Eating well

If you are having trouble eating or are losing weight before your transplant, you should ask to see the haematology dietitian in your area.

Good nutrition before a BMT is important for:

- maintaining a healthy weight and improving protein and muscle stores
- providing essential nutrients for fighting infections and promoting wound healing and recovery
- boosting your energy levels and ability to cope with treatment.

Fertility

The high doses of chemotherapy and/or the total body irradiation treatment (TBI) you have before your BMT will damage the cells needed for reproduction – the eggs or sperm.

In most people this damage is permanent, causing infertility, and in others only temporary. A number of factors affect the likelihood of infertility, including your age, gender, the type of conditioning therapy used and your previous treatment. The strongest predictor of permanent post-BMT infertility is the age of the patient at the time of transplant and the drugs used for conditioning – e.g.. after TBI or Busulphan, most patients will be permanently infertile.

This can be devastating news for people who have not had children or haven't completed their family. Fortunately, there are ways to store eggs, ovarian tissue or sperm for later use. This provides the best means for increasing the chance of being able to have a child after BMT.

If you want to store sperm or ova (eggs), you will be referred to the fertility centre your BMT hospital uses.

It is important to note that there is no evidence that children naturally conceived by patients after a BMT will be affected in anyway. There is also no evidence that these children have a higher chance of genetic abnormality or developing cancer themselves. However, it is recommended that a condom is used for the first six months after BMT. If you are unsure, check with a member of your BMT team.

Key points

- Some routine medical tests, called the 'work up', will be done before the BMT to determine whether your body is fit enough to cope with the physical stresses of the transplant.
- The mouth is one of the major sources of bacteria that can cause infections during BMT, so it is important to have a dental checkup and have any problems fixed before the transplant.
- Good nutrition is important. If you are having trouble eating or are losing weight before your BMT, talk to the haematology dietitian.
- It is important to think about fertility issues before deciding to go ahead with the BMT because reproductive tissue MUST be stored before the conditioning therapy. Please ask your BMT team to discuss these issues with you before transplantation.

CHAPTER 5

Taking Care of Yourself Before and During a BMT

Much of the information covered in this chapter may also be relevant after the BMT. It is important to consider these issues before the transplant so you and your family can plan for the challenges you may face during transplant.

Being diagnosed with a life-threatening illness can be a traumatic experience. It is common to feel overwhelmed by the amount of information you receive and the need for urgent treatment or hospitalisation. Each person feels and responds differently. People will find some aspects of the treatment process more stressful than others.

It is important to remember that for most patients having an autologous BMT the transplant process itself involves no more, and sometimes less, discomfort or danger than the treatment they have already received for the disease.

Dealing with stress

Everyone has their own way of coping with emotional stress and physical discomfort. Psychological discomfort, like physical discomfort, is a normal ‘symptom’ of the BMT experience.

You don’t have to cope alone. Social workers and psychologists/psychiatrists are part of your BMT team. It is helpful to establish a relationship with your social worker or psychologist/psychiatrist early in the process of diagnosis and treatment. You don’t need to wait until things are really stressful before you ask to talk to someone.

For some people, just talking honestly with a social worker can be very helpful. Some people worry they may be judged as ‘not coping’ if they ask for help. There is no right or wrong way of managing all the challenges and stresses that BMT throws at you. There is only the method that works for you.

Communicating with your team

BMT is a team effort and you are the central and most important person in this

team. Understanding your treatment plan and clear communication are essential elements in maintaining your emotional and psychological wellbeing. People often say it is the unexpected symptom, complication and treatment that upsets or frightens them the most. A BMT already involves a degree of uncertainty. Poor communication can add unnecessary stress to this situation.

Don't hesitate to clarify any aspect of the process. If something is not clear, no matter how insignificant it may seem, don't be afraid to ask about it. Ask for information to be repeated as often as you need. If you still have a niggling doubt, ask. Recognising and addressing any doubts can ease your anxiety and help you to understand the treatment plan.

People vary in how much information they need about the transplant. Some will want to speak to others who have had a BMT. Some will want to research every aspect of the transplant process. Others will only want minimal facts about the treatment.

Whichever category applies to you, it's important you have all the information you need before your transplant. There is no right or wrong amount of information. There is only the amount you need to meet your needs.

Focus on your goals

Some people feel as though they have no choice but to have a BMT – that the transplant is their best chance to enjoy as normal a life as possible.

It is important to be clear about your reasons for having the transplant. What are the things in your life that make it worth fighting for? For many people this may be partners, children and other family. For others, it may be friends, work, travel, adventure and much more.

During the BMT, when you are having a hard day, it will be important to remember why you decided to have the transplant. It can help you see past the setbacks to what the future promises.

Impact on relationships

Role changes

Not surprisingly, BMT has a big impact on family relationships. Some people find that their main role changes. They may take time out from being the primary income earner or main carer of children. There can be other changes to the position and the roles that people have in a family.

The hospital stays and recovery can mean that your partner and others in your family take on some of your day-to-day roles. Similarly, the experience of being seriously ill and being away from home can change the relationships you have with your loved ones.

It is important that you and your family discuss the changes, and recognise that they are essential, even if they are difficult for some members of the family. It can help to talk to the social worker on your team about these issues.

Different ways of coping

The time before and during the transplant can be stressful, and can cause tension in relationships with loved ones, such as partners. People have different ways of coping when someone close to them is going through a transplant. Some people need to talk openly about feelings while others prefer to keep things to themselves, or to use stress management and problem-solving techniques. It is important to respect different ways of coping and communicating.

Try to keep the lines of communication open with family and friends throughout the transplant. Don't assume that friends or family don't care because they are not there – they may just need time out.

Sexuality

Previous treatment and the emotional stress that occurs in the lead up to BMT can have an undesired effect on body image and sexuality.

Some people may have had difficulties in sexual relationships before the BMT.

Body changes from initial treatment can leave people feeling less confident about the way they look and can impair sexual functioning and libido.

Sexual intercourse during BMT is not recommended because of the risk of infection and the potential to expose the partner to toxic drugs. Condoms should be used for the first six months after BMT.

Sexuality means more than physical appearance or having sex – it is about you and your partner as individuals, who you are and what you feel. It is about your touch, your warmth, how you laugh and smile, how you care and your personality. These will not change before or during BMT.

Talking to children

It is difficult to know how to talk with your child about your transplant and about being in hospital for long periods. As a parent, you have the best understanding of your child and their strengths and needs. If you need help, the social worker or psychologist in your team can give you information about how to talk to your children and what to say.

Protecting children by not telling them about your disease or transplant can sometimes make things worse, as children often imagine things that are worse than reality.

Try to explain your diagnosis and the transplant to your children in language they will understand. It is good to have honest communication with your child so that they can ask questions. Sometimes they will be worried about certain aspects of the transplant and may need reassurance.

Give them regular updates about your progress, and stay in touch with your children as best you can during the transplant process. This may be difficult at times, due to the nature of the transplant and concerns about infections. Relationships with children can be maintained by talking on the phone, making videos, letters or drawings etc.

Children vary in their responses to the transplant and its effects on you and the family. Here are some general examples of responses of children at different ages:

- **Babies and toddlers:** will feel some sense of loss and will often pick up on the concern of a parent or caregiver. They are likely to notice changes to routines, and may change their eating, sleeping or toileting habits.
- **Children under five:** may respond to the extended hospitalisation of a parent with periods of sadness, questioning or withdrawn behaviour.
- **Young children:** are often puzzled and confused by the experience of a parent going through transplant. The family is the centre of their world and they are likely to be very aware of the absence of a parent. They have little understanding of time. They generally do not have logical thinking and tend to connect things that are not related. For example, they may think that something they have done has made their dad sick.
- **Adolescents:** their ways of thinking are adult, but they are likely to be unsure of how to handle their emotions and may need adult help with coping. Some have to take on some of the roles of the parent and may resent this at times.

If you have children at school, it can be useful to tell the school and your child's main teacher about your situation so they can be supportive and be more understanding if your child's mood and ability to concentrate are affected. Talk to the school counsellor for more help.

For more information about talking to children, talk to your social worker. CanTeen has programs for teenagers dealing with their own cancers as well as those with parents or siblings with cancer – ask your social worker or nurse how to contact CanTeen.

Family and friends

It can be hard for family and friends to know how to support you during a transplant. People want to help you through the transplant process but may be unsure of your needs. They will want to be useful and to visit and talk to you. They won't want to waste your energy, cause distress or be a nuisance.

Your family and friends are your support base and, just like your BMT team, you need to let them know what you need. Communicate clearly with them and get the help that you need. It can be useful to suggest practical ways to help and allocate these jobs to each family member or friend. You might find it useful to get one friend or family member to be the main contact and to organise people to do various jobs. There is no right or wrong way of enlisting their support – only the method that works best for you.

Tips for carers

It can be stressful and tiring to be the main carer and to see your loved one in discomfort. You may feel frustrated at not being able to ease their discomfort all the time. Sometimes they will seem dependent on you for their care and at other times they will feel quite unwell and may not want any visitors. It is a fine balance.

Offer your support and encouragement. Just be there with them – even if they don't feel like talking they'll know that you care. Try to understand the feelings that they are expressing, both positive and negative. Allow them to talk about negative thoughts. The transplant process is difficult and such thoughts reflect the reality of their situation. If you are asked to leave, don't take it personally. They probably just want some rest and space.

If you find it emotionally or practically difficult to keep visiting, it can help to talk about your feelings with a member of the BMT team.

It is vital to look after yourself if you want to properly care for your loved one throughout a BMT. Ensure you get regular breaks, and have your own support in place, including close family and friends. Support services for carers, such as the social worker or psychologist at the hospital, can help maintain your health and wellbeing. For more information on caring for someone through a BMT, see www.bethematch.org.

Dealing with your emotions

Putting your life on hold

When diagnosed with a serious illness, all normal life experiences are put on hold. Arrangements have to be made for caring for family members, education, employment and social activities. Health care issues now dominate a life where previously they were scarcely considered. Any family who experiences this trauma will feel confused, disoriented and, at times, overwhelmed.

This change in normality can be very difficult. There is no easy way to accept the changes. You will work out your own way of managing. Support and reassurance from family, carers, close friends and the BMT team are vital. It can help to have a tour of the unit before admission, so you feel familiar with the surroundings and staff. Your social worker can recommend support services that may be able to help you during this time.

> "I used to be in control of my life. I used to be the captain of the ship, steering the boat down the river through life. I would decide how fast to move, which turn to make, where to stop, who would share my life. When I was diagnosed with cancer, it was as if someone reached down, picked me up off the ship and placed me on the riverbank. Now I watch from the riverbank as my life goes on. I do not feel in control of the ship. Someone else is directing my life."
>
> *A patient describing their perception of being diagnosed with cancer and then facing a BMT*

'No one understands'

People who have not had a BMT usually find it hard to understand what you're going through. You will experience strong emotions and psychological challenges, at times in isolation, and even those closest to you will be unaware of your turmoil. Always keep in mind that you can talk to your social worker about these issues. It is important that you and your family have realistic expectations of each other, and respect and recognise each other's experience and limitations. Family and friends will support you but can't possibly understand every experience you will have. Nevertheless, they can still respect and recognise your experience even though they may not fully understand the complexity of the moment.

Be positive

A positive outlook and encouraging support from others will help you deal with the demands of treatment. But you and your carers may feel that others expect you to be strong and positive even when you don't feel like it. This pressure to be positive can mask your true emotions and make it harder to understand each other's reality.

Lighten your load. If this feels comfortable for you, take the opportunity to share your feelings and concerns with people you trust, whoever they may be. It helps many people to do this.

Make the most of the positive news, big or small. From a simple improvement in mouth ulcers to engraftment day, feeling good about it can help you get through the day and feel better about your overall progress.

Uncertainty – living in limbo

Living with uncertainty is a constant stress during BMT. Somehow people work out how to cope with such stress. Some people choose to tackle their worst fears immediately and look for honest rather than reassuring opinions from their team. Others prefer uncertainty than to face the fear of bad news.

It is not possible to know for sure how you will respond to your treatment, the symptoms you will experience, or how long it will take your body to recover.

You are doing well to manage at all. People are often surprised by their determination and their ability to tough it out. Your BMT team and community providers are able to support you in living with the daily uncertainty.

Spiritual beliefs

If you are a spiritual person, your beliefs may be more important than ever and provide you with comfort and inspiration during the BMT. Pastoral staff in the hospital can come and talk to you and your carers at any time – just ask your nurse or social worker to arrange it.

If you have other ways of expressing your spiritual beliefs and need privacy in hospital to do this, talk to your social worker about setting aside time for this important part of your day.

Changes in your body

A BMT often means changes to your body and appearance, such as temporary hair loss, having a Hickman catheter or changes in weight. These changes may be upsetting but are related to your treatment drugs and are temporary.

Changes in your level of independence

One of the frustrating aspects of having a transplant is the lack of control – you no longer have control over your own body, and you have no control over the treatment you receive or the side effects that occur.

During a long hospital stay, you may have little control over your environment. For people who are used to being independent, it can be hard to adjust to needing help to do basic things such as showering, walking or going to the toilet.

During your transplant you may find yourself in a contradictory situation. You may have trouble walking without help, feel exhausted after your morning shower or even struggle to get out of bed, yet your BMT team assures that you are right on track.

"How can I be on track when I feel this bad?" This is a common question among transplant patients. Talk to your BMT team if something seems inconsistent or unclear. You need to remain as independent as possible, but be open to assistance when it is required. This can be important in helping maintain your own sense of independence.

Creating privacy

Your concept of privacy may change after you spend time in hospital. Some people describe the hospital stay as like living in a fish bowl.

The need for privacy is unique to the individual and can vary day to day. Privacy can be very important on some days, particularly if you're feeling vulnerable. Nurses, specialists and cleaners can constantly interrupt you when you're trying to have a private phone conversation, having some personal time with people close to you, or even having a shower.

There are ways to create privacy, even in hospital. Discuss this issue with the nurse looking after you and set aside some time each day when you will not be disturbed. You can put a sign on your door during that time.

If you need time alone, with no visitors or phone calls, you can ask for your phone to be diverted to the front desk where the ward clerk can take messages, and let family and friends know that you want time alone.

Managing your 'space' in hospital

You will probably spend many long and perhaps trying days in your hospital room. Familiar surroundings can be reassuring, so personalise your room to make it feel more like 'your place' and help you feel connected to your life outside hospital. Personal possessions can help provide comfort and reassurance, particularly at night when sleep may be difficult and you're alone.

Ask the ward's Nursing Unit Manager if you can use a laptop computer or tablet to get Internet access. E-mails are a good way to keep in touch with family and friends from your hospital bed at a time that suits you.

Twenty-four hours in a hospital bed can seem like an eternity. The sameness of the routine can make the hours pass very slowly. Sometimes it seems as though nothing is happening. Night-time and being on your own can also make your thoughts seem more exaggerated.

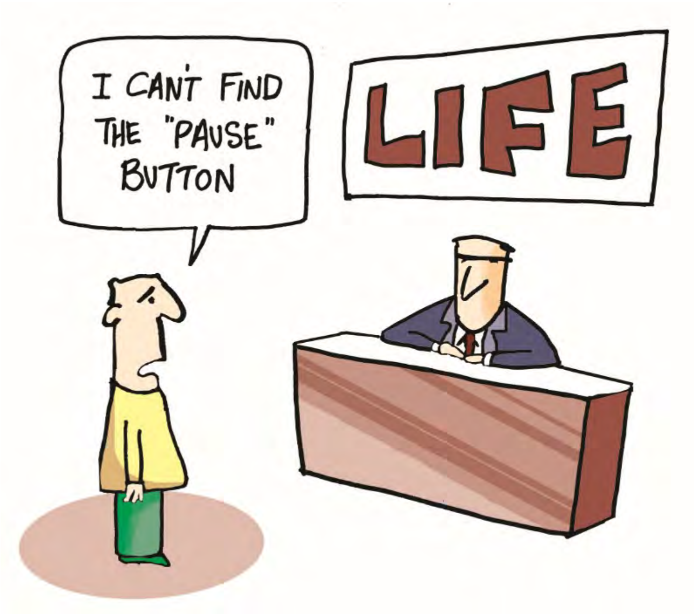
Try these tips for breaking up the endless hours:

- Plan a schedule for your day and night so you have regular activities to keep you occupied, but be prepared to be flexible as the hospital routine may interfere at times.
- Roster your visitors to arrive at different times.
- Make an effort to consider ideas about how to make the time pass. Get some ideas from others. Explore these ideas with friends, family and staff, if necessary.

Tiredness and fatigue

Most people experience fatigue during the transplant and for a significant time after it. This is normal. The amount of fatigue and how long it lasts varies from person to person. It may last for months after your transplant. For most people, it will ease gradually but slowly, which can be frustrating.

Maintaining your physical condition throughout the treatment process can help you cope with fatigue and help your progress. Try to stay active in hospital. Simple activities can help to keep your body in good condition throughout all stages of transplant. Ask the hospital physiotherapist for more information.



Practical issues

Finances

For many people, treatment for their initial illness already has made it hard to work full time. The transplant process and long recovery period often makes this situation even more difficult, which may lead to financial problems.

For those who have to travel away from home for a BMT, these may be more pronounced.

It is important to explore your options to ease any financial burden, such as:

- **Work:** ask your employer what types of leave are available.
- **Superannuation:** if you are in a superannuation scheme, check if you can get access to some of your funds.
- **Government assistance:** you may be eligible to receive payments from Centrelink or from the NSW Government's Mortgage Assistance Scheme.
- **Banking:** if you have a mortgage, talk to your lender about restructuring the payments for a period.

The social workers at your home hospital or on the BMT team are experienced in these matters and can help you.

Accommodation

BMT is a specialised procedure, so many people have transplants far from their local hospital.

If you have to travel far from home, you will need accommodation close to the treatment hospital for yourself and your family. There may be accommodation available at the hospital.

Patients who are required to travel more than 200km from home for treatment may be eligible for assistance with travel and accommodation expenses through the Isolated Patients Travel Accommodation and Assistance Scheme (IPTAAS).

Talk to the hospital or BMT team social workers for more information about accommodation and IPTAAS.

Transport

You family will visit you many times in hospital, so it is a good idea to ask about the availability of parking and public transport at the hospital.

Also, after the transplant you will need close follow-up, and will visit hospital regularly. When you leave hospital, your immune system will be compromised for some time. It is best not to travel by public transport, initially, to avoid contact with large numbers of people. You will therefore need someone to bring you to your follow-up appointments. If this is not possible, see your social worker about community transport options.

Legal and financial advice

Think about seeing a solicitor and financial adviser before the transplant. It is important to consider your current situation and think about what relevant measures may need to be put in place, such as:

- making or updating your will
- drawing up an enduring Power of Attorney/enduring guardian
- bank account arrangements
- financial plans
- sickness benefits
- carer's pension.

If necessary, your social worker may be able to arrange appointments with a solicitor or Centrelink.

Key points

Ask for help

Some people think they'll be judged as 'not coping' if they ask for help. There is no right or wrong way of managing all the challenges and stresses that BMT throws at you. There is only the method that works for you.

Ask questions

If something is not clear, no matter how insignificant it seems, don't be afraid to ask about it. Ask for information to be repeated as often as you need. If you still have a niggling doubt, ask again.

Focus on your goals

During the BMT, when you are having hard days, it will be important to remember why you decided to have the transplant. It can help you see past the setbacks to what the future promises.

Be open about role changes

It is important that you and your family discuss changes in roles during a BMT, and recognise that they are essential and may be difficult.

Be honest with your kids

Protecting children by not telling them about your disease or transplant can make things worse, as children often imagine things are worse than reality. Try to explain your diagnosis and the transplant to your children in language they will understand.

Call in the cavalry

Your family and friends are your support base and, just like your BMT team, you need to let them know what you need. Communicate clearly with them and get the help you need.

Caring for the carer

It is vital to look after yourself if you want to properly care for your loved one throughout a BMT. Ensure you get regular breaks, and have your own support in place, including close family and friends. Support services for carers, such as the social worker or psychologist at the hospital, can help maintain your health and wellbeing. For more information on caring for someone through a BMT see www.bethematch.org.

Make the most of good news

Make the most of the positive news, big or small. From a simple improvement in mouth ulcers to engraftment day, feeling good about it can help you get through the day and feel better about your overall progress.

Have time for yourself

There are ways to create privacy, even in hospital. Discuss this issue with the nurse looking after you and set aside some time each day when you will not be disturbed. If you want, put a sign on your door during that time.

Try to stay active

Maintaining your physical condition can help you cope with fatigue and help your progress. Try to stay active in hospital. Simple activities can help keep your body in good condition throughout all stages of transplant.

Get organised

Explore options to ease any financial burden, such as restructuring loan payments or applying for financial assistance. Get legal and financial advice before you go into hospital, so you can make sure the necessary paperwork has been done, such as Power of Attorney and updating your will.

CHAPTER 6

Conditioning Therapy

As discussed in Chapter 1, conditioning or preparative therapy is a crucial part of the transplant process. It is done in the days before the stem cell infusion and usually involves giving very high doses of chemotherapy drugs, occasionally with total body irradiation therapy.

The conditioning therapy will be administered over 1-7 days. The stem cells will often be given the next day or after a rest day.

The conditioning therapy has two important aims:

- **To kill cancer cells:** if you're having a BMT for cancer, these higher doses of chemotherapy may kill more cancer cells than the chemotherapy you have had before. It is hoped that this will provide you with a long remission and, depending on your diagnosis, possibly cure your disease.
- **Suppress the immune system:** in people having a transplant for immune-related diseases.

Treatment with chemotherapy and radiotherapy can increase the risk of developing another cancer later in life. Your BMT doctor will discuss the risks and benefits of your individual treatment with you.

Common conditioning protocols

Although many drugs have been trialled in conditioning therapy protocols over the past 30 years, most BMTs done in Australia rely on a few, well-established treatment protocols. The details of the specific drugs and their side effects are covered later in this chapter.

Conditioning treatment can be a single chemotherapy agent or a combination of chemotherapy agents.

It is often easier to understand the process of BMT if you have copies of:

- your treatment protocol
- your day-to-day regimen
- a sheet to record your blood counts.

Most units will supply these. If you don't have them, you can ask for them. Also, you can ask your nurse or doctor for your daily blood count.

Your BMT team will use codes when deciding the timing of your conditioning treatment. The days in the lead up to BMT are known as minus days, e.g., D-6 is six days before BMT and D-1 is 1 day before BMT. The day of the BMT is Day 0.

The most common regimens are described below.

High-dose melphalan

High-dose melphalan is often given as a single drug for patients with myeloma. It is administered as a short infusion through the drip on D-1.

Busulphan /cyclophosphamide (Bu/Cy)

This regimen is commonly used for patients with acute myeloid leukaemia. It is used as a conditioning therapy for both autologous and allogeneic BMTs.

Busulphan, which is administered first, is given by mouth, either as a suspension or tablets four times a day for four successive days. An intravenous form is used in some countries but is not widely available in Australia.

After you've had busulphan, you will be given two doses of cyclophosphamide, as a short intravenous infusion on consecutive days. You will also have lots of IV fluids to help flush out the toxic breakdown products of the drug.

BEAM

Several regimens are used for lymphoma. One of the common regimens, BEAM, consists of four chemotherapy agents given over the six days before BMT.

The drugs are:

- carmustine (BCNU) – one dose on D-6
- etoposide – daily on D-5 to D-2
- cytarabine (Ara-C) – daily on D-5 to D-2
- melphalan – one dose on D-1

All the drugs are given as short IV infusions. You may be given some extra IV fluid with the melphalan to help your kidneys flush out the drug.

CBV

This regimen is an alternative to BEAM for patients with Hodgkin's or non-Hodgkin's lymphoma. It consists of three different chemotherapy drugs, given over five days before the BMT, leaving one rest day (D-1).

The drugs are:

- cyclophosphamide – daily on D-6 to D-3
- carmustine (BCNU) – one dose on D-2
- etoposide (VP16) – twice daily on D-6 to D-3

The cyclophosphamide and the etoposide are given first, as short infusions. You will have large amounts of IV fluids continuously from the start of this regimen until 24 hours after completion of the cyclophosphamide. The fluids will help to flush out the toxic breakdown products of the drug.

LACE

LACE can be used for people with Hodgkin's or non-Hodgkin's lymphoma, acute myeloid leukaemia or myelodysplasia.

This regimen consists of four different chemotherapy drugs given over six days, leaving D-1 as a rest day.

The drugs are:

- lomustine (CCNU) – single dose on D-7 (tablets)
- cytarabine (Ara-C) – daily on D-6 and D-5
- cyclophosphamide – daily on D-4 to D-2
- etoposide (VP16) – single dose on D-7, six hours after the lomustine

Etoposide is given as a four-hour infusion through the drip, cytarabine as an infusion lasting three hours each day, and cyclophosphamide as a three-hour infusion each day.

You will also require lots of IV fluid from the time you start the cyclophosphamide until 24 hours after stopping the cyclophosphamide, to help flush out the toxic breakdown products of the drugs. You may also be given a drug called mesna at the same time and after the cyclophosphamide.

Drugs and treatments used in conditioning therapy

Cyclophosphamide

This is a chemotherapy drug widely used in conditioning therapy for BMT. Cyclophosphamide is given as an intravenous infusion, usually over one or two hours. It is one of a class of anti-cancer drugs called alkylating agents, which act by damaging the DNA in cancer cells and stopping or slowing their growth. Cyclophosphamide also has a strong suppressive effect on the immune system.

Common side effects

- nausea and vomiting
- metallic taste in the mouth during the infusion
- drop in the blood count, especially the white blood cells
- hair loss
- infertility

Less common side effects

- bladder irritation. This is called haemorrhagic cystitis and is caused by the breakdown products of cyclophosphamide in the urine irritating the lining of the bladder. This condition can start days to weeks after the drug is given. Symptoms include painful urination, the urge to urinate frequently and blood and clots in the urine.
  To reduce the risk of this complication, large quantities of IV fluids are given after cyclophosphamide.
  Sometimes another drug called mesna is given as well.
- second cancers

Busulphan

Like cyclophosphamide, busulphan is an alkylating agent. It is a strong stem cell poison and has strong anti-leukaemia activity. Busulphan is given by mouth, usually four times a day for four days, either in tablet form or as a suspension of crushed tablets.

Common side effects

- nausea and vomiting
- damage to the lining of the mouth and intestines
- hair loss
- seizures during the days when the drug is being given. An anticonvulsant drug, such as clonazepam, is given during this time to prevent this complication.
- drop in the blood count

Less common side effects

- lung damage, leading to a condition causing stiff lungs (pulmonary fibrosis)
- increased skin pigmentation
- second cancers

Melphalan

Melphalan is also an alkylating agent, given intravenously, usually as a single dose.

Common side effects

- nausea and vomiting
- increased risk of infection due to impairment of the body's immune system, irrespective of whether the white blood cell count is normal or low

Less common side effects

- second cancers

Carmustine

Carmustine is from a class of drugs called nitrosourea (nitrogen mustard) group. These drugs were derived from the nitrogen mustard gas used during World War II. Carmustine is an alkylating agent, which is usually used in combination with other drugs.

Common side effects

- drop in blood counts
- nausea and vomiting
- flushing of skin, burning or pain at the site during the infusion

Less common side effects

- damage to liver and kidneys
- damage to lungs

Etoposide

Etoposide is in a class of agents called plant alkaloids. It stops cancer cells from dividing. It is derived from the mandrake plant and is used in many different chemotherapy regimens.

Common side effects

- drop in blood counts
- drop in blood pressure during the infusion
- nausea and vomiting
- hair loss

Less common side effects

- damage to the heart muscle
- flare reaction from previous radiotherapy site
- decrease in feeling of fingers and toes

Cytarabine

Cytarabine is in a class of drugs called antimetabolites, which stop cancer cells from making and repairing DNA, which they need to grow and multiply.

Common side effects

- nausea and vomiting
- drop in blood counts
- hair loss
- decrease in sensation to fingers and toes
- damage to the lining of the mouth and intestines

Less common side effects

- fever and flu-like symptoms shortly after infusion
- confusion and disorientation
- skin rash
- eye irritation

Lomustine

This is another drug from the nitrosourea class, and is a strong alkylating agent. This drug is only available in tablet form and should be taken on an empty stomach.

Common side effects

- nausea and vomiting
- drop in blood counts
- diarrhoea

Less common side effects

- damage to lungs
- confusion, disorientation and lethargy

Total body irradiation (TBI)

Total body irradiation (TBI) is radiotherapy to the entire body. It is used along with chemotherapy for some people having an autologous BMT.

The radiation oncologist uses a machine called a linear accelerator, which is designed to give individual treatments tailored to each person. Organs of your body that are sensitive to radiation, such as your lungs, may be shielded for part of the TBI.

During TBI you may be asked to sit, stand or lie, but in each position you will be kept still within a brace. You will be alone in the room, but can talk with the radiation therapist who will watch you at all times.

Usually TBI is given twice daily for a total of six doses, but this may vary depending on your individual protocol.

In most cases you will be given lorazepam, a drug that will both relax you and decrease any nausea.

Possible side effects:

- nausea and vomiting
- hiccoughs
- skin redness
- mouth dryness due to decreased saliva production
- mouth ulcers
- thickened saliva
- dry eyes due to decreased tear formation
- diarrhoea
- bone marrow suppression

Key points

- Conditioning therapy is a crucial part of the BMT process, which usually involves very high doses of chemotherapy drugs, occasionally with total body irradiation. It has two important aims:
    - **To kill cancer cells:** higher doses of chemotherapy may kill more cancer cells than previous chemotherapy, in the hope of a long remission and possible cure.
    - **Suppress the immune system:** in people having a transplant for immune-related diseases.
- Conditioning therapy is administered in the 1-7 days before the stem cell infusion and can be a single chemotherapy drug or a combination of drugs.
- Total body irradiation – radiotherapy to the entire body – is used in conditioning therapy for some people having an autologous BMT.

CHAPTER 7

Dealing with Side Effects

Unfortunately, the BMT process often has a number of unpleasant side effects. The most common side effects, and some ways to control or reduce them, are described in this chapter.

Nausea and vomiting

Many of the drug treatments given as part of your BMT can cause nausea and vomiting. Nausea is most commonly experienced during conditioning therapy, when strong anti-cancer drugs and radiation therapy are given. However, nausea and vomiting may result from other drugs, especially some antibiotics, or from damage to the lining of the intestines from drugs and radiation.

There are many drugs that control nausea and vomiting. Sometimes it takes a while to find the combination that works for you.

The major anti-nausea drugs are ondansetron, dolasetron and tropisetron, usually used in combination with other drugs.

Other drugs used to prevent or control nausea include Maxolon, Stemetil, cyclizine and haloperidol. Your team will work out which ones are best for you to use.

If you feel squeamish or nauseated, tell the nurses immediately, because it's harder to get the nausea under control once you've started vomiting.

Diarrhoea

Just as for nausea and vomiting, many of the treatments used for the BMT can cause diarrhoea.

You can lose a lot of fluid very rapidly from diarrhoea, so it's important to tell the nurses about the severity of the diarrhoea, such as the number of times you have to go each day. Severe diarrhoea can cause dehydration and can severely affect kidney functioning.

A number of drugs control diarrhoea and, again, it may take some time to find the one that works for you. These drugs include loperamide and narcotic drugs such as codeine phosphate. Once the best medication is found, tell your team when your diarrhoea is easing up, so they can reduce the amount of medication, or you might become constipated.

Mouth and throat problems

People having a BMT often experience a condition called mucositis, which leads to mouth and throat discomfort. It is caused by a number of factors, including chemotherapy, TBI, low white cell count and infections. You may have pain and discomfort from mouth and throat ulcers, dryness and changes in taste.

For many people, mucositis is the most distressing aspect of their BMT, so it is important that you keep your team accurately informed of how well your pain is controlled. It is often accompanied by a large amount of thick saliva, which is difficult to swallow due to pain and swelling in the mouth and throat.

Mucositis pain can be difficult to completely control, but these tips might help:

- Increasing the number of times you perform your mouthwashes may soothe your mouth pain.
- Suck on hard lollies to help remove the saliva.
- Use gentle suction to remove your saliva so that you don't have to worry about swallowing.

Pain

A number of methods of pain control may be tried, including Panadol and Xyolocaine viscous and narcotic agents, such as mouthwash or morphine.

Narcotics, which are needed in many cases, can be given in tablet or liquid form, by injection under the skin, or intravenously.

Initially, the analgesic drug may be given on request. Eventually, depending on your pain and preference, it will be given either intermittently on a regular basis (e.g., every four hours) or by continuous IV infusion. Another option is for you to control the dose of pain control by pressing a button on a remote control device, which injects a preset dose intravenously. This is called patient controlled analgesia or PCA.

In most cases, the hospital's acute pain team will assess you for pain relief and make a recommendation. The team will review your requirements regularly until your pain resolves. The amount of narcotics needed will vary. Some patients fear they will become addicted to morphine or another narcotic. This is unusual, as the pain team will monitor you closely and assess your analgesic requirements against your pain, as rated by you.

Key points

- Nausea is a common side effect of medications used during a BMT. If you feel nauseated, tell the nurses immediately, because it's harder to get the nausea under control once you've started vomiting.
- There are many drugs that control nausea and vomiting, and sometimes it takes a while to find the combination that works for you.
- Many BMT treatments can cause diarrhoea. You can lose a lot of fluid very rapidly from diarrhoea so tell the nurses about the severity of the diarrhoea. Once the best medication is found, tell your team when your diarrhoea is easing up, so they can reduce the amount of medication or you might become constipated.
- People having a BMT often experience a condition called mucositis, which leads to mouth and throat pain and can be distressing. It can be difficult to completely control but there are ways to relieve the discomfort.
- Most BMT patients have mouth discomfort or pain. There are a number of ways to ease your pain. In most cases, the hospital's acute pain team will assess you for pain relief and make a recommendation.
- In most cases morphine or another narcotic medication is required for pain relief. Some patients worry they will become addicted to morphine or another narcotic. This is unusual.

CHAPTER 8

Nutrition and BMT

Eating well is important for good health. Food provides the fuel our body needs to grow and function. We need protein-rich foods to build and repair muscle and body tissues, and vitamins and minerals to keep our body systems functioning properly. Good nutrition is also important to help fight illness and infection, and to cope with treatment side effects.

Nutrition assessment, education and support are vital parts of your medical care before and after the BMT. You will need extra energy and protein to cope with the physical demands of the transplant.

Also, your eating patterns will be affected because of the side effects of conditioning therapy and other treatments. These side effects, including lack of appetite, taste changes, nausea, vomiting, diarrhoea and mucositis, affect your ability to eat sufficient food for weeks or months after the transplant, increasing the risk of malnutrition. It is expected that you will not necessarily have the best nutrition during your transplant, but the BMT team will work with you to help maximise it.

Food can be a source of micro-organisms such as bacteria or fungi, especially if it is not handled correctly or hygienically prepared, so it is important to follow good food hygiene practices before and after the transplant, until your immune system has returned to normal.

Nutrition assessment

Wherever possible, the BMT dietitian should assess all patients in the week before the transplant or on admission to hospital.

The dietitian will assess your:

- height and weight
- recent weight changes
- gastrointestinal symptoms, such as nausea and diarrhoea, which may affect how much food you can eat and absorb
- energy and protein requirements
- usual diet habits, which may be affected by other factors such as illness and medications, religion and alternative therapies

The dietitian will arrange an individual nutrition care plan for you. The type and amount of food you eat in hospital will be monitored, and you may be asked to fill out daily food charts.

Nutrition support

All conditioning treatments significantly affect the lining of the gastrointestinal tract, from the mouth to the bowel. This is one of the main reasons people need nutrition support during a BMT.

Most people develop oral and oesophageal mucositis and gastrointestinal disturbances and discomfort 3-10 days after chemotherapy. The severity and the duration of these side effects can vary greatly between patients.

Your appetite and food intake may change from day to day. At times, you may find it difficult to eat enough food because of mouth problems or stomach upset. The dietitian can help you find ways to change your diet, such as eating soft or liquid food, or specialised nutritional high-energy/high-protein supplements.

A very small number of people will need more intensive support for short periods, such as nasogastric tube feeding or intravenous feeding, which is called total parenteral nutrition or TPN. The medical team will discuss this with you if required.

You may experience one or more of these side effects of treatment listed in this chapter. These suggestions may help you cope.

Appetite and weight loss

Treatment side effects – as well as anxiety, depression and fatigue – can contribute to decreased appetite and weight loss.

Tips

- Have small frequent meals and nourishing snacks.
- Eat foods you enjoy, even if higher in fat and sugar.
- Limit low-calorie foods and fluids.
- Try nutritional supplements as recommended by the dietitian.

Nausea and vomiting

These are common problems, especially during the conditioning period. Mild symptoms may persist for several weeks.

Tips

- Try six small meals and snacks a day, rather than three main meals.
- Include high carbohydrate foods and fluids.
- Have cold foods and clear fluids.
- Limit high-fat foods.
- Avoid strong odours and cooking smells.
- Take anti-nausea medication as prescribed.

Sore mouth and swallowing difficulties

Depending on the type of treatment you have, you may develop mouth or throat pain around 7-10 days after conditioning therapy. Infection and certain medications can also cause mouth discomfort and mucositis. This usually improves once the white blood cell count returns to normal.

Tips

- Avoid foods that sting your mouth such as spicy or salty foods, fruit juices and very hot or cold foods.
- Try soft, moist or pureed foods.
- Choose nourishing fluids, such as soups, milk drinks and commercial supplements.
- Keep your mouth fresh and clean and use mouthwashes as recommended.

Diarrhoea

Chemotherapy, total body irradiation, infections and some antibiotics can increase bowel activity and lead to diarrhoea.

Tips

- Drink plenty of fluids.
- Limit caffeine and spicy foods.
- Try a low-lactose diet as you may be temporarily lactose intolerant.
- Limit high-fibre foods such as legumes, whole grains and seeds.
- Take anti-diarrhoea medication as prescribed.

Taste changes

Some medications, such as antibiotics and pain relief, may change the taste of food. This can last for several months after the transplant, and longer for those who have had total body irradiation.

Tips

- Increase the flavour of food by adding salt, garlic, cooked herbs and spices.
- Marinate meat, fish, poultry or tofu to add flavour.
- Add sugar or honey if food tastes metallic or salty.
- Add salt, lemon juice or vinegar if food tastes too sweet.

Other side effects

Heartburn, constipation, abdominal discomfort and fatigue are other common side effects.

The dietitian can advise you how to reduce these symptoms.

Food hygiene

You will be at increased risk of infections from food, so it is essential to maintain good personal and food hygiene practices. You and your family can reduce the risk of food-borne infections at home and in hospital by following these simple guidelines.

Clean	wash hands and kitchen surfaces often.
Separate	prevent cross-contamination of foods by separating raw and cooked foods.
Cook	ensure food is cooked thoroughly and reheated properly.
Chill	refrigerate all food promptly.
Avoid	high-risk foods, such as: – foods close to or past their use-by date – foods from salad bars, smorgasbords and self-serve restaurants – pre-prepared takeaway foods – soft uncooked cheeses; brie, ricotta, camembert and fetta – soft serve ice-cream, yoghurt with live culture – raw or undercooked meats, chicken, fish, shellfish, eggs, tofu, salami, deli meats, pates and dips – sprouted seeds, fresh herbs and raw mushrooms – unwashed raw vegetables and fruit

You should follow these safe food hygiene practices for 3-6 months after discharge as recommended by your transplant doctor.

To minimise the risk of infection, some hospitals provide low-microbial/low-bacterial diets. The benefits of these restricted diets have not been scientifically proven but they may reduce the risk of harmful organisms from food and food handlers.

For more information on food hygiene, talk to the dietitian at your hospital.

Alternative dietary therapies

Some BMT patients, while following prescribed medical treatments, also like to explore alternative therapies. If you're considering an alternative dietary therapy, talk to your transplant doctor or dietitian first, because some alternative diets are nutritionally incomplete and unbalanced.

Despite research over many years, there is no evidence that special foods or diets can cure cancer. Diets that restrict food groups, such as meat and dairy, make it difficult to achieve adequate protein and energy intake and may lead to weight loss and increased tiredness.

Before changing your usual meal plan, consider if the new diet:

- provides adequate energy to maintain body weight
- is well balanced in vitamins, minerals and fibre
- is difficult to buy, expensive or takes a lot of time to prepare
- has any proven health benefits

If you are in any doubt, talk to your dietitian or your doctor.

It's also important to talk to your doctor or dietitian before taking alternative products, such as herbs, high-dose vitamins, antioxidants and other 'health food' preparations. These products may contain contaminants such as bacteria and fungi, which may interfere with your treatment or be toxic to organs such as the kidney and liver.

However, other alternative therapies such as meditation and relaxation may complement your treatment and help you feel better. Talk to your BMT team for more information.

Key points

- Eating well is vital for BMT patients because it helps:
  - you to cope better with treatment and side effects
  - damaged tissue to heal
  - your body to fight off infection
- Nutrition support is a key part of your medical care before and after the BMT. It helps to ensure you eat enough of the right sort of food to cope with the physical demands of the transplant and the side effects.
- Treatment side effects can affect your eating patterns and can cause problems such as nausea, diarrhoea and mucositis. These side effects can make it difficult to eat enough food for weeks or months after the transplant, increasing the risk of malnutrition.
- Food hygiene is very important after a BMT to reduce the risk of infections from food.
  When preparing food, follow these guidelines:

Clean	wash hands and kitchen surfaces often
Separate	prevent cross-contamination of foods by separating raw and cooked foods
Cook	ensure food is cooked thoroughly and reheated properly
Chill	refrigerate all food promptly
Avoid	high-risk foods

- There is no evidence that special food or diets can cure cancer or stop it recurring. If you are considering an alternative dietary therapy, talk to your transplant doctor or dietitian first.

CHAPTER 9

Complications

How to read this chapter

This chapter is very long and detailed, and contains important information about complications.

Reading this chapter may be confronting or scary, but it is important to remember that it is very unusual for one person to get all of the complications discussed.

Everyone who has a BMT is an individual with their own medical history and, therefore, their own risk factors. You may get none of the following complications, or you may get one or more. There is no way of predicting your particular case.

You may decide to skim through this chapter initially and only read it in depth if and when you need to.

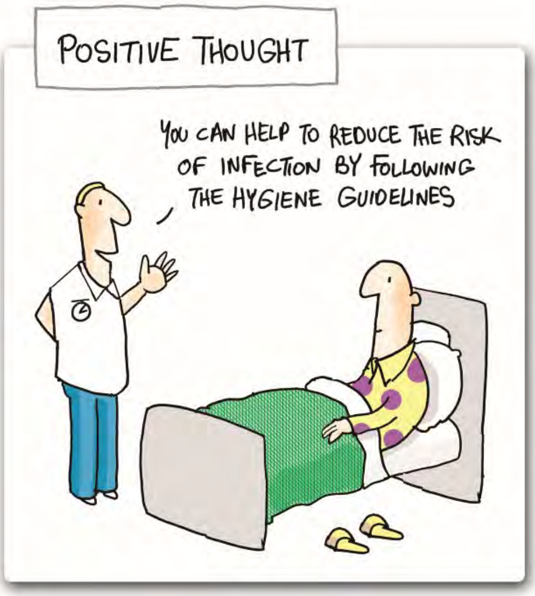
Whatever you decide, remember – it is unlikely that all the complications will happen to you, but the information is here if you need it.

After reading this chapter you may feel frightened and overwhelmed by the possible complications. You may want to ask more questions about these important issues, or ask to talk to someone who has experienced complications. It is important to keep in mind that their experience is unique to them and will not necessarily apply to you. Talk to your BMT team about your concerns.

Infection and living with a compromised immune system

Everything we do in our daily activities, from eating, breathing and contact with people and animals, is a potential source of infection. For people with a normal immune system, these everyday encounters are not a major problem. The body and its immune system work to prevent infections by recognising and destroying harmful organisms if they enter the body.

But for people who have had, or are about to have a BMT, the normal function of the immune system is disrupted. Conditioning therapy before the BMT affects all cells in the body, both cancerous and normal. The rapidly dividing cells found in the mouth, gut, bone marrow and hair are affected the most. Conditioning therapy decreases the number of circulating blood cells, including the white cells and particularly the neutrophils, which are responsible for fighting infection.



The skin and mucous membranes lining the mouth and nose provide the body's first line of defence against infection and repel millions of potentially harmful organisms and foreign substances each day. Normally, if you cut yourself, white blood cells or leukocytes spring into action to fight the infectious organisms that enter the body. This process is disrupted during your BMT and in the months after it. Proteins called antibodies, which all humans make in response to contact or infection with a variety of bacteria or viruses such as measles, cytomegalovirus (CMV) or chicken pox, are also depleted or destroyed. This means you may get these infections again. (For more detail on the function of white blood cells and the immune system, see Chapter 2.)

Until your immune system returns to normal, you are extremely vulnerable to infections and in some cases these may be life threatening.

The first 10 days to three weeks after the transplant is a critical time as the new bone marrow finds its way, via the blood stream, into the cavities of the large bones and begins producing new blood cells. This is the time when you will be at most risk of infection.

Although the risk of infection steadily decreases once the transplanted marrow successfully engrafts, your immune system remains compromised (not at full strength) for 3-6 months after the transplant.

Your role in preventing infection

Good hygiene is extremely important.

- Ensure all visitors, including staff, carefully wash their hands with antiseptic soap before touching you (hands are a primary carrier of infectious agents). If you are not sure if they have washed, ask.
- Shower or wash every day (including hair or scalp) using the antibacterial skin wash or liquid soap you have been given. Don't use cake soap.
- Use disposable wash cloths or change your washer daily.
- Examine your body daily and report anything you feel is not normal for you.
- If you need to shave, use only an electric razor. The razor should be cleaned thoroughly after each use, or if using a ward razor, the disposable blade should be discarded.
- Try to avoid constipation – tell your BMT team if you're having problems.
- Report any abnormalities when passing urine, such as burning, stinging or blood in the urine.
- Use a mouthwash at least four times a day. Good mouth care may not prevent ulcers, but it will reduce the risk of infection. It generally doesn't matter which mouthwash you use, as long as you have a regular routine.
- Use a soft toothbrush and avoid any extra trauma to the gums by only brushing your teeth.
- Limit the number of family and friends who visit you in hospital and keep visits to two people at a time. Apart from the risk of infection, visits can be very tiring. Tell family and friends not to come if they have any symptoms of cold, flu, diarrhoea or any other potentially infectious disease, or if they have had any recent vaccination. If they're not sure, they should check with staff before visiting you.
- Ask visitors not to bring flowers and plants (both live and dried) to you in hospital. They can harbour harmful bacteria or fungi and are generally not encouraged in the room while you are neutropenic.
- Eat sensibly and avoid foods that may be a potential source of infection.

The dietitian will discuss the sorts of food you should eat and also those that you should avoid until your immune system has returned to normal. (See Chapter 8 for more information about diet.)

Bacterial infections

Bacteria are microscopic organisms that can cause infection anywhere in the body. They secrete toxins that can interfere with normal organ functions or cause problems when they multiply rapidly. Some pneumonias, for example, are caused by bacteria that fill up the spaces in the lungs where air is normally absorbed into the body.

Bacterial infections are most common in the first few weeks after a BMT and affect more than half of BMT patients. These infections occur most often in the gastrointestinal tract (gut), on the skin (especially around a Hickman catheter or central line) and in the mouth. They also occasionally occur in the bladder and can cause pneumonia in the lungs.

Bacterial infections anywhere in the body can suddenly become extremely serious and can be fatal.

If you have an infection you may have some or all of the following symptoms:

- high fever (but not always)
- high pulse rate
- low blood pressure
- fast breathing rate
- discoloured mucus from lungs (sputum)
- pale appearance and clammy (sweaty) skin

If you have an infection or sepsis (bacteria or their toxins in your bloodstream), you will be monitored closely for any changes in your condition. Occasionally, if you have pneumonia, you may need a machine to help you breathe. This may be able to be done on the ward, or you may require transfer to intensive care. Sometimes, the decision to help you with your breathing is made early, before it is necessary, and this will be discussed fully with you. This may be done because your breathing rate is very fast, making you extremely tired and your breathing inefficient.

Life-threatening bacterial infections

Sometimes, complications can occur suddenly and progress quickly. These complications can lead to septic shock, a life-threatening condition that occurs when an overwhelming infection leads to low blood pressure and low blood flow.

If septic shock occurs, large amounts of extra fluids or drugs are given to try to increase blood pressure. If this does not work, you may need to move to intensive care where your condition can be monitored even more closely and you can be given special drugs to maintain blood pressure.

This is important because a long period of low blood pressure can cause major damage to important body organs, particularly the kidneys. Organs in the lower part of the body can be damaged if they don't get enough oxygen, because not enough blood is being pumped through them. You may also need help with breathing via a machine.

Dealing with an emergency

Unfortunately, in times of medical emergencies, such as septic shock, treating your physical condition is the medical team's first priority and there may not be enough time to explain everything fully, so it is important that you and your carers discuss these issues, in advance, with your BMT team.

If you become seriously ill, it is stressful for you and your carers, and it is difficult for everyone to think clearly. It is important to remember that such serious complications are relatively rare and that you and your carers will be involved as much as possible in discussing treatment options.

Prevention

You will be given oral antibiotics before and after your BMT to try to prevent common infections that come from your gut. These antibiotics may include ciprofloxacin and Flagyl. Fever is often the only obvious sign of infection, so your temperature will be monitored at least every four hours while you are neutropenic.

Treatment

If your temperature goes above 38°C, samples of blood, sputum, urine and stool will be taken to try to find the source of infection. An X-ray of the chest may be done. Treatment with antibiotics is started immediately, without waiting to identify the source of infection. This may take a few days, but often no source of infection can be identified. Some examples of antibiotics that are commonly used include gentamicin, vancomycin, cephalosporins and penicillins (see page 76).

The antibiotics are given intravenously over a number of days, depending on the severity and response of the infection. Your doctor may change the combination of drugs until the best for your particular infection is found.

Fungal infections

Fungal infections occur infrequently in people having an autologous BMT. Fungi may be a yeast (candida or thrush is the best known example) or a mould (such as those found on old bread). Some fungi live in our bodies without causing problems. However, the use of antibiotics before and after BMT to treat bacterial infections also destroys the beneficial bacteria in the body that keep fungi under control.

Prevention

Candida and aspergillus are the most common fungal infections after BMT. Candida, which is the fungus that causes thrush, is very common. It normally lives inside the mouth, vagina or gut, but beneficial bacteria that also live in these areas keep it under control.

Aspergillus is a common type of fungus that grows on decaying vegetation, such as compost heaps and fallen leaves. It can also be found in air-conditioning systems and at building sites. Aspergillus infections occur most often in the sinus passages or lungs and can cause pneumonia.

If your doctor believes you are at risk of developing a fungal infection, you may be given a drug called fluconazole daily. If you are having trouble swallowing tablets, you may be given the drug into your drip.

If you have had an aspergillus infection in the past, you may be given amphotericin or itraconazole instead.

At some BMT centres, special air-filtering equipment is installed in hospital rooms to remove fungi and other potential infections from the air. Eliminating fresh plants, fruits and vegetables from your environment also reduces the risk of fungal infections.

Treatment

Fluconazole and amphotericin are used to treat candida infections. Amphotericin and other antifungal drugs are given to treat aspergillus infections. Treatment may continue for a long time, until after discharge from hospital, as the infection is difficult to treat (see page 78).

A number of other drugs are used to treat fungal infections, and you will be given information about these if they are prescribed for you.

Viral infections

Viruses are tiny parasites that need other organisms (hosts), such as human cells, to survive and multiply. Viruses enter the host cell, change the genetic machinery of the cell and turn it into a factory that produces more of the virus. The virus eventually destroys or cripples the host cell and moves to nearby cells.

In healthy people, T-cells and antibodies produced by B-cells protect against invading viruses. Because these cells are destroyed or depleted after your conditioning therapy you will be more at risk of viral infections. Viral infections can be difficult to treat because they tend to recur repeatedly.

Viral infections after a BMT are caused by either exposure to a new virus, or reactivation of an old virus that had been dormant in your body. They are most common in the first year after a BMT, but may occur as late as two years after BMT. The most common fungal infections in BMT patients are caused by the cytomegalovirus (CMV), herpes simplex virus (HSV) and varicella zoster virus (VZV).

Herpes simplex virus (HSV)

Herpes simplex infections are caused by two separate viruses: herpes 1 and herpes 2. The herpes 1 virus causes cold sores in and around the mouth. About 70% of people are exposed to the herpes 1 virus, usually during childhood. The virus is highly contagious and is transmitted through contact with people who have active cold sores on their mouths.

Herpes 2, or genital herpes, is transmitted through sexual intercourse with an infected partner. Active infection causes blisters on the genital area.

Herpes infections often recur after the first episode. The virus can lie dormant in the body for many years, usually flaring up at times of stress or exposure to sun or wind. Some people who have the virus may not remember ever having had an active case of herpes, but the virus may still be in their body and will show up on a blood test.

Herpes infections usually occur in the first month after BMT and are mostly caused by the virus that is already present in your body. As well as the cold sores of a herpes 1 infection, BMT patients sometimes get skin lesions.

Prevention and treatment

If you know that you have had herpes, or blood tests show that you have, you will be given acyclovir tablets three times a day to prevent the infection reactivating. If you can't swallow tablets, you will be given this drug into your drip three times a day.

Herpes simplex is treated with acyclovir, or another antiviral agent, orally or intravenously, at higher doses than for prevention.

Varicella zoster virus (VZV)

Infection with VZV is often called shingles or herpes zoster. It is the same virus that causes chickenpox and only occurs in those who have already had chickenpox.

Symptoms include an itchy blister-like skin rash that follows the path of the body's nerve branches. This rash can be extremely painful due to the involvement of the nerve endings under the skin. Even a gentle touch to the skin can hurt. The ophthalmic nerve to the eye can also be affected. The painful rash can affect the nerve path on the forehead and eyelids and, if not treated promptly, can damage the eye.

If you develop VZV, it is important to contact your GP or BMT doctor as soon as possible, so treatment can be started immediately.

Prevention and treatment

Since VZV is highly contagious, patients who have never had chickenpox or who have had a negative blood test for the virus should avoid people with chickenpox or shingles for the first year after a BMT. It is treated with acyclovir, or another antiviral agent, either into a drip or orally, depending on the severity of the infection.

Cytomegalovirus (CMV)

About half the general population is exposed to CMV during their lifetime. It is more common in people who live in cities. You may not even know that you have been infected because CMV gives you flu-like symptoms and causes no long-term effects, unless your immune system is compromised.

Prevention and treatment

Before the BMT, you will have a blood test to see if CMV is in your body. If not, you are said to be CMV-negative and care is taken to prevent exposure to CMV before, during and after the BMT. Whenever possible, only blood products that are CMV-negative are used, and special filters are used when transfusing blood products to stop blood-borne transmission.

CMV infections occur only occasionally in autologous BMT patients and may develop in several different organs including the liver, colon, eye and lungs. If you develop a CMV infection, you will need treatment with a drug called ganciclovir.

Other viruses

Many other viruses – such as adenovirus, Epstein-Barr virus (EBV), respiratory syncytial virus (RSV) and human papilloma virus (HPV) – can cause infections after a BMT, but are not common. Adenovirus and RSV infections can cause pneumonia and can be serious.

Adenovirus can also cause infections in the kidneys or gastrointestinal tract and blood in the urine. In rare cases, the Epstein-Barr virus infects the lymph system, creating a lymphoma-like condition.

Commonsense measures, such as avoiding crowded public places or people with colds and flu, and good personal hygiene, reduce the risk of these infections.

Protozoa

Protozoa are single-cell parasites and, like viruses, need human cells to replicate. Infections from protozoa are less common than other infections but can cause serious problems for BMT patients who are T-cell deficient.

Pneumocystis carinii is a protozoa that usually lives harmlessly in the trachea or windpipe of healthy people, but can enter the lungs and form tiny cysts when the immune system is suppressed. This is called *Pneumocystis jiroveci* pneumonia (PJP). Bactrim and pentamidine are highly effective in preventing and treating this type of lung infection.

Toxoplasmosis

Another infection called toxoplasmosis occasionally develops in patients whose immune system is compromised. Toxoplasmosis is caused by a protozoan called *Toxoplasma gondii*, which is often transmitted in the faeces of cats. It may infect the brain, eyes, muscles, liver and/or lungs. A painful, inflamed retina in the eye is a common symptom of the disease, which, without prompt treatment can damage the eye.

It is vital to limit all contact with pets and to wash your hands thoroughly if you do have contact. Emptying the kitty litter is off limits.

Bactrim is effective in preventing toxoplasmosis infection.

Drugs used to treat infections

In this section we describe some of the drugs commonly used to treat infections. This list is by no means complete as there are hundreds of drugs available and the appropriate choice changes as new agents are developed or new evidence emerges.

Antibiotics

Initial treatment of infections consists of broad-spectrum antibiotics, which kill a variety of different bacteria and are effective against either Gram positive or Gram negative bacteria. These drugs are particularly important during the time of neutropenia early after BMT.

Commonly a combination of a cephalosporin or a penicillin is used, plus one of the aminoglycosides, usually gentamicin. Vancomycin may be started up front or added about two days after starting the initial combination therapy.

Cephalosporins

Cephalosporins are a group of antibiotics that kill certain bacteria by preventing the bacterial cell wall from forming. Brand names for these drugs include Cefepime, Ceftriaxone, Claforan and Keflex. They are effective against a variety of bacteria that cause infections in the respiratory, skin, blood, urinary and skeletal body systems.

Bacteria that are susceptible to the cephalosporins include streptococcus and staphylococcus species and *Escherichia coli* (E. coli). They should not be given if you have a history of allergy to penicillin.

Cephalosporins may be given into a drip or orally, but in BMT they are usually administered into the drip once or twice a day.

Possible side effects

- rash
- allergy
- decreased kidney function
- gut disturbances including nausea and diarrhoea

Penicillins

The penicillins are a group of antibiotics that kill bacteria by preventing cell wall production. Brand names for these drugs include Timentin and Tazocin. The types used in BMT are broad spectrum and are used to treat infections caused by bacteria such as E. coli, pseudomonas and staphylococcus. Substitutes are available if you are allergic to penicillin.

They are usually given into your drip 3-4 times a day, with each dose taking about 30 minutes.

More common side effects

- rash
- pain at the site of infusion if not given via a central line

Less common side effects

- anaphylaxis
- nausea and vomiting
- decreased kidney or liver function

Aminoglycosides

The aminoglycosides are a group of antibiotics that kill certain bacteria by preventing the formation of proteins essential for the maintenance of the bacteria. Brand names of these drugs are Gentamicin and Tobramycin.

They are effective against many Gram negative bacteria such as E. coli and pseudomonas, and some Gram positive bacteria such as the staphylococcus species. These organisms or bacteria cause infections in many body systems including respiratory, skin, blood, urinary and skeletal.

Gentamicin and Tobramycin are both given into the drip once a day.

More common side effects

- decrease in kidney function
- ringing in the ears or deafness (usually temporary and dependent on dose)

Less common side effects

- rash
- allergy
- gut upsets (mainly diarrhoea)

Drug levels are monitored regularly with doses changed if needed to prevent or decrease the chances of hearing loss or kidney damage.

Vancomycin

Vancomycin is an antibiotic that attacks bacteria by preventing the bacterial cell wall from forming. It also damages the cell membrane, which eventually results in killing the cell.

It is effective against bacteria such as *Clostridium difficile*, and the streptococcus and staphylococcus species.

Vancomycin is given orally for clostridium infections and into the drip for all other bacteria up to four times a day.

As with aminoglycosides, the drug levels are monitored regularly to prevent or decrease the chances of hearing loss or kidney damage.

More common side effects

- decreased kidney function
- ringing in the ears or deafness (usually temporary and dependent on dose)

Less common side effects

- moderate to severe flushing of the upper body and head ('Red man syndrome'), low blood pressure or cardiac arrest. These are possible side effects of rapid infusion.
- gut disturbances, such as nausea, vomiting and diarrhoea
- hypersensitivity, causing chills, nausea, rash and fever
- resistance by some organisms, such as vancomycin resistant enterococcus (VRE). This can result from prolonged overuse of vancomycin.

Antifungal drugs

Antifungal drugs are used to prevent or treat infections caused by fungi such as candida (Monilia), cryptococcus or aspergillus. It works by altering the membrane of the fungal cells to allow some of the small molecules in the cell to flow out, ultimately killing the cell.

They can be given orally or intravenously. Treatment may continue for months. Many patients will be given a premedication to prevent or decrease the severity of the side effects.

Many preparations of antifungal agents are available. Examples include itraconazole, pozaconazole, caspofungin, voriconazole and AmBisome.

More common side effects

- chills, rigors and fever
- decreased kidney function
- nausea and vomiting
- decreased appetite causing weight loss
- abnormal electrolyte levels, especially potassium

Less common side effects

- rash
- ringing in the ears or deafness, usually temporary
- hypotension, cardiac arrest
- abnormal liver function
- kidney failure

Antiviral drugs

Acyclovir

Acyclovir is an antiviral drug used to treat and prevent viral infections, particularly with herpes simplex or varicella zoster viruses.

Acyclovir is given either orally, or into the drip, three times a day, depending on your ability to swallow and retain the dose. It will start on day +1 and continue until engraftment is well established.

More common side effects

- rashes, susceptibility to sunburn
- decreased kidney function
- nausea and vomiting

Less common side effects

- allergy
- confusion, hallucinations, changes in level of consciousness, agitation
- change in liver function

Anti-protozoal agents

Cotrimoxazole

Cotrimoxazole (Bactrim DS) is an antibiotic consisting of two drugs, trimethoprim and sulfamethoxazole, which is used to prevent and treat *Pneumocystis jiroveci* pneumonia (PJP) and toxoplasmosis infection. Cotrimoxazole works by interfering with the building blocks of the protozoal cell leading to cell death.

To prevent PJP, cotrimoxazole is given twice daily, twice a week. To treat PJP, cotrimoxazole is given in high doses by vein.

The use of Bactrim for several months is very important, otherwise there is a serious risk of getting PJP (see page 84).

More common side effects

- nausea and vomiting
- lack of appetite
- rash
- bone marrow suppression, particularly when receiving treatment doses or on long-term treatment
- increased risk of sunburn
- liver dysfunction

Less common or rare side effects

- kidney dysfunction
- light-headedness, dizziness, unsteady walking
- headache
- ringing in the ears
- low blood sugar levels
- allergic reaction, particularly to the sulphur component
- electrolytes disturbances, high potassium

Liver complications

How the liver works

The liver, which lies under the ribs on the right side of the upper abdomen, is responsible for a variety of essential functions. Liver cells cleanse the blood of toxins and other waste materials, produce a fluid called bile to aid digestion and control the excretion of bilirubin, a by-product of red-cell breakdown.

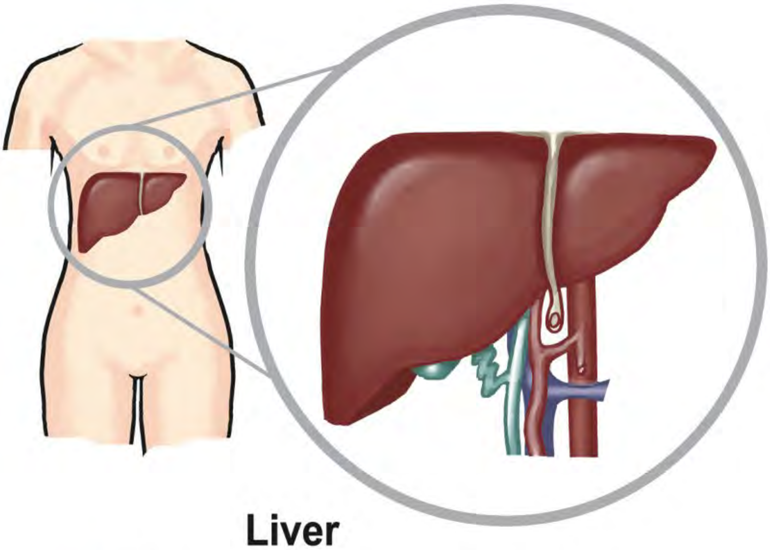
The liver also stores energy and makes proteins that control blood clotting.

As blood flows through the liver it passes through smaller channels called sinusoids, which are lined with liver cells. The cleansed blood flows out of the liver through a network of veins back to the heart.

The bile travels through the liver in the opposite direction to blood. It enters the gallbladder via bile ducts, where it is stored until needed in the intestine to aid digestion.

The liver's many essential functions may be disrupted during the transplant process. If the sinusoids become obstructed or liver cells are damaged, the liver cannot properly rid the body of toxins, drugs and other waste products.

Similarly, if the bile ducts become obstructed, excess levels of bilirubin, cholesterol and other chemicals build up in the body, interfering with the function of the liver and other organs.



Liver

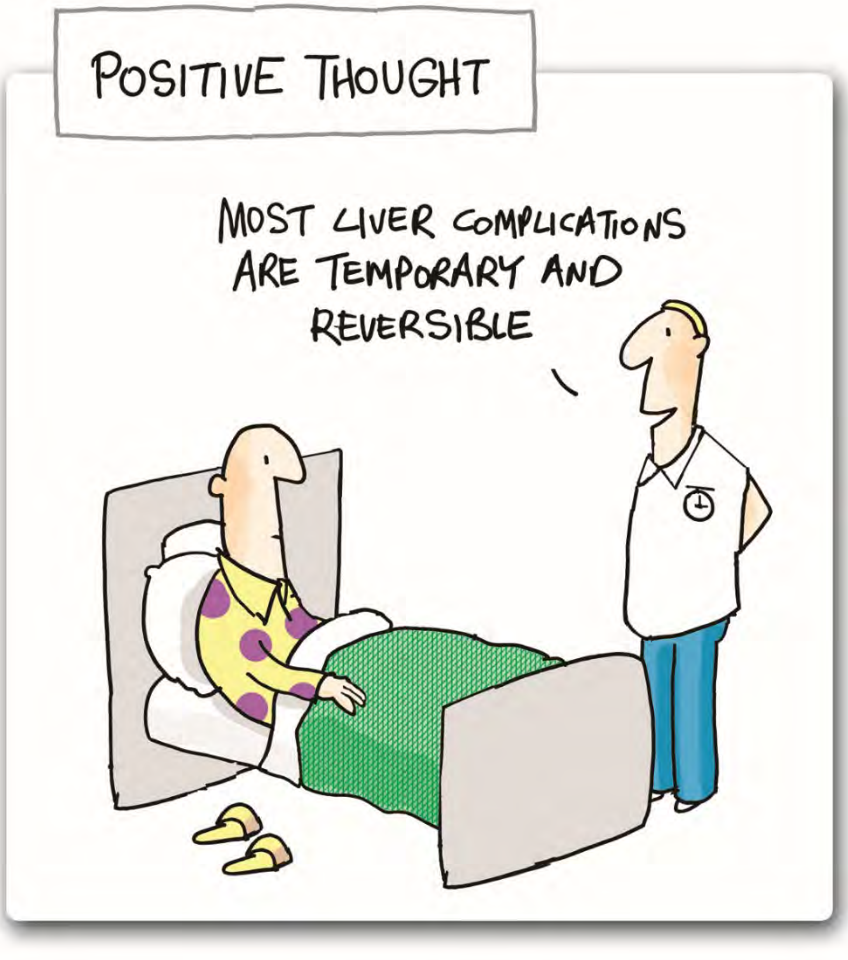
- Stores energy & makes proteins that control blood clotting.
- Cleanses blood of toxins & other waste material.
- Produces bile to aid digestion
  & control bilirubin (a by-product of red cell breakdown).

Disorders of the liver can be grouped in three types:

- those that directly affect the liver cells
- those that affect the vessels that transport blood through the liver
- those that affect the bile ducts that carry bile from the liver to the gallbladder and intestines.

More than one type of liver complication can occur at the same time. Most liver complications are temporary and reversible, but some can become serious and may be fatal. As many of the potential complications present in a similar manner, it may take time for the correct diagnosis to become clear.

In autologous BMT, many patients will develop abnormalities of liver function that usually resolve within 1-3 weeks.



Risk factors for liver complications

People who had abnormal liver function before the BMT may have a higher risk of developing severe liver complications during and after the transplant.

Before the BMT you will be tested for signs of fungal liver infections, hepatitis (inflammation of the liver usually caused by a virus) and gallstones or other obstructions of the bile duct.

Any treatment, such as removing fungal lesions or gall stones, will be done before the transplant, allowing time to recover before admission. The pre-transplant tests also give the BMT team information that may help prevent serious liver problems.

Many tests are used through all periods of the transplant to detect and identify liver complications.

While abnormal liver function tests commonly occur after an autologous BMT, it is uncommon for patients to have any symptoms or for these abnormalities to require any tests or treatment.

Liver problems

A number of factors can cause liver abnormality after an autologous BMT. The most common causes are drug related – either chemotherapy or drugs used to prevent or treat infection. In most cases these abnormalities resolve when the drug is stopped and/or within three weeks.

Other less common causes include:

- veno-occlusive disease also known as sinusoidal obstructive syndrome (very rare)
- bloodstream infections
- fungal liver disease
- viral hepatitis
- biliary disease

If you develop any of these problems, your BMT team will talk to you about them.

Lung problems

A variety of problems can damage the lungs after a BMT. The complications can be a result of infections, bleeding, damage from chemotherapy drugs or radiation.

Lung problems in the first 100 days

Bacterial pneumonia

Bacterial infection in the lungs is a relatively common complication in the 2-3 weeks after BMT. It is largely due to the low white blood cell counts that are typical during this time.

Pneumonia after a BMT results from infection with bacteria that are different from those that usually cause this condition in the community. These may be less responsive to antibiotics and more difficult to treat.

Symptoms include:

- fever and chills
- chest pains
- cough
- yellow or green sputum
- difficulty breathing

The BMT team will order chest X-rays to diagnose the problem and take blood and sputum samples to try to determine which bacteria are causing the infection. Bacterial pneumonia is treated with antibiotics given into the drip. Oxygen will often be needed. Occasionally, when the infection is severe, artificial support on a ventilator may be necessary.

Fungal infections

Fungus infects the lungs because it is inhaled from the environment. The symptoms are similar to bacterial pneumonia.

Often BMT patients will be nursed in areas that have filtered air to reduce the risk of developing fungal infections, and may be given anti-fungal drugs as a preventive measure. Chest X-rays or CT scans will diagnose the problem, and treatment is an anti-fungal drug, such as amphotericin.

Factors that increase the risk of fungal infections include:

- low white cell count, particularly neutrophils
- previous fungal infections in the lungs

Pneumocystis jiroveci pneumonia (PJP)

This form of lung infection can occur in people with a suppressed immune system. It is due to a small parasite, called *Pneumocystis jiroveci*, which normally lives in the airways in the lungs without causing illness, but can grow when the immune system is damaged, causing pneumonia. The symptoms are fever, dry cough and difficulty breathing.

PJP can be prevented and treated with varying doses of Bactrim.

Pulmonary haemorrhage

This is a relatively rare complication, usually occurring in the first month after BMT. Bleeding or haemorrhage from the lungs results in coughing up blood and difficulty in breathing. The causes are usually thought to be faulty blood clotting, especially low platelet count, and damage from the drugs used in conditioning therapy.

Treatment consists of correcting the clotting problems with transfusion of platelets and plasma products, giving large doses of steroid drugs, and assisting breathing by giving oxygen and sometimes artificial support on a ventilator.

Interstitial pneumonia

This condition occurs less commonly, but is still a potentially serious complication. It may be due to viral or protozoal infection, damage from radiation and drugs, or from unknown causes. It usually occurs in the first few months after BMT. Symptoms usually include fever, dry cough and difficulty breathing. Treatment involves drugs to treat any underlying infection, and giving oxygen, steroids and artificial breathing support as necessary.

Kidney and other complications

A variety of complications can affect the kidneys and urinary tract after a BMT. Often these are side effects of drugs, but infection and other complications may cause kidney problems.

Kidney failure

The function of the kidneys is to excrete excess water and eliminate waste products of cell metabolism in the urine. Some degree of failure of normal kidney function is common after a BMT.

Kidney function is measured by the volume of urine produced each day and the amount of various breakdown products in the blood. The most commonly measured of these is creatinine, a normal breakdown product of muscle. Regular analysis of blood samples after BMT will allow doctors to monitor the ability of the kidneys to excrete substances such as creatinine. In some patients, this will show early signs of reduced kidney function, well before more serious problems, such as reduced production of urine, occurs.

Several drugs routinely used after BMT can damage kidney function. Cyclosporin, in particular, commonly impairs kidney function. Both the creatinine level and the concentration of cyclosporin in the blood need to be measured regularly, and the dose of the drug adjusted if there are signs of kidney failure.

A number of antibiotics and antifungal drugs, particularly gentamicin and amphotericin, can damage kidney function, and kidney function and drug levels need to be closely monitored. Low blood pressure, usually due to serious infection, can lead to poor kidney function and failure.

Treatment of kidney failure will depend on the circumstances and its severity. Sometimes it will only involve omitting or changing doses of antibiotics, and waiting for the creatinine level in the serum to return to normal. In other situations antibiotics will need to be changed, and supportive fluids and drugs given to improve blood pressure.

Uncommonly, dialysis will be needed for severe kidney failure. This involves processing of blood using a dialysis machine to correct fluid and salt abnormalities. A central venous line, as well as any you already have, may need to be put in to allow dialysis to be done.

Severe kidney failure requiring dialysis is usually a correctable complication that can be fully reversed.

Haemorrhagic cystitis

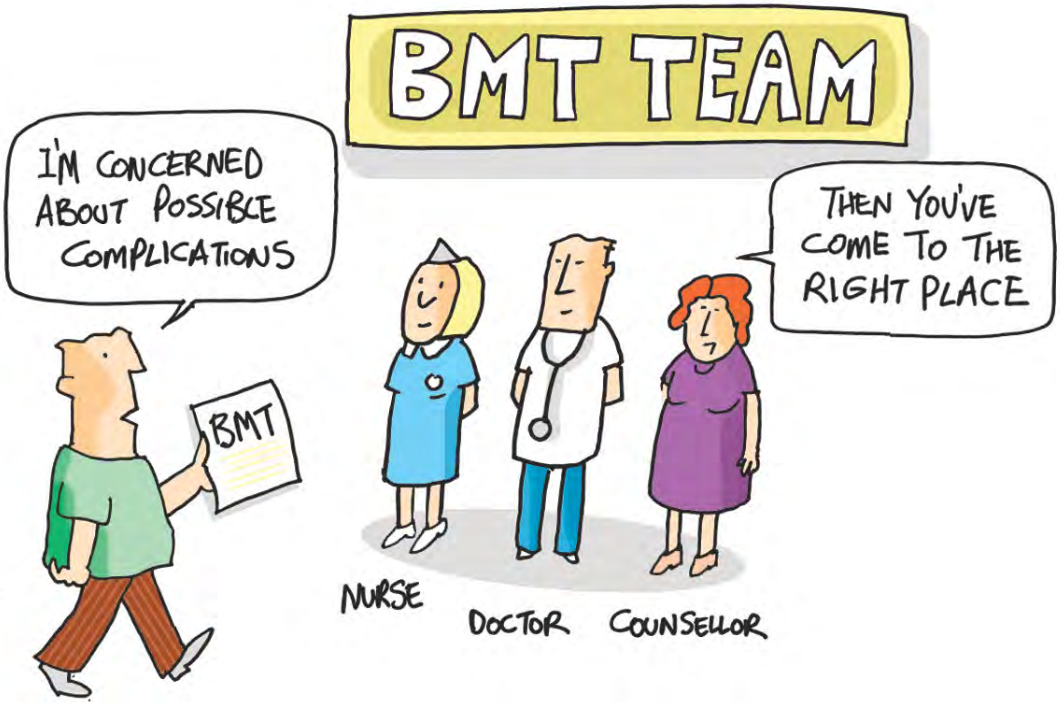
This condition results from damage to the lining of the bladder from drugs or viral infections. Symptoms include pain when passing urine, increased frequency of urination, and blood and clots in the urine.

Haemorrhagic cystitis, which may occur weeks to months after BMT, can vary from mild to severe. It is often associated with the use of cyclophosphamide during conditioning therapy, which can damage the lining of the bladder.

Certain viruses, particularly cytomegalovirus and parvovirus, can also cause haemorrhagic cystitis. There is no proven effective treatment for this condition, and treatment is supportive, i.e. blood and platelet transfusion, and washing the bladder out with fluids through a catheter as required.

Often the condition is mild and self-limiting, and resolves in a few weeks. Sometimes it is more severe, with considerable blood loss requiring transfusion.

Clots in the bladder may block the passage of urine, and a catheter may need to be inserted into the bladder to drain the urine and wash out clots with saline solution.



Key points

- Every person who has a BMT is an individual with their own risk factors. You may get no complications, or you may get one or more. There is no way of predicting your particular case.
- After an autologous BMT, your immune system will not be at full strength for 3-6 months. You are extremely vulnerable to infections during this time, and it is important to follow the hygiene guidelines to minimise the risk.
- Because your old immune system has gone after a BMT, you will have lost the immunity you previously had to certain infectious diseases and you will need revaccination against these diseases, plus some other vaccinations that you may not have had.
- Most liver complications are temporary and reversible, but some can be very serious. People who had abnormal liver function before the BMT have an increased risk of liver complications.
- Most kidney complications are also temporary and reversible, and are often related to the drugs given to treat other complications, especially some of the antibiotics used to treat infections.

CHAPTER 10

Life after a BMT

Going home

After being in hospital for a long time you may feel nervous about leaving. Some people say they feel a little daunted by the 'outside'.

Don't expect too much too soon. Like your experiences in hospital, just take life on the outside one step at a time. You will have some good days and some days when you don't have much energy. Try to be kind to yourself and realistic in your expectations. Remember to call or visit the BMT clinic if you have any concerns.

Start yourself on a gentle daily exercise program, such as walking, and gradually increase this as you feel able. Your body will be your best guide as to how much you can do.

Your carers will play a significant role in helping you adjust to life at home. In the first few weeks at home, you may need help with many normal daily activities until your strength improves. Early on, your carer may need to help you get to your clinic appointments.

You and your carer should also tell the team about any changes or difficulties you are having at home.

> "Survival is a privilege beyond price. It is a testimony to the survivor's toughness and resilience, as well as a piece of good fortune. All these things may be true in part but there is another side to survival, and for many people it is a darker side."
>
> *(Little et al, 2000)*
>
> *Surviving Survival, Life After Cancer*

Preventing infections

Your immune system will need at least 3-6 months to fully redevelop after the transplant. It is important to be careful to prevent infections during this time, particularly if your white cell count and neutrophils are low.

Some ways to help prevent infection include:

- Avoid crowded places like public transport, shopping centres and movie cinemas at peak times.
- Avoid or limit contact with people who are unwell, or who have had contact with others, particularly children with illnesses such as chickenpox or measles or who have been recently vaccinated.
- Don't go swimming if you still have a Hickman catheter or central line. If you want a bath, ensure the water level is below the exit site.
- Avoid gardening or contact with soil or potting mix because of the risk of contact with live bacteria.
- Don't wear contact lenses until you have discussed this with your team.

On discharge your transplant team will give you information about how to care for yourself at home. Make sure you report any symptoms when you attend the clinic – and call the clinic to get advice on your concerns.

Medications

When you leave the hospital, you will still be on medications to aid your recovery after the transplant. Continue to take your medications as directed by the team, as these are crucial to your recovery and the success of your transplant.

Your medications will be adjusted during your follow-up appointments with the transplant team. As your recovery progresses, the amount of medication should gradually decrease. Some people will need medication for several years after the transplant.

The BMT team will write out your medication schedule for you and it will be helpful to take this information to each clinic visit. Remember to ask early for extra supplies.

Follow-up clinic visits

You will have regular checkups at the BMT clinic at the hospital where you had your transplant. These visits give you an opportunity to get feedback on your progress from the BMT team and to raise any concerns.

The frequency of checkups varies between individuals, but generally they become less frequent as you recover.

If you live outside Sydney, you may need to stay near the transplant centre for several weeks after you leave hospital. Some complications of a BMT, such as an infection, can occur after discharge, so follow-up clinic visits allow the transplant team to keep a close eye on you.

The duration of clinic appointments varies. As well as seeing the BMT team, you may need blood or platelet transfusions or IV drugs, which can be done in the outpatient clinic.

It is normal to feel anxious before follow-up appointments, no matter how long it has been since your transplant. Talk about your worries with your doctor. Often just asking can help to put your mind at ease.

Revaccination

Because your immune system has been destroyed, you will have lost immunity to certain infectious diseases and will need revaccination against these diseases, plus other vaccinations that you may not have had. Revaccination is a way of educating your new immune system to cope with common infections. Revaccination will not be necessary or effective until at least a year after the transplant. Your BMT doctor will explain what you need, and organise the vaccinations through your GP. Depending on their individual situations, some people will need a different set of vaccinations to others. The BMT+CT Network has a patient vaccination card and guidelines for your GP. Ask you BMT Team for a copy.

Returning to work or study

An important part of going home and being on the road to recovery will be your return to work or study. Your transplant specialist will say when you can do this. It can be a good idea to initially work part time or reduced hours to see how you manage, and then increase gradually as you feel able. Most people find they can go back to work about 3-6 months after their transplant date.

Surviving BMT: recovery and a new 'normal'

Until recently, most people believed that once medical treatment was over, life could get back to how it was before the diagnosis. Recent research, however, has shown that many people don't simply "get back to normal" after a transplant.

The challenge of a life-threatening illness can leave people with a different sense of what is important in life. People may experience a range of physical, emotional and psychological changes and feel that the stress of treatment has changed their life and relationships.

Some may feel a stronger sense of gratitude for loved ones and find they are more mature, compassionate and accepting of other people and other situations.

> "The single most important strategy survivors indicate is important in making a successful adjustment post-treatment is that of accepting an altered sense of normalcy. The challenge is not to return to your pre-diagnosis self, but rather to accept and build on your new reality."
>
> *(Pam McGrath, 2001)*

Many people find their priorities have changed, that they are different to the person they were before the transplant. They may feel unsure about how they fit into the "post-treatment world". This sense of unease is normal and is to be expected.

Research has shown that the best thing you can do after the transplant is to accept your new normal, whatever it is, and build on the new reality.

It may take some time to adjust. If you need help to cope, talk to family and friends. It can help to make contact with others who have had similar experiences. Stay in touch with your BMT team and talk to them about how you are feeling.

Feelings about surviving BMT

Many BMT patients find it difficult to describe their feelings about surviving, even to their partners, families or friends.

Many have contradictory emotions about their cancer, their transplant and their 'new' self. While most are happy to be alive and to have got through the transplant, some feel scared, confused or depressed. Others may feel guilty about surviving the transplant where other people, some of whom became friends, have not survived. All of these emotions are common.

> "Getting better forced me to re-evaluate everything I'd ever believed in and plunged me into a despair I could hardly contain, let alone explain."
>
> *(Miles, 2000)*

Fear of recurrence

People who have had cancer often describe a changed relationship with their body. They no longer trust their body, or feel they can't rely on it to stay healthy, as it has failed them. This is especially true of haematological cancers, as many have few or no signs of symptoms, and are only revealed by abnormalities on blood tests. These feelings sometimes become particularly apparent before follow-up visits, which may create significant anxiety. For many people, clinic visits bring fears about the disease coming back, making the time before each visit very stressful.

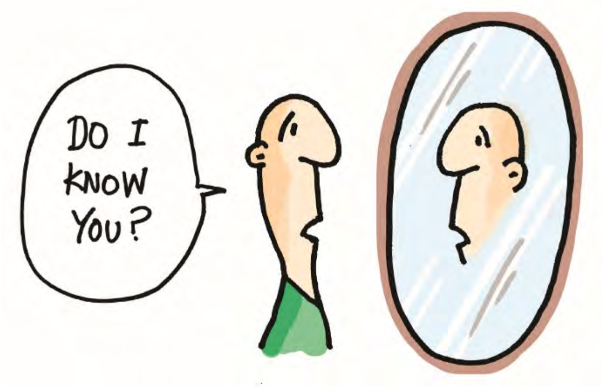
> "I felt that I didn't belong to either my old life or my new one."
> *(Miles, 2000)*

Many people worry that every symptom they experience, such as a cold or flu, is a sign that their disease has recurred. These are very real concerns, which most people have after BMT, and should not be ignored or dismissed.

Altered body image or sense of self

BMT survivors often experience many body changes. With hair loss, weight loss, loss of muscle tone and definition, skin changes that may occur due to chemotherapy or radiotherapy, and the effects of drugs such as steroids, it is little wonder some survivors say they are "no longer able to recognise themselves".

Your body shape and size may change throughout the BMT process, mainly because of medication or excess fluid. This can sometimes be hard, but try to remain flexible as your body adapts to the treatment.



Hair loss is one of the most noticeable changes. When your hair grows back, it may have a different colour or texture or it may be significantly reduced. Very rarely, it does not grow back. Ask to be referred to your hospital's wig library, if you haven't been already.

Changing relationships after transplant

BMT is not only difficult for you, but for the people close to you. The experience can place great strains on relationships and change them in ways that are difficult to explain or cope with.

Partners live through the experience of treatment and see parts of it that are very frightening. They are also forced to consider the possibility that their loved one may die.

The experience of cancer treatment and BMT disrupts day-to-day roles in relationships. Partners often take on the role of the carer, and may find that the need to provide support at home and at the hospital threatens their work and financial security. All these changes significantly affect the dynamics of a relationship. Partners may find it difficult to understand, or adapt to, how the cancer and BMT have changed their loved one. After the transplant, couples may feel like they have to start the relationship again, as the experience has changed them both. These difficulties are not impossible to overcome but need time, patience and understanding.

Sexuality

You and your partner may experience problems in your sexual relationships, resulting from the treatment process. The treatment involved and the emotional effects of BMT can impact negatively on the way you feel about your body image and sexuality.

The changes that occur in your body may leave you feeling less confident about the way you look. Side effects of the conditioning therapy can impair your sexual functioning and libido. These physical effects, fatigue and emotional difficulties can combine to make sex an after thought.

Despite such physical and emotional hurdles you can still have a fulfilling sex life. Sexuality is not only about how you look; it is about who you are and what you feel. It is your touch and warmth, how you laugh and smile, how you care and your personality.

If you want more information about sexual issues, talk to your BMT team.

Eating well

By the time you leave hospital you may have just returned to a more normal meal plan. Side effects, such as taste changes and poor appetite, while improving, may last for a long time and make it difficult to quickly regain weight.

It is important to eat well to restore weight, strength and condition, but remember that these are long-term goals. After discharge, weigh yourself weekly to check your progress.

You may need follow-up appointments with the dietitian until your nutritional status has returned to what it was before the BMT. Ask for the contact details for the dietitian before you leave hospital.

Medications, poor diet and illness may also make it difficult to control levels of electrolytes (essential for normal body function), particularly potassium and magnesium.

Your doctor may prescribe oral supplements, but you can help by increasing your intake of certain foods that are good sources of these electrolytes.

Potassium is in many foods but the best sources are fruits and vegetables including:

- tropical fruit, such as bananas, mangoes and paw paws
- stone fruit, such as peaches, nectarines and plums
- melons, especially rockmelons and honey dews
- dried fruits, such as prunes, dates and raisins
- fruit juices
- potatoes, spinach, silverbeet and mushrooms
- dried peas and beans
- chocolate (including cakes and biscuits) and licorice
- dried fruits or nuts
- wholemeal bread and cereals
- meat, chicken, fish and eggs

Potassium is also in drinks including:

- fruit and vegetable juices, vegetable soups
- broths made from meat, vegetable and yeast extracts, such as Bonox and Vegemite
- chocolate drinks such as cocoa, Milo, drinking chocolate
- beer and wine (check with your doctor first)

Magnesium also occurs widely in foods but the following foods are particularly good sources:

- wholemeal cereals and breads (especially wheat germ and bran)
- nuts
- green leafy vegetables
- legumes (dried peas and beans)
- dried fruit
- bananas and citrus fruits

Possible long-term side effects

Infertility

Conditioning therapies can have serious long-term consequences for the endocrine and reproductive systems.

Infertility is a risk with any anti-cancer treatment. In BMT, the high-dose treatment used in myeloablative conditioning treatment will often cause women's periods to stop and reduce or stop sperm production in men. Occasionally, however, sperm production will return after some months or years. The production of male sex hormones by the testes is relatively unaffected, so hormone replacement is generally not required.

In women, the ovaries are usually severely affected. This results in infertility in most women, as well as premature menopause, with symptoms of hot flushes, vaginal dryness, ceasing of menstrual periods and mood changes. This can be diagnosed with a blood test and is usually treated with hormone replacement therapy.

Although infertility is usual after a BMT, it cannot be taken for granted, so contraception is still needed.

Second cancers

Long-term survivors of BMT are at an increased risk of developing a second cancer, largely due to exposure to strong doses of drugs such as cyclophosphamide and to total body irradiation, which damages the DNA of cells.

The risk of second cancers is not great, but it is enough to justify careful follow-up of BMT patients in the long term.

Skin cancers are a particular problem in Australia because of the high levels of UV radiation, so it's important to stay out of the sun in the middle of the day and to use sunscreen and protective clothing.

Key points

- Be easy on yourself when you go home. Don't expect too much too soon.
- Your immune system won't be fully recovered until at least 3-6 months after you leave hospital, so it's important to avoid sources of infection.
- When you leave hospital, your transplant team will give you information about how to care for yourself at home.
- You will need to visit the hospital BMT clinic for regular checkups. When you visit the clinic, make sure you report any symptoms. You can also call the clinic to ask about any worries.
- It is normal to feel anxious before follow-up appointments. Talk about your worries with your doctor. Often just asking helps you feel better.
- Most people return to work or study 3-6 months after the transplant. It's a good idea to work part time at first.
- Many people are anxious about their disease recurring after the BMT. This is an understandable concern, which should not be ignored or dismissed.
- There are many changes after a transplant affecting your physical appearance, your emotions, relationships and sex life. It can take some time to get used to your 'new normal'.
- Medications, poor diet and illness may make it difficult to control levels of electrolytes, particularly potassium and magnesium, which are essential for normal body function. Your doctor may prescribe supplements but you can help by eating foods that are good sources of these electrolytes.
- It may take a long time to get back to your normal eating habits. However, with regular monitoring and support, you should be able to cope with your body's changing nutritional needs.
- Long-term side effects may include infertility and second cancers.

Glossary

allogeneic bone marrow transplant
A transplant that uses stem cells donated by another person.

apheresis
A process in which stem cells are collected or harvested from the patient's blood.

apheresis machine
A machine like a big centrifuge, which spins blood and separates it into white blood cells, red cells and plasma. It skims off stem cells from donated blood.

aspergillus
A common type of fungus that grows on decaying vegetation, such as compost heaps and fallen leaves. It can also be found in air-conditioning systems and construction sites or where buildings are being remodelled.

autologous bone marrow transplant
A transplant that uses the patient's own blood stem cells.

bacteria
Microscopic organisms that can cause infection anywhere in the body.

bile
A thick digestive fluid secreted by the liver and stored in the gall bladder. It aids digestion by breaking down fats.

bilirubin
A by-product of the breakdown of red cells. It can be measured to monitor liver function.

biopsy
The removal of a small sample of tissue to help in diagnosing a disease.

bone marrow
The soft, spongy part in the centre of the bones where blood cells are produced. The bone marrow makes stem cells.

bone marrow harvest
A procedure in which bone marrow is collected from bone while the patient is under general anaesthetic.

bone marrow transplant (BMT)
A treatment option for some people who have life-threatening blood or immune system diseases. It is the process of replacing unhealthy bone marrow cells with healthy cells.

broad-spectrum antibiotics
Drugs that kill a variety of different bacteria.

bronchoscopy
A procedure to look at the lungs and take a biopsy if necessary, using a bronchoscope, which is a flexible tube that is inserted through the nose or mouth and down the windpipe.

Bu/Cy protocol
Conditioning therapy with the drugs busulphan and cyclophosphamide.

candida
The common fungus that causes thrush. It normally lives inside the mouth, vagina or gut but beneficial bacteria that also live in these areas keep it under control.

central line
Also known as Hickman catheter. A catheter that is inserted under the skin of the chest into a vein. It is a long, hollow tube that usually has two or three passages (called lumens), which stays in place during the BMT and is used to collect blood samples and give medications and fluids.

committed progenitor cells
The offspring of myeloid and lymphoid stem cells that can only turn into one type of mature cell.

computerised tomography (CT or CAT scan)
A detailed picture of inside your body, made up of X-rays.

conditioning or preparative therapy
Giving very high doses of chemotherapy drugs, sometimes with whole body irradia- tion, before a BMT. This kills cancer cells and suppresses your immune system, allowing the donor’s cells to engraft and start working in your body.

creatinine
A normal breakdown product of muscle.

dialysis
A process for removing toxic substances (impurities or wastes) from the blood when the kidneys are unable to do so. A dialysis machine is similar to the apheresis machine, which is used to collect peripheral blood stem cells.

dietitian
A health professional who specialises in human nutrition.

electrolytes
Salts in the blood and other body fluids that carry an electric charge and are mainly responsible for the movement of nutrients into cells and of waste out of cells.

engraftment
New cell growth. It takes place after the bone marrow transplant when there is a sustained rise in new blood cell production.

erythrocytes
See red blood cells.

gated heart pool scan (GHPS or 'gate')
A test for heart damage done in the nuclear medicine department of the hospital.

glomerular filtration rate (GFR)
A test of kidney function.

granulocyte colony stimulating factor (G-CSF)
A synthetic copy of a naturally occurring bone marrow hormone. It stimulates the growth of bone marrow stem cells and releases stem cells from the marrow into the blood.

haemoglobin
A protein that carries oxygen from the lungs to all parts of the body and gives blood its red colour.

hepatitis
Inflammation of the liver, usually caused by a virus.

Hickman catheter
See central line.

jaundice
Yellowing of the skin, the mucous membranes or the eyes.

lactose
A type of sugar found in milk and some milk products.

leukocytes
See white blood cells.

liver
The organ that lies under the ribs on the right side of the upper abdomen and is responsible for a variety of essential functions. Liver cells cleanse the blood of toxins and other waste materials, produce a fluid called bile to aid in digestion, and control the excretion of bilirubin, a by-product of red-cell breakdown.

lumbar puncture
A test of the fluid surrounding the spinal cord and brain (cerebrospinal fluid) for certain diseases. A needle is carefully inserted between the bones in your spine to take a sample of the fluid.

lymphocytes
A type of white blood cell that fights viral infections and helps destroy parasites, bacteria and fungi.

mobilisation
When the bone marrow increases production of stem cells, which then spill out into the circulating blood.

monocytes
A type of white blood cell that ingests and destroys bacteria and fungi, and cleans up cellular debris left behind after infection.

mucositis
A side effect of BMT treatment that causes mouth and throat pain.

mucous membranes
Moist surfaces of the eyes, mouth and gut.

neutrophils
A type of white blood cell that ingests and destroys bacteria.

nutrition
The process of eating and digesting food the body needs.

nutrition supplement
A food or drink that provides extra energy, protein and/or vitamins.

patient controlled analgesia (PCA)
A method of pain relief where the patient presses a button on a remote control device to inject a preset dose intravenously.

peripheral blood stem cell harvest
A procedure in which stem cells are collected from the circulating blood.

peripheral blood stem cell transplant
A BMT using stem cells collected from circulating blood (the peripheral blood).

platelets
A type of blood cell that initiates clotting to stop bleeding.

pluripotent stem cell
An early-stage cell in the bone marrow that is able to make copies of itself. These cells also make lymphoid and myeloid stem cells, which evolve into the different types of blood cells.

precursor cells
Cells that are almost mature.

protein
An essential nutrient that helps the body build and repair connective tissue, cell membranes and muscle cells.

protozoa
Single-cell parasites which, like viruses, need human cells to replicate.

red blood cells
Also called RBCs or erythrocytes. Contain haemoglobin, and transport oxygen to, and remove carbon dioxide from, the body tissues.

septic shock
A life-threatening condition that occurs when an overwhelming infection leads to low blood pressure and low blood flow. Vital organs, such as the brain, heart, kidneys and liver, may not function properly or may fail.

spleen
An organ that collects lymphocytes and destroys blood cells at the end of their lifespan. It is situated high in the abdomen on the left side.

stem cells
Early-stage cells that produce other cells. Each tissue in the body contains stem cells that renew and replace that tissue when needed due to damage or wear and tear. Stem cells generate all blood cells in the human body, including red cells, white cells and platelets.

total body irradiation (TBI)
Radiotherapy to the entire body.

total parenteral nutrition (TPN)
Nutrition that is delivered intravenously.

viruses
Tiny parasites that need other organisms (hosts), such as human cells, to survive and multiply.

white blood cell
Also called WBCs or leukocytes. Fight infection and protect the body against foreign organisms.

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Arrow Bone Marrow Transplant Foundation is a registered charity committed to improving the quality of life for all bone marrow transplant patients.

We do this by:

- providing financial assistance and information to bone marrow transplant patients, their families and carers
- supporting the educational and professional development needs of nurses and other health care professionals working in the transplant field, and
- investing in medical research that improves bone marrow transplant patient outcomes.

Arrow's support of this patient information book is an important part of our patient support program.

You can help Arrow continue our support of these publications and other activities by donating online at www.arrow.org.au. You can also call us or email us to have a chat about ways you can help.

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