

DONATING TO YOUR RELATIVE



**WHAT TO EXPECT WHEN YOU'RE DONATING
STEM CELLS TO A FAMILY MEMBER**



What's in this booklet?

This booklet was developed to help adults who are thinking about donating stem cells to their relative. The information comes from blood cancer experts, and the stories that donors have shared about their experiences. It is designed to:

- give you and your family information that is easy to understand
- help you work through how the donation and transplant process works
- help you work through the emotional challenges you may face when donating to your family member.

This booklet is designed as a personal record for you to keep. You might find it helpful to record:

- these details for your own reference
- what happens and when, with space to write down the main points discussed
- any questions you want to ask
- details of your experiences between donor work-up and the donation and maybe your personal thoughts/feelings.

Not all of the booklet will be relevant to you. You don't have to read it all at once – you might find that you look at some parts and come back to others later. The aim is for you to use this as a tool to fill in any gaps in terms of information or support you might need.

We hope it will help you to feel confident about checking information and asking for help from the healthcare team.



Version 1.0 | May 2018
CMM Jun'18 0143_mg



Contents

What is this booklet?	2
Learning about blood cancer	4
What is blood cancer?	4
What is a stem cell transplant?	6
Learning about donor search and selection	8
What is tissue typing?	8
Stem cell donation process	9
Step 1: Getting ready to donate	9
Step 2: Donating peripheral blood stem cells or bone marrow	10
Step 3: Recovery and follow up	11
Donating peripheral blood stem cells	12
Donating bone marrow	14
Will I need to donate again?	15
What happens if you're unable to donate?	15
Common challenges for family donors	16
We asked, they answered	19
The emotional side of the experience	20
What's next for your relative	23
Engraftment	23
Potential post-transplant side effects	23
More information	25
Questions prompt list	28
Donor dictionary	30
References	33
Acknowledgements	34

“

*It was a very rewarding experience, made me feel very proud,
you know... to be chosen... I guess chosen for this role and... yeah, I felt you know...
a deep connection to my brother through this procedure.*

Cameron (front cover), who donated stem cells to his brother Patrick

”

Learning about blood cancer

Learning about blood cancer may help you to better understand your relative's disease and treatment options. The following information is a general summary of blood cancer and stem cell transplantation.

What is the difference between a bone marrow and a stem cell transplant?

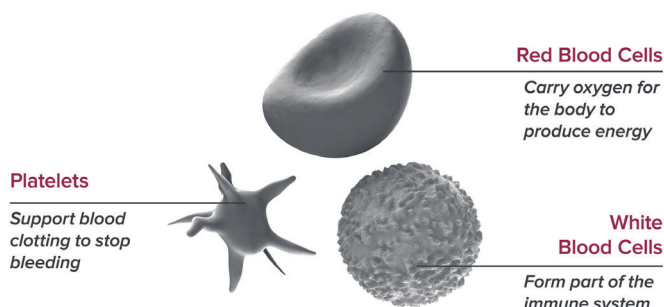
The terms 'bone marrow transplant' and 'stem cell transplant' are often used interchangeably. However, technically speaking – bone marrow transplants use stem cells collected directly from the bone marrow whereas stem cell transplants use blood stem cells collected from the bloodstream (also called a peripheral blood stem cell transplant).

Today, transplanted stem cells are most often collected from the bloodstream.

Be aware that there is a lot of information about blood cancer and stem cell transplantation on the Internet. Not all of it is scientific, and even if it is scientific it might give you details about treatments which are done differently, for example overseas. We encourage you to use the reliable websites listed at the end of this booklet.

What is blood cancer?

Blood cancers affect the production and function of the cells created in the bone marrow. Bone marrow is the spongy tissue inside our bones and it is the place where new blood cells are produced. Our bone marrow produces red blood cells for carrying oxygen, platelets to help blood clot and white blood cells that fight infections.

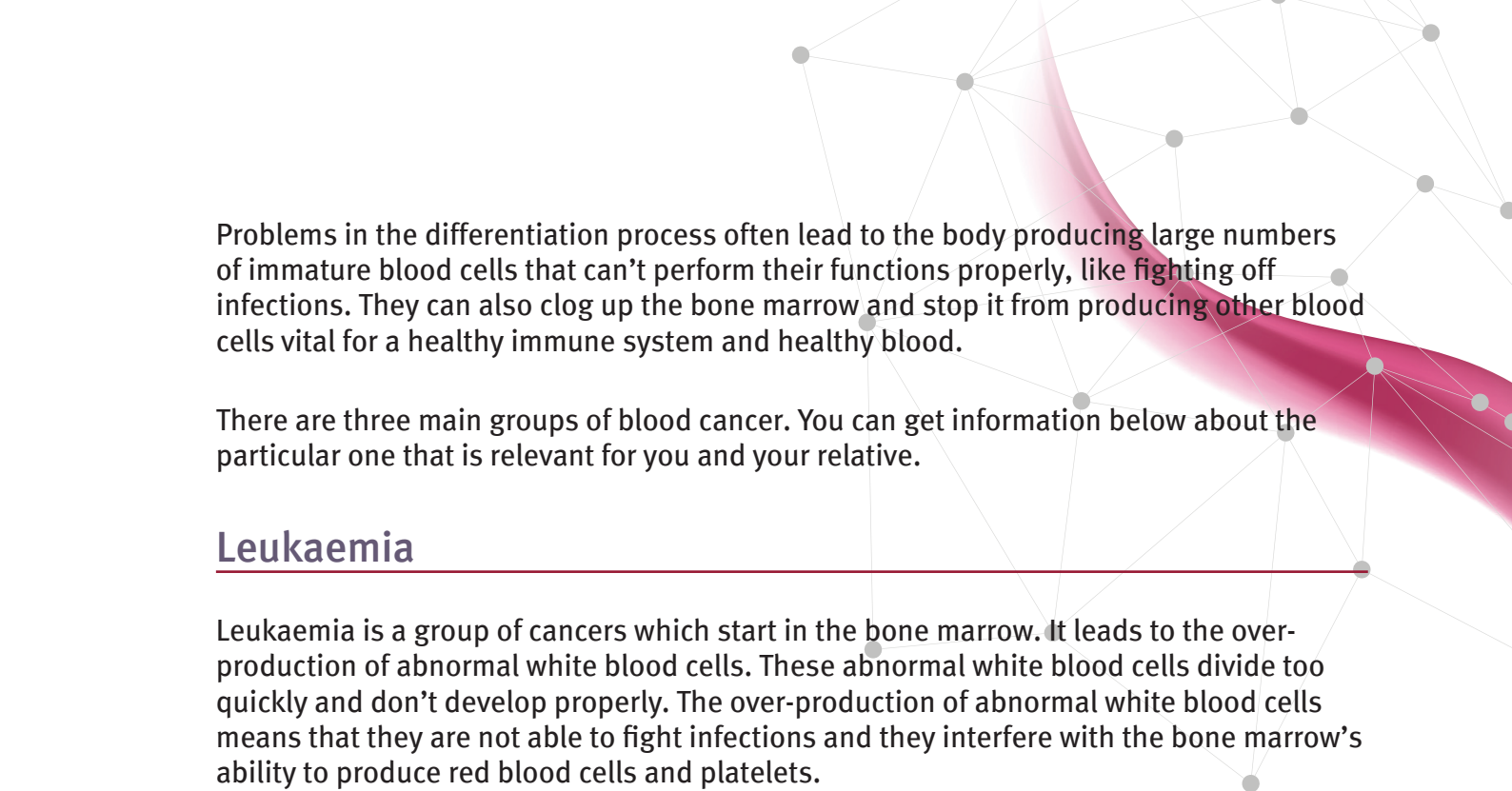


(*This image was provided by the Leukaemia Foundation)

These different cells all develop from stem cells in the bone marrow through a process of 'differentiation', meaning immature cells dividing and maturing into mature blood cells depending on the body's requirements. If the

process of differentiation is interrupted, it can lead to the development of blood cancers. The type of blood cancer your relative has depends on exactly when and how this interruption took place.

Every day, 35 Australians are diagnosed with blood cancer.
That's over 12,000 Australians per year.



Problems in the differentiation process often lead to the body producing large numbers of immature blood cells that can't perform their functions properly, like fighting off infections. They can also clog up the bone marrow and stop it from producing other blood cells vital for a healthy immune system and healthy blood.

There are three main groups of blood cancer. You can get information below about the particular one that is relevant for you and your relative.

Leukaemia

Leukaemia is a group of cancers which start in the bone marrow. It leads to the over-production of abnormal white blood cells. These abnormal white blood cells divide too quickly and don't develop properly. The over-production of abnormal white blood cells means that they are not able to fight infections and they interfere with the bone marrow's ability to produce red blood cells and platelets.

The different types of leukaemia are categorised as either 'acute' or 'chronic' based on how they behave. In acute leukaemia, the number of abnormal white blood cells increases rapidly and the disease gets worse. Acute conditions therefore need treatment as soon as possible. In chronic conditions, some abnormal white blood cells are present but the cells are more mature and can perform some of their functions. The number of abnormal white blood cells also increases more slowly than in acute conditions, so intensive treatment may not be needed.

There are four common types of leukaemia:

- Acute lymphoblastic leukaemia (ALL)
- Acute myeloid leukaemia (AML)
- Chronic lymphocytic leukaemia (CLL)
- Chronic myeloid leukaemia (CML).

Other types of leukaemia include:

- Acute promyelocytic leukaemia (APL)
- Hairy cell leukaemia (HCL)
- Large granular lymphocytic leukaemia (LGL)
- T-cell acute lymphoblastic leukaemia (T-ALL)
- Chronic myelomonocytic leukaemia (CMML).

Lymphoma

Lymphoma is a type of blood cancer that develops when lymphocytes (white blood cells) in the lymphatic system behave abnormally. They divide in an abnormal way or do not die when they should. The lymphatic system is part of the body's immune system and plays an important role in protecting the body from infection and disease. It is made up of a lymph; a fluid that carries lymphocytes and other immune cells, lymph vessels and lymphoid tissue. Lymphoid tissues are present in many parts of the body, including lymph nodes, bone marrow, blood, spleen and other organs.

Lymphoma can develop in any part of the body that has lymphoid tissue. Lymphomas tend to collect in lymph nodes which then enlarge to form cancerous lymph nodes. They can also sometimes spread to other parts of the body. There are two main types of lymphoma, based on how they behave and their treatment:

- Non-Hodgkin lymphoma
- Hodgkin lymphoma.

Myeloma

Myeloma is a blood cancer that affects a type of white blood cell called plasma cells. Normal plasma cells are found in the bone marrow. They are part of the immune system and produce antibodies which play an important role in the body's ability to fight infection. In myeloma, large numbers of abnormal plasma cells spread throughout the bone marrow. Myeloma can therefore develop anywhere there is bone marrow, including the pelvis, spine and ribcage. Myeloma is often called multiple myeloma because most people have myeloma in several places in the body.

What is a stem cell transplant?

A stem cell transplant may be recommended for people with blood cancers such as leukaemia, lymphoma or myeloma. Not all people with blood cancers will need a transplant. A stem cell transplant may be required if the cancer worsens, the cancer does not go away after other treatments or the cancer type is known to reoccur after treatment.

How does a stem cell transplant work?

A stem cell transplant uses chemotherapy (and sometimes radiotherapy) to destroy the abnormal cells within the bone marrow. As an unwanted effect, chemotherapy and radiotherapy may also damage healthy stem cells in the bone marrow which then need to be replaced.

A stem cell transplant itself replaces the damaged bone marrow with healthy stem cells. The new stem cells will rebuild the body's blood and immune systems.

There are two different types of stem cell transplant; autologous and allogeneic.

Autologous transplant

When the patient donates his or her own stem cells, we call it an autologous transplant. The patient's blood stem cells are collected in advance (while they are in remission, or the disease level has been reduced as much as possible) and then returned to them after they receive chemotherapy.

Allogeneic transplant

When the stem cells are coming from a donor (related or unrelated donor) we call it an allogeneic or allograft transplant. The donor is usually chosen based on how well they 'match' up with the patient. This means their tissue type or human leukocyte antigen (HLA) needs to be as similar as possible to the person receiving the stem cells. We analyse this using a method known as 'tissue typing'.

Each year, over 1,500 stem cell transplants are carried out in Australia.
About one third of these are allogeneic transplants.

What issues does this raise for me?
Are there questions or concerns?

Learning about donor search and selection

What is tissue typing?

Matching of stem cell donors to a recipient is determined by comparing tissue types, also known as their Human Leukocyte Antigen (HLA) types. Your HLA is what makes you ‘you’ – it’s your very own genetic fingerprint, like your blood group, only much more unique to every individual. It’s made up of genes, and within the genes are five key sites, or loci.

Each one of these five sites has two alleles (types of genes) – one inherited from your father and one from your mother, making 10 in total. There are millions of different combinations of these HLA types – and some are more common than others. For some patients, there could be thousands of people out there who match their HLA. For others, it could be a challenge to find even one. It’s important that we find the best possible match because the donor’s stem cells need to be accepted by the patient’s body. This is called engraftment.

If you’re a sibling, you’re normally tested first. As a sibling you have a 25 per cent chance of being a match for your brother or sister. This is because our individual tissue types are a combination of both our parents’ tissue types. So not every combination will be the same and not every sibling will be a close enough match to donate.

Recent medical advances have made it possible to use stem cells from a family member whose HLA is half matched. We call this a ‘haploidentical’ match. Parents are always a half-match for their children, and vice versa. Siblings have a one-in-two chance of being a half-match for each other. Almost all people have at least one potential haploidentical match in their family.

With improvements in medical treatment, complications of a haploidentical transplant, such as graft-versus-host-disease (described in more detail on page 25) appear to not be increased compared to transplanted cells from HLA matched sibling donors or unrelated donors. The transplant team will consider a haploidentical match if a sibling match cannot be found and provide you with the relevant guidance.

Once tissue typing has been completed, the most suitable person is asked if they are willing to be the donor and advised of the stem cell collection process. The steps involved in this process are discussed in the next section.

Stem cell donation process

There are several steps in the donation process. These steps are in place to ensure that you as a donor are the best match for your family member and that you are medically able to donate. This section deals with what you need to consider once you have been identified as a suitable donor for your family member.

Step 1: Get ready to donate

All stem cell donors must undergo a 'donor workup' to assess their ability to donate their stem cells. A BMT Donor Coordinator will contact you to discuss a mutually convenient location to have the workup. This may be at the hospital where the transplant will happen or with your local General Practitioner (GP). Generally, the workup must be completed within 30 days of the stem cell collection. You should highlight any concerns, anxieties, planned holidays, financial difficulties or work dilemmas to the BMT Donor Coordinator so he/she can assist you as much as possible. At the work-up, you will be asked to:

- Participate in an information session. You will be given detailed information about the donation procedure and recovery process, including risks and side effects. If you agree to donate, you will sign a consent form
- Have a physical exam and give blood samples to make sure the donation is safe for both you and the patient
- Have the veins in your arms checked by a registered nurse to see if they are suitable for the procedure. If your veins are not suitable for stem cell collection, a booking will be made in the X-Ray department for you to have a special line called a 'Vascath' inserted. A Vascath is a temporary plastic tube which will allow blood to be taken and returned during the stem cell collection.

It may take up to 7 days before the doctor has formally declared you fit to donate and signed the final donor clearance forms. The BMT Donor Coordinator will be in close contact with you and keep you informed of the next steps.

As part of getting ready to donate, we recommend that you start thinking about making plans for being driven home by a relative or friend after your donation and pre-arranging time off work.

Step 2: Donate peripheral blood stem cells or bone marrow

At the donor workup, both peripheral blood stem cell donation and bone marrow donation will be discussed with you. You have the right to select one collection method over another and we encourage you to disclose your preferences to the BMT Donor Coordinator as early as possible. At the donor workup, the donation date will be confirmed.

Sometimes, these dates may need to change – if, for example, your family member's condition changes close to the transplant and the doctors decide the process needs to be delayed. The BMT Donor Coordinator will liaise with you if this is the case.

There are two main methods of donation:

Peripheral blood stem cell (PBSC) donation

In most cases, donation is done by a process called peripheral blood stem cell collection (PBSC). PBSC is a non-surgical procedure. For 4 days leading up to donation, you will be given injections of granulocyte colony-stimulating factor (G-CSF, described in more detail on page 12). G-CSF is a medication that increases the number of blood-forming cells in your bloodstream. On the day of donation, blood is removed through a needle on one arm and passes through a machine called apheresis that separates out the blood-forming cells. The remaining blood is returned to you through the other arm.

You might like to bring something with you to do, e.g. an electronic device to watch a movie or listen to music/podcast. Keep in mind that it will be hard to bend your arms during the procedure. Once you are on the apheresis machine you will be unable to visit the toilet so try to use the toilet right before the procedure. Assistance will be provided if you do need to use the toilet once you are connected to the machine.

Bone marrow donation

Some donate their bone marrow, which is a surgical procedure that takes place in a hospital operating room and requires a general anaesthetic to minimise discomfort during the procedure. Doctors use needles to withdraw liquid marrow from the back of the pelvic bones.

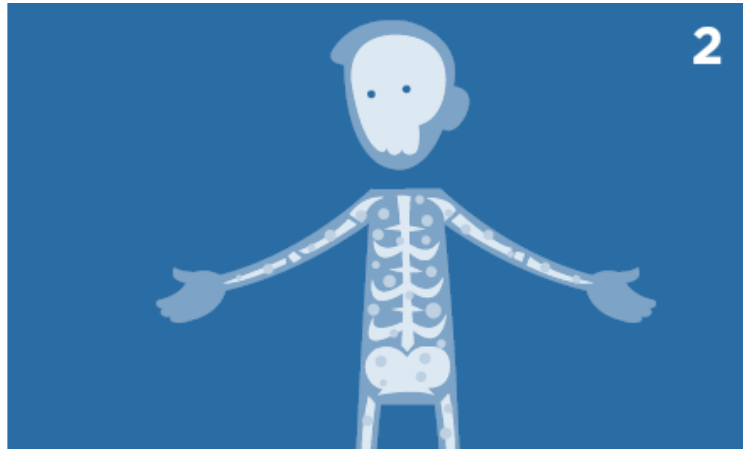
We briefly describe the two different methods on the next pages, but the transplant team will discuss both of them with you in more detail during your donor assessment. Talk to them about any concerns you have, and find out who to contact in case you've got any questions once you've donated.

Donating peripheral blood stem cells



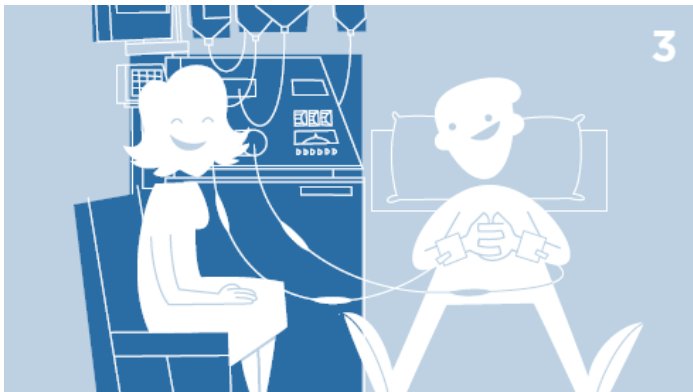
Donor work-up

At the donor work-up, you will have some tests done at the transplant centre (blood tests, chest x-ray). The BMT Donor Coordinator will let you know your test results and confirm details for your donation.



Daily G-CSF injections

Once a day for four or five days before the stem cell collection, you'll have granulocyte colony-stimulating factor (G-CSF) injections. G-CSF is a naturally-occurring hormone which stimulates the blood stem cells in your bone marrow to enter the blood stream. G-CSF can be administered by a nurse at the hospital or self-administered.



The donation day

While you're resting in a comfortable chair, the apheresis machine will draw blood from your arm, collect the stem cells, and return your blood to the other arm. This can take four to five hours. Most of the time enough stem cells can be collected in one day. But you may be asked to come back the

next day if not enough cells have been collected. We recommend that you ask a relative or friend to drive you home afterwards.

Recovery

After the donation, you might feel tired and experience some symptoms similar to a cold or the flu. These pass after a few days. Most people find that having rest, eating well and maintaining adequate fluids helps them to feel better.

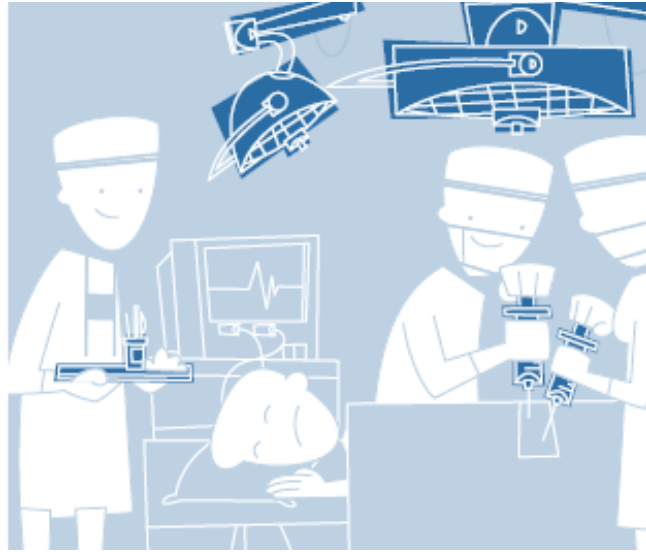


Donating bone marrow



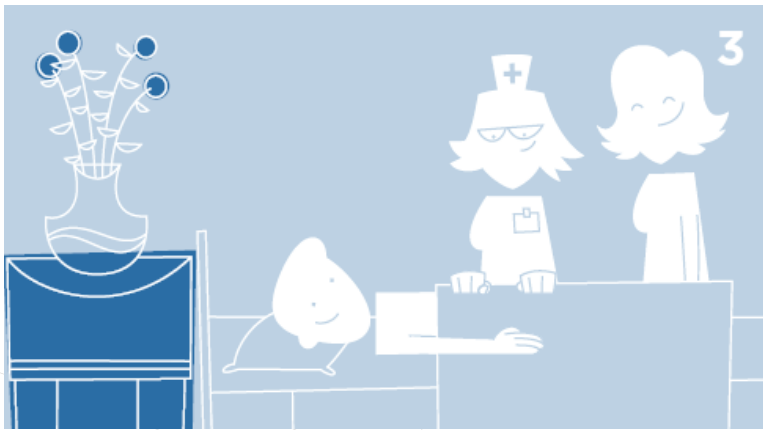
Donor work-up

As with donating by PBSC, you will have some tests done at the transplant centre. The hospital will let you know the test results and confirm details for your donation.



The donation day

Bone marrow donation takes place in a hospital operating room under general anaesthetic. After you are asleep, two needles are inserted into the back of your hip bones to extract bone marrow.



After your donation

You wake up with two plasters over the marks where the needles were inserted.

Generally you can go home the same day but sometimes you might need to stay overnight in hospital recovering from the anaesthetic.

Recovery

After the procedure, you might feel tired and experience some pain where the needles were inserted for a few days. Most people find that taking paracetamol, having rest, keeping up fluids and healthy eating is helpful.

**These illustrations were provided by Anthony Nolan who support improving information for patients and donors.*



Common challenges for family donors

We know that donating can be challenging, particularly to a loved one. Following are some of the challenges you may face, and tips from previous donors that may help you cope with these challenges. These are included with the consent from donors. Their names have been changed to protect their confidentiality.

Feeling anxious

As you are not only a relative to someone who is seriously ill but also a donor, it is normal to feel anxious. You might be concerned about different parts of the donation or transplant procedure.

I'm terrified it won't work. I quit smoking two months ago and I'm carrying some guilt from that particularly related to the outcome. – Ben, donor for his brother

If it rejected or failed, if something failed, he would... I would let him down.
– Charmaine, donor for her brother

Oh God, what if I'm one of those people that has a terrible reaction? – Sarah, donor for her brother

I've got to sit there for four to six hours. I'm just like, I'll be honest... it's just freaking me out. Madonna, donor for her sister.

I was just a bit anxious about my veins and a little bit anxious about whether we'd do this once or twice. I'm now a little bit more anxious about whether the actual thing's going to work or not. Jacob, donor for his brother.

Things that may help:

- Find people who will listen to you and don't be afraid to express your feelings.
- Get in contact with your BMT Donor Coordinator. It is their job to help you feel prepared about what to expect and where you can get more support. Remember, what you say to the BMT Donor Coordinator is confidential and will not be repeated to the recipient. Sometimes people feel more at ease with one person than another. If this is the case, you should feel free to speak with the BMT Donor Coordinator you feel most comfortable with.
- Ask questions.

Things to avoid:

- Hiding your feelings from others.
- Trying to “be positive” all the time when you feel really stressed
- Feeling selfish or guilty about your worries – talk to your BMT Donor Coordinator
- Comparing your role to that of your recipient's.

Feeling lonely, isolated or unimportant

When we feel understood by the people in our lives, we feel comforted and supported in the challenges we face. However, when dealing with challenges that people don't fully understand, it can make us feel lonely, isolated, or even unimportant.

Everybody just kind of thought I was giving some blood, all good and it wasn't ... There were some acknowledgement ... I don't want to sound like I was craving acknowledgement, but it was just a very weird feeling and um... I guess everybody else is focused on what lies ahead, which is much more the bigger thing in their minds and this was probably a big milestone for me to get through, but um... not in the scheme of things for everyone else if that makes sense? Connor, donor for his brother

I don't know. I think it's ... for me personally, it was more a ... Everybody's like "You'll be right". You know, and then they go "You're doing a big thing". But it's that "You'll be right". And it's like, to me it was a huge thing emotionally. So I think it's alright for everyone else to go "Yeah, it's alright". Vivian, donor for her sister.

I feel bad because I feel selfish about how I feel, but people say to me, "You've got to feel how you feel. If you're really scared, you're really scared." Which I am. Sally, donor for her sister

I'm getting nervous about how this is done, like after the talk that she had and the anticoagulant I think is what scares me the most. How much I have to put in and the side effects of that, but other than that, I think what Dad's going to be going through is hundred times worse than anything I'll have to do. Caroline, donor for her father.

Things that may help:

- Talking to your family or close friend about how you are feeling
- Talk about your concerns with a BMT Donor Coordinator, social worker, psychologist or counsellor
- Speak with your GP.

Things to avoid:

- Hiding your feelings from others
- Feeling guilty about the thoughts and feelings you have about donating and concerns for yourself – talk about your concerns
- Comparing your role to that of your recipient's.

Side effects

You may experience some side effects from the G-CSF injections or the donation procedure. Lots of donors ask how they should feel after donating stem cells – but everybody is different. The important thing is to give your body rest and time to recover. Eating well and maintaining adequate fluids will also help for recovering after your donation.

It was like three days in it really started hurting, which they say is a good sign and then

it was only ... On the last day it actually stopped hurting. I wasn't sure if I had done something wrong, but um... it seems to have all done it's magic. Connor, donor for his brother

Working and taking those (G-CSF) kind of took its toll a bit more. Liam, donor for his sister

Just aches and just felt like a really big gym session. Liam, donor for his sister

I felt a bit ... I felt like I'd just been on a night out or something. Just a bit tired and stuff, a bit of ache. Vivian, donor for her sister

If you have questions or concerns about any of your symptoms, please contact your BMT Donor Coordinator at the hospital.

Transplant delays

A delay in your family member's transplant can trigger uncertainty and anxious waiting. Most donors find it helpful to talk with their BMT Donor Coordinator and their relative's doctor to get a better understanding of their relative's situation.

So, you've just gone through all those feelings of finally getting there and then it's like, "Oh, no. It's not happening." And then I was actually surprised with myself because when I got there I was fine, and then we sort of found out, "Don't know how long it's going to delay." So, it was like, "Okay, I'll stay in Brisbane." And then it was the week, and then it was, "Oh, no, it's going to be postponed six weeks." And I was like, "Oh, I can go home now." But then it's like, "But I want to stay, but my family's at home so I've got to go home." – Emma, donor for her mother

The only thing I was waiting for was a date. That was the unknown thing, and that date kept moving. I just needed to know for work in terms of how to plan my work for the next three months. Or what was gonna happen, it was just knowing when it was gonna happen. Liam, donor for his sister

We had it set, and then we had to wait another three weeks. Vivian, donor for her sister

Dealing with loss

- Unfortunately stem cell transplants are not always successful. This is difficult to cope with and you may experience a lot of strong emotions. Grief is a natural process, but it can be overwhelming.

Some donors cope best with help and support from family and friends. It's also normal to want to talk with someone who isn't a family member or a close friend. There are support services available to you and we have listed some options at the end of this booklet.

I've actually gone and seen someone myself probably... Yeah, because my husband was like, "I don't know how to help you. I want you to go see someone." So, yeah, and I sort of knew ... I described it, it just feels like you're sort of skating on very, very thin ice, and you know the cracks are there, and any moment the crack might just go and you're going to fall through. – Emma, donor for her mother

I've kind of dialled back my expectations of what I'm gonna get through each day. – Connor, donor for this brother

Should I have gone to the doctor more? Should I have asked more? Should I have asked about ... I've been doing a lot of that stuff. Just a lot of that. Should I have asked more questions of the doctor? – Emma, donor for her mother

We asked, they answered

Is there anything else that would have helped you prepare for donation?

It was all really good. I was prepared for everything except not being able to go to the toilet. – Katherine, donor for her mother

I think the main thing was that I would have liked to have known how long the process was going to take in the beginning, but that's probably my fault too, not asking the questions. Roslyn, donor for her sister.

I tried the business of how long I can sit on the lounge for without moving my arms, but it got a bit boring after half an hour. When I have to do it, I'm going to do it, but yeah. I'm that kind of person that wants everything to be covered, but it's out of my hands really. Madonna, donor for her sister.

Today, in this day they could have little videos of what the process is... interviews with real people. That's how we learn the most, actually. You meet other patients who've been through it, or other donors and you know, that's where you get a lot of your information and some videos with people who had been through it would probably help more people ... Tricia, donor for her brother.

People can sit down in any medical class and talk about what's going to happen, but I think it's different to hear from someone that's physically going through it themselves. I feel like that definitely helps prepare you more... Because things can be written in a book, anyone can read it out, but for someone to say how exactly they're feeling... what physical thing, what mental things they're going through. Anything like that. I think just the journey of it all. Caroline, donor for her father.

I was always under the assumption, and have been for many weeks that it was like a bone marrow. It wasn't until about a week or two before, probably about three, four weeks ago, I found out it was actually a lot simpler. That's probably something that needs to be communicated more. Liam, donor for his sister

What or who has helped you during the donation experience?

I've had phone calls from people at the hospital, how are you going with your needles, how's things going, which is good. Makes you feel like somebody cares. – Roslyn, donor for her sister.

I went to the meetings he had with his doctor. I find them the most useful for me. The coordinators are good, and help, and that gives you a point of contact, which is important as where to go and what to do. Tricia, donor for her brother.

Most of the procedure really is just sitting in a bed and so it makes a big difference just having somebody who's got charisma and can fill in the time. In many ways, that's possibly more support ... possibly support that you're just not left sitting there wondering and worrying. Connor, donor for this brother.

When I came here last week and I spoke to the nurse in there. That was very beneficial. That kind of gave me more of an idea ... and seeing what it (apheresis machine) looked like, gave me a bit more confidence and peace of mind. Liam, donor for his sister.

I tried to be as calm as I could, and read some relaxation techniques and stuff, but I don't think they make much difference. But I did try to ... I didn't just go in there blasé. Vivian, donor for her sister.

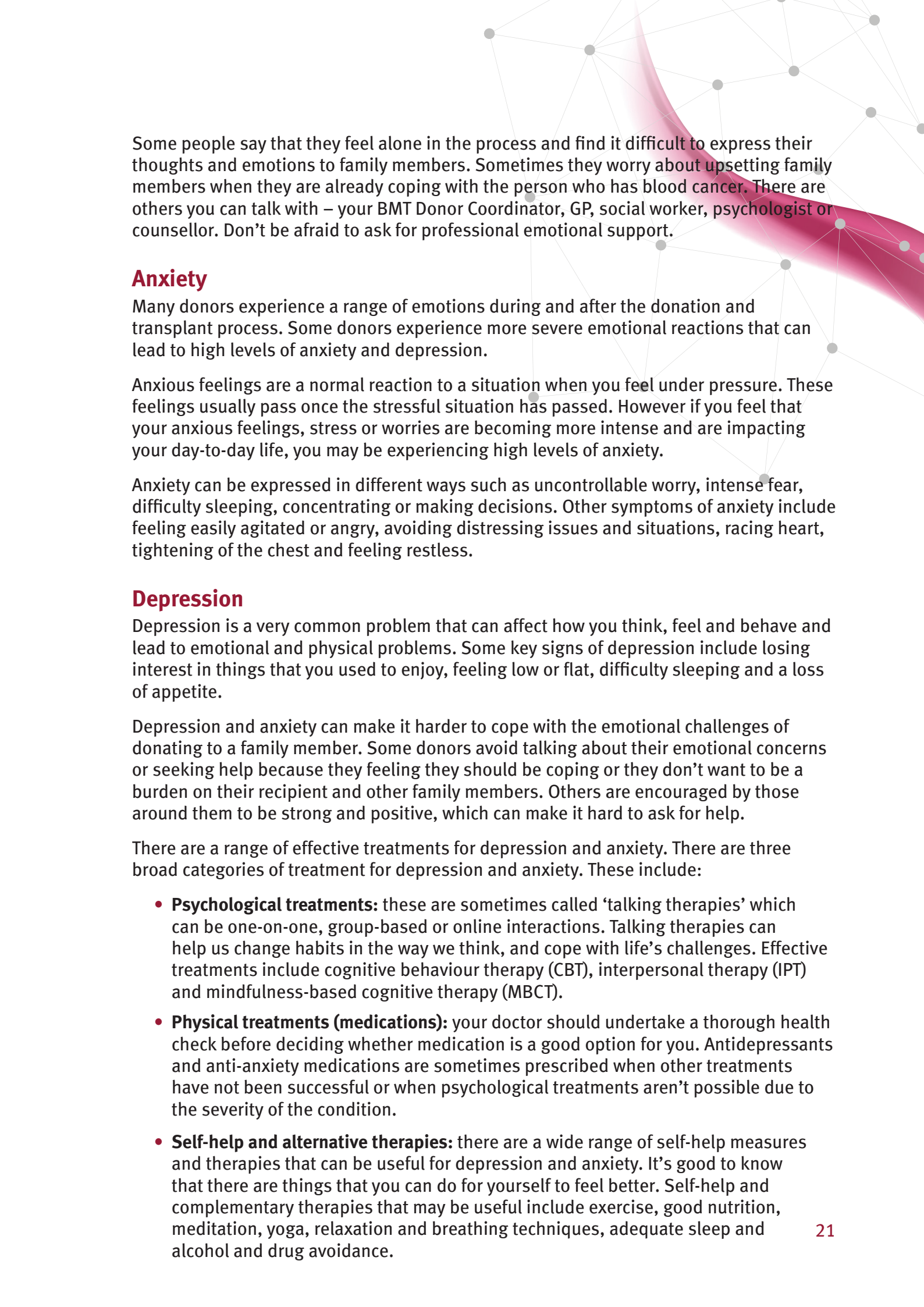
The emotional side of the experience

Families are complicated. Sometimes there has been tension, sometimes members have drifted apart or there may even have been major disagreements. Then being asked to be a donor can be especially challenging – hard to refuse, yet maybe even feeling “used”, or alternatively seen as a chance to “make things better”.

Everybody responds in different ways. It is a complex process. Each donor responds in their own way; this is normal. By being a relative to someone who is seriously ill but also a donor you may go through any or all of the following emotions and thoughts:

- A sense of relief that you're a match
- Sadness about your relative's diagnosis
- Gratitude for the opportunity to help
- Happiness
- Fear or uncertainty about the donation and what's next for your relative
- Hope for the future
- Guilt about transplant side effects
- Frustration about the expectations of others
- Responsibility for the transplant outcome or side effects
- A sense of lack of control as there's nothing more you can do after donating
- Positive experiences in family relationships and a sense of closeness
- Anger
- Feelings of loneliness, isolation or unimportance
- Disappointment if you're unable to donate or your relative's transplant is delayed
- Grief

Draw on your support networks. The love and support of family and friends usually form an important part of the donation process. It often helps to talk with others and you may want to share your emotions and thoughts with trusted people close to you. Talk with your family about your concerns if you feel comfortable to do so.



Some people say that they feel alone in the process and find it difficult to express their thoughts and emotions to family members. Sometimes they worry about upsetting family members when they are already coping with the person who has blood cancer. There are others you can talk with – your BMT Donor Coordinator, GP, social worker, psychologist or counsellor. Don't be afraid to ask for professional emotional support.

Anxiety

Many donors experience a range of emotions during and after the donation and transplant process. Some donors experience more severe emotional reactions that can lead to high levels of anxiety and depression.

Anxious feelings are a normal reaction to a situation when you feel under pressure. These feelings usually pass once the stressful situation has passed. However if you feel that your anxious feelings, stress or worries are becoming more intense and are impacting your day-to-day life, you may be experiencing high levels of anxiety.

Anxiety can be expressed in different ways such as uncontrollable worry, intense fear, difficulty sleeping, concentrating or making decisions. Other symptoms of anxiety include feeling easily agitated or angry, avoiding distressing issues and situations, racing heart, tightening of the chest and feeling restless.

Depression

Depression is a very common problem that can affect how you think, feel and behave and lead to emotional and physical problems. Some key signs of depression include losing interest in things that you used to enjoy, feeling low or flat, difficulty sleeping and a loss of appetite.

Depression and anxiety can make it harder to cope with the emotional challenges of donating to a family member. Some donors avoid talking about their emotional concerns or seeking help because they feel they should be coping or they don't want to be a burden on their recipient and other family members. Others are encouraged by those around them to be strong and positive, which can make it hard to ask for help.

There are a range of effective treatments for depression and anxiety. There are three broad categories of treatment for depression and anxiety. These include:

- **Psychological treatments:** these are sometimes called 'talking therapies' which can be one-on-one, group-based or online interactions. Talking therapies can help us change habits in the way we think, and cope with life's challenges. Effective treatments include cognitive behaviour therapy (CBT), interpersonal therapy (IPT) and mindfulness-based cognitive therapy (MBCT).
- **Physical treatments (medications):** your doctor should undertake a thorough health check before deciding whether medication is a good option for you. Antidepressants and anti-anxiety medications are sometimes prescribed when other treatments have not been successful or when psychological treatments aren't possible due to the severity of the condition.
- **Self-help and alternative therapies:** there are a wide range of self-help measures and therapies that can be useful for depression and anxiety. It's good to know that there are things that you can do for yourself to feel better. Self-help and complementary therapies that may be useful include exercise, good nutrition, meditation, yoga, relaxation and breathing techniques, adequate sleep and alcohol and drug avoidance.

There are many resources and support services available to help you work through any challenges you may be facing. That support could be through the transplant team or even your GP.

How do you know if what you're feeling is normal?

Sometimes it can be difficult to know exactly what we are feeling and to put into words what's going on in our minds. A *distress thermometer* can be very helpful in putting your feelings into words.

The *distress thermometer* allows you to identify exactly how you are feeling on a distress scale from zero to 10. It asks you to rate how much distress you have been feeling over the past week including today using a scale that ranges from 'no distress' (zero) to 'extreme distress' (10). It is recommended that people with a distress score of four or more receive further clinical evaluation and/or some form of professional support.

The thermometer also comes with a list of problems different people face. You can circle any problems that you have encountered in the past week including today. This can open up the opportunity to talk about any challenges you may be facing.

An example of the *distress thermometer* is located on page 334. The distress thermometer is referenced with permission from the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Distress Management V.2.2018. © National Comprehensive Cancer Network, Inc. 2018. All rights reserved. Accessed [May 7, 2018]. To view the most recent and complete version of the guideline, visit NCCN.org.

What's next for your relative

Engraftment

During the first few days after transplantation, the stem cells travel through the recipient's bloodstream and find their way to the bone marrow. Here they begin the process of making new healthy blood cells.

This process is known as engraftment and it usually happens within the first 30 days after your recipient's transplant. Engraftment means the new cells are working properly and starting to rebuild your relative's immune system. Evidence is seen in a rise in the number of normal cells on blood tests. White blood cells are the first cells to engraft, followed by red blood cells and platelets.

Your relative will be monitored very carefully in the early days following the transplant. Once the stem cells have engrafted, it will take some time for your relative to recover and return to a normal level of functioning. This may take up to twelve months.

Potential post-transplant side effects

Here we discuss some of the potential side effects that may occur in the first few weeks after your relative's transplant.

Infections

Infections are common after a stem cell transplant. This is because your relative will have fewer white blood cells than normal. White blood cells are the part of the immune system that help prevent or fight infections. The transplant team will help protect your relative from infections and treat any infections that develop.

Sore mouth

It is common to experience a sore mouth after a stem cell transplant. This is called mucositis. Your relative may experience some soreness in the mouth and throat and develop ulcers.

Graft-versus-host-disease (GVHD)

Your relative may develop a condition called graft-versus-host-disease (GVHD). GVHD generally appears once the donor stem cells start engrafting and re-establishing the body's new immune system. The new immune system recognises the recipient's body as 'foreign' and begins to attack it. The new immune system is only doing its job and believes it is protecting its new home.

Your relative will be given special drugs called 'immunosuppressants' to suppress the new immune system and to reduce GVHD. If GVHD does develop, your relative may be given other drugs, including steroids to further suppress the new immune system and reduce the symptoms your relative is experiencing.

More information

There is a lot of information about blood cancer, stem cell donation and transplantation on the Internet, and it is not all trustworthy. Many of these sites are based in the United States and United Kingdom who have different donation and transplantation practices. Here we list some reliable websites.

RESOURCES ABOUT STEM CELL DONATION

Australian Bone Marrow Donor Registry (ABMDR)

The ABMDR discusses tissue typing, donor work-up and stem cell collection in more detail. They also have donor brochures available for download. Visit www.adbmdr.org.au and refer to the donor tab of their website.

Leukaemia Foundation

The Leukaemia Foundation provides information on the steps involved in becoming a stem cell donor. Visit leukaemiaqld.org.au and refer to their 'becoming a stem cell donor' section.

Amgen

Amgen's *Neupogen Filgrastim Consumer Medicine Information* discusses granulocyte-stimulating factor in detail. The leaflet can be downloaded from the consumer medicine information section of their website www.amgen.com.au.

RESOURCES ABOUT STEM CELL TRANSPLANTATION

Leukaemia Foundation

The Leukaemia Foundation provides a range of information resources on blood cancers and treatment:

- The Leukaemia Foundation's *Understanding Allogeneic Transplants – A Guide for Patients and Families* discusses allogeneic bone marrow and peripheral blood stem cell transplantation in more detail. Visit www.leukaemiaqld.org.au to download the booklet.
- The Leukaemia Foundation has a list of booklets that explain common and rare blood disorders in detail. The booklets can be downloaded from www.leukaemiaqld.org.au or you can order a copy of the booklet using their online resource order form.
- The Leukaemia Foundation has a YouTube channel with various videos about stem cell transplants presented by specialist doctors and allied health professionals and patient stories. Visit www.youtube.com/LeukaemiaQld.
- The Leukaemia Foundation also offers disease-specific and general education programs throughout Australia. To learn more about upcoming education and support events, call 1800 620 420 or visit www.leukaemiaqld.org.au.

Australian Bone Marrow Donor Registry (ABMDR)

The ABMDR provides detailed information on stem cell transplantation and recovery. They also have a patient brochure available for download. Visit www.adbmdr.org.au and refer to the patient tab of their website.

Be the Match (USA)

Be the Match provides detailed information on the basics of stem cell transplantation, the steps leading up to the transplant, the transplant day and recovery. They also have videos from patients and caregivers who have been through the process along with transplant experts. Visit www.bethematch.org.

SUPPORT SERVICES

BMT Donor Coordinators

BMT Donor Coordinators provide coordination, education and support to patients and donors before, during and after the transplant.

- Call (07) 3646 0980, (07) 3646 8807 or (07) 3646 8746 to speak with one of the BMT Donor Coordinators at the RBWH Cancer Care Services.
- Call (02) 8890 5200 to speak with one of the BMT Donor Coordinators at the Westmead Hospital.

Social workers

Social Workers assist in dealing with the emotional and practical issues that may arise because of an illness or the illness of a loved one. If you would like to speak with a social worker at the hospital you can ask your BMT Donor Coordinator or:

- Call (07) 3646 8268 to speak with one of the Social Workers at the RBWH Cancer Care Services
- Call (02) 8890 5200 to speak with one of the Social Workers at the Westmead Hospital

Psychologists

Clinical Psychologists provide assessment, diagnosis and treatment of psychological, emotional and behavioural disorders. If you are experiencing ongoing distress you can ask your BMT Donor Coordinator or another member of the cancer care team to send a referral to a Psychologist. It is also possible to see a Psychologist privately in the community. Your GP can prepare a mental health treatment plan which can give you subsidised treatment.

Leukaemia Foundation

Leukaemia Foundation's support services team provides support for recipients and their families. Call the support team on 1800 620 420

Cancer Council Australia

Cancer Council Queensland's offers a range of support services, including:

- Free telephone counselling service to people affected by cancer, including family and friends. Trained health professionals are there to offer guidance, support and tips on coping with the effects of cancer. Call 13 11 20 to speak to one of the Information and Support Coordinators who can refer you to the Cancer Counselling Service.
- Cancer Connect is a telephone peer support service that connects people diagnosed with cancer, or family and friends with someone who has been through a similar cancer experience. Cancer Connect is free and confidential. For more information call 13 11 20.
- The Cancer Council Online Community is an online discussion forum that allows you to connect and talk with others in a similar situation. Visit cancerconnections.com.au.

CanTeen

CanTeen helps young people (aged 12-25) cope with cancer in their family and offers a number of information and support services:

- CanTeen offers free and confidential counselling over the phone, on live chat or secure email. Call 1800 835 932 or email support@canteen.org.au to find out more or to organise a time to see a counsellor.
- You can connect with others on the CanTeen online community. This is a virtual space for young people to share stories, ask questions and get peer support. Registration to the online community also provides access to professional and relevant information tailored to your needs. Visit canteen.org.au/join to explore the community.
- CanTeen's camps and recreation days give young people the opportunity to meet others affected by cancer and learn new ways to cope with the effects of cancer. CanTeen programs range from half a day to three days long. Call 1800 835 932 to find out about upcoming programs near you.
- The CanTeen website also has a list of books available for download. For example, *Dealing with your Parent's Cancer*, *Dealing with your Brother or Sister's Cancer*. Visit www.canteen.org.au/resource for a list of books you can download.

beyondblue

beyondblue has information on depression and anxiety, and where to get help. Visit www.beyondblue.org.au or call 1300 224 636.

Question prompt list

Questions to ask the BMT Donor Coordinator:

.....

.....

.....

.....

.....

.....

.....

Questions to ask the Registered Nurse or Apheresis Nurse Practitioner:

.....

.....

.....

.....

.....

.....

.....

My BMT Donor Coordinator is:

.....

My relative's doctor is:

.....

My first appointment is (date, time and place):

.....

The dates that I will have granulocyte colony-stimulating factor (G-CSF) administered:

Day 1:

Day 2:

Day 3:

Day 4:

The dates of my stem cell donation is (date, time and place):

.....

Who is the person that I should contact if I have questions or concerns about my donation?

.....

Donor dictionary

We know that the terms associated with stem cell transplantation and donation can be confusing. Below is a list of common terms that you may come across.

Allogeneic stem cell transplant

A transplant that uses stem cells taken from a donor. The donor can be a sister, brother, parent or child or a voluntary unrelated donor.

Autologous stem cell transplant

A transplant that uses the patient's own stem cells which are returned to them after chemotherapy.

Blood stem cells

Cells found in the bone marrow that can produce blood cells.

Bone marrow

Bone marrow is the spongy tissue inside our bones and it is the place where new blood cells are produced.

Bone marrow transplant

Bone marrow transplants use stem cells collected directly from the bone marrow whereas stem cell transplants use blood stem cells collected from the bloodstream (also called a peripheral blood stem cell transplant).

Central venous catheter

This is also called a central line. It is a flexible line or tube inserted into a large vein in the neck, chest or groin and into the central blood circulation. It can be used for giving blood, fluids and medications without the need for repeated needles.

Cytomegalovirus (CMV)

A common virus which can cause serious infection in people with a weakened immune system.

Engraftment

The process of transplanted stem cells starting to grow and make new healthy blood cells. Engraftment means the new cells are working properly and starting to rebuild your recipient's immune system.

Full blood count

A blood test that measures the number of blood cells, including white blood cells, red blood cells and platelets.

Granulocyte-colony stimulating factor (G-CSF)

G-CSF is a colony stimulating factor. Colony stimulating factors are naturally occurring and man-made proteins that stimulate the bone marrow's stem cells to produce more neutrophils (a type of white blood cells).

Graft rejection

When the new graft fails to grow.

Graft-versus-host disease (GVHD)

An immune system reaction which occurs when the transplanted donor cells recognise the patient's body as foreign and attack it. The skin, gut and liver are common targets of GVHD. Acute GVHD occur within the first 100 days after transplant. Chronic GVHD occurs after this time.

Graft-versus-malignancy effect

A response that happens when the transplanted donor cells attack any of the recipient's leftover cancer cells.

Haematologist

A doctor who specialises in the diagnosis and treatment of diseases related to the blood, bone marrow and immune system.

Immune system

The body's defence system that protects against infection and disease.

Immunosuppression

The use of drugs to suppress or reduce the strength of the body's immune system.

Neutrophils

A type of white blood cell. Neutrophils help the body fight infections.

Oncologist

A doctor who specialises in treating cancer and providing medical care for a person diagnosed with cancer.

Peripheral blood stem cell collection

The collection of stem cells from the bloodstream.

Platelets

Small disc-shaped fragments that circulate in the blood and help your body form clots to stop bleeding.

Prognosis

A prediction of the likely course of a disease.

Red cells

A type of blood cell made in the bone marrow and found in the blood. Red blood cells contain haemoglobin, which carry oxygen to all parts of the body.

Relapse

The recurrence of the prior disease.

Stem cell mobilisation

The use of growth factors that cause blood stem cells to leave the bone marrow and circulate into the bloodstream.

Tissue typing

Matching the tissue type of the stem cell donor to the patient.

Voluntary unrelated donor (VUD) transplant

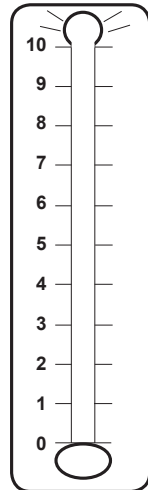
An allogeneic stem cell transplant where the stem cells are coming from a donor who is unrelated to the patient.
References

NCCN Distress Thermometer and Problem List for Patients

NCCN DISTRESS THERMOMETER

Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week including today.

Extreme distress



No distress

PROBLEM LIST

Please indicate if any of the following has been a problem for you in the past week including today.

Be sure to check YES or NO for each.

YES	NO	<u>Practical Problems</u>	YES	NO	<u>Physical Problems</u>
<input type="checkbox"/>	<input type="checkbox"/>	Child care	<input type="checkbox"/>	<input type="checkbox"/>	Appearance
<input type="checkbox"/>	<input type="checkbox"/>	Housing	<input type="checkbox"/>	<input type="checkbox"/>	Bathing/dressing
<input type="checkbox"/>	<input type="checkbox"/>	Insurance/financial	<input type="checkbox"/>	<input type="checkbox"/>	Breathing
<input type="checkbox"/>	<input type="checkbox"/>	Transportation	<input type="checkbox"/>	<input type="checkbox"/>	Changes in urination
<input type="checkbox"/>	<input type="checkbox"/>	Work/school	<input type="checkbox"/>	<input type="checkbox"/>	Constipation
<input type="checkbox"/>	<input type="checkbox"/>	Treatment decisions	<input type="checkbox"/>	<input type="checkbox"/>	Diarrhea
			<input type="checkbox"/>	<input type="checkbox"/>	Eating
			<input type="checkbox"/>	<input type="checkbox"/>	Fatigue
			<input type="checkbox"/>	<input type="checkbox"/>	Feeling swollen
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with children	<input type="checkbox"/>	<input type="checkbox"/>	Fevers
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with partner	<input type="checkbox"/>	<input type="checkbox"/>	Getting around
<input type="checkbox"/>	<input type="checkbox"/>	Ability to have children	<input type="checkbox"/>	<input type="checkbox"/>	Indigestion
<input type="checkbox"/>	<input type="checkbox"/>	Family health issues	<input type="checkbox"/>	<input type="checkbox"/>	Memory/concentration
			<input type="checkbox"/>	<input type="checkbox"/>	Mouth sores
			<input type="checkbox"/>	<input type="checkbox"/>	Nausea
			<input type="checkbox"/>	<input type="checkbox"/>	Nose dry/congested
<input type="checkbox"/>	<input type="checkbox"/>	Depression	<input type="checkbox"/>	<input type="checkbox"/>	Pain
<input type="checkbox"/>	<input type="checkbox"/>	Fears	<input type="checkbox"/>	<input type="checkbox"/>	Sexual
<input type="checkbox"/>	<input type="checkbox"/>	Nervousness	<input type="checkbox"/>	<input type="checkbox"/>	Skin dry/itchy
<input type="checkbox"/>	<input type="checkbox"/>	Sadness	<input type="checkbox"/>	<input type="checkbox"/>	Sleep
<input type="checkbox"/>	<input type="checkbox"/>	Worry	<input type="checkbox"/>	<input type="checkbox"/>	Substance abuse
<input type="checkbox"/>	<input type="checkbox"/>	Loss of interest in usual activities	<input type="checkbox"/>	<input type="checkbox"/>	Tingling in hands/feet
<input type="checkbox"/>	<input type="checkbox"/>	<u>Spiritual/religious concerns</u>			

Other Problems: _____

Version 2.2016, 07/25/16. The NCCN Clinical Practice Guidelines (NCCN Guidelines®) are a statement of evidence and consensus of the authors regarding their views of currently accepted approaches to treatment. Any clinician seeking to apply or consult the NCCN Guidelines is expected to use independent medical judgment in the context of individual clinical circumstances to determine any patient's care or treatment. The National Comprehensive Cancer Network® (NCCN®) makes no representations or warranties of any kind regarding their content, use or application and disclaims any responsibility for their application or use in any way. The NCCN Guidelines are copyrighted by National Comprehensive Cancer Network®. All rights reserved. The NCCN Guidelines and the illustrations herein may not be reproduced in any form without the express written permission of NCCN. ©2016.

Reproduced with permission from the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Distress Management V.2.2018. © 2018 National Comprehensive Cancer Network, Inc. All rights reserved. The NCCN Guidelines® and illustrations herein may not be reproduced in any form for any purpose without the express written permission of NCCN. To view the most recent and complete version of the NCCN Guidelines, go online to NCCN.org. The NCCN Guidelines are a work in progress that may be refined as often as new significant data becomes available. NCCN makes no warranties of any kind whatsoever regarding their content, use or application and disclaims any responsibility for their application or use in any way.

References

Anthony Nolan. (2016). *Donating to your relative*. Retrieved from https://www.anthonynolan.org/sites/default/files/529PA_Donating_To_Relatives_A5_Digital.pdf

Leukaemia Foundation. (2017). *Allogeneic stem cell transplant, a guide for patients and families*. Retrieved from <https://www.leukaemia.org.au/disease-information/transplants/allogeneic-transplants/>

National Comprehensive Cancer Network. (Version 2.2016). *Distress Management*. Retrieved from https://www.nccn.org/patients/resources/life_with_cancer/pdf/nccn_distress_thermometer.pdf.

Nivison-Smith, I., Bardy, P., Dodds, A. J., Ma, D. F., Aarons, D., Tran, S., Wilcox, L., & Szer, J. (2016). A review of hematopoietic cell transplantation in Australia and New Zealand, 2005 to 2013. *Biology of Blood and Marrow Transplantation*, 22(2), 284-291. doi: 10.1016/j.bbmt.2015.09.009

Reavley NJ, Allen NB, Jorm AF, Morgan AJ, Ryan S, Purcell R. (2nd Edition, 2013). *A guide to what works for anxiety*. Retrieved from <http://resources.beyondblue.org.au/prism/file?token=BL/0762>

Acknowledgements

This booklet was developed by a multidisciplinary working group:

Ms Nienke Zomerdijk

Prof David Gottlieb

Prof Jane Turner

Ms Stephanie Deren

Prof Geoffrey Hill

Ms Rachel Turner

Ms Annette Barnes

Prof Jason Connor

Dr Jason Butler

A/Prof Glen Kennedy

Dr Kate Markey

Thank you to Marie Greco, Graphic Designer from the Royal Brisbane and Women's Hospital Clinical Multimedia. Thank you to Anthony Nolan and the Leukaemia Foundation for providing the illustrations.

We are most grateful to the Royal Brisbane & Women's Hospital Cancer Care Services Consumer Engagement Group, the many donors and health professionals who took the time to review and comment on drafts of this booklet.



Queensland
Government