

DKMS X

WE DELETE BLOOD CANCER



Donor Handbook

**>> Together against
blood cancer**

There are survivors because there are lifesavers

Cover image: **James Moore**, donated by peripheral blood stem cell collection at our Sheffield clinic.

Dear potential donor

If you are reading this handbook you have very likely been asked to donate some of your blood stem cells to someone in desperate need. When you registered with DKMS, you submitted a cheek swab to determine your tissue type. You have now been identified as a match to a patient. This makes you very special, as you could be someone's only hope of survival. Or maybe you are reading this because you are considering registering as a potential blood stem cell donor and want to find out more. Whichever stage you are at, this handbook will help you to understand the process of blood stem cell donation and outline the support offered to you by the team at DKMS.

The DKMS organisation started in Germany in 1991 around one family's search for a donor. This search for potential donors still goes on today for every patient in need of a blood stem cell donation. DKMS has grown to become the largest international organisation to recruit donors.

Today over 11 million potential donors have registered with DKMS and over 105,000 donations have taken place, to give people a second chance at life. New hope opens up for patients worldwide, as our international registry of donors expands both in size and ethnic diversity, meaning that currently 21 people per day get that second chance at life.

Thank you for making the commitment to saving lives. DKMS will support you at every step of your lifesaving journey.



Emily Paulford
Donor Request Manager

How you are matched

To be considered a match, the donor and patient must share similar tissue characteristics. With more than 17,000 known characteristics that can occur in millions of combinations, finding a match is challenging and requires the availability of a large number of donors.

As a potential stem cell donor, your tissue type is matched using Human Leukocyte Antigen (HLA) typing. HLA are proteins or markers found on all cells in your body.

These proteins are used by your immune system to recognise which cells belong to your body and which cells do not. If these proteins do not match, the patient's body would reject the stem cells given by the donor. A close match means that the patient's immune system would recognise the donor's blood system as its own.

The patient's doctor will look for a matching donor within the patient's family first. However, about 70% of patients who need a transplant do not find a suitable donor within their family. In these cases, the patient's doctor will search for an unrelated adult donor.



Analysing tissue characteristics (HLA) in our labs

The confirmatory typing process at a glance



1. First contact

We will contact you to confirm your availability and willingness to proceed, discuss what it means to be a shortlisted match and ensure you are in good health.



2. Paperwork

We will ask you to complete and return a comprehensive health history questionnaire and consent form.



3. Blood test

We will arrange for your registered GP or local hospital to take a blood sample.



4. Blood analysis

Your blood sample will be confirmed as an HLA match and screened for infectious diseases.



5. Waiting

It can take up to 12 weeks before we hear from the patient's clinical team as to how they would like to proceed.



6. Thumbs up!

If you're the best match for the patient, an official request for donation is received. You are on your way to being a lifesaver!

Confirming you are a match

1. Get informed

We will call you to explain the process and answer any questions you may have. Donating is a serious commitment so we recommend that you discuss it with your family and friends to help you make your decision.

2. Submit the health history questionnaire and consent form

The health history questionnaire provides us with information regarding any medical conditions that may prevent you from donating. Your consent enables us to move forward with a blood test. You can complete these forms online via the link we sent to you by email. We can also send you a paper copy of the forms if you prefer and you can return them by Freepost envelope or by scanning and emailing them to ct@dkms.org.uk.

Your health and safety is our top priority. Any medical condition will be reviewed by our medical team and if donating poses any additional risk to you, you will not be asked to proceed. Depending on your health status, it is possible that you may be temporarily unavailable to donate, or need to be permanently removed from the registry.

3. Provide a blood sample

A blood sample will be taken to compare your tissue type with that of the patient, and to search for infectious disease markers. This process is called Confirmatory Typing.

- We will schedule an appointment for you with your GP or local hospital to take your blood sample
- We will inform you and your GP as necessary of any unexpected results and you can request all test results from us.
- All test results are strictly confidential.

The patient's doctor will inform us if you are a confirmed match for the patient and if they would like you to move to the next stage and donate your stem cells. Not everyone goes on to donate their stem cells due to a number of reasons (for example, a better matched donor is chosen, the patient's treatment plan changes) but a DKMS coordinator will inform you either way and answer any questions you may have.

4. Keep us updated and be ready

Once you have completed your blood tests, you become an essential part of the patient's treatment. It can take up to three months to schedule the final phases of your donation.



“It’s an amazing feeling to know that you’ve given someone a second chance at life.”

Sohel Umarji, blood stem cell donor, with his daughter

You've been selected to donate

1. Donation method

Once it is determined that you are a confirmed match, you will find out whether you will be requested to donate via peripheral blood stem cell collection or bone marrow collection (see next chapter). The patient's doctor will select which method is best for the patient. A DKMS coordinator will contact you to schedule the next steps.

2. Medical assessment

This will take place at the hospital that will carry out your donation and will take one day including travel time. Its purpose is to assess your suitability as a donor and includes:

- counselling on donation methods
- physical examination and health history check
- an electrocardiogram (to check your heart)
- lab work (urine analysis, blood tests, pregnancy test)

Your peripheral veins (ie in the arms and hands) will also be assessed to see if they are suitable for peripheral blood stem cell collection. If not, a central line catheter (a thin plastic tube placed into a large vein) may be discussed as a final option.

During the assessment, the doctor will also take you through the risks of the donation procedure and will ask you to sign consent forms. By signing the forms you are consenting to the donation procedure. The decision to donate is yours and you

can withdraw from the process at any point even after consent has been signed.

After the medical assessment, your results will be reviewed. If you are medically cleared to donate and you still wish to proceed, the patient will be prepared to receive your stem cells. If you have any concerns please speak to your DKMS coordinator as soon as possible as the patient is at serious risk if you decide not to continue once they have been medically prepared.

3. Special circumstances

Sometimes a patient needs a very urgent blood stem cell donation. In these cases the patient's doctor will select one donor who is identified as the best match, meaning that the Confirmatory Typing process is done at the same time as the medical assessment. This will save valuable time and means that you could be requested to donate your stem cells within four to six weeks of us contacting you.

There are also occasions where a patient has many donor matches and the patient's team don't need a Confirmatory Typing blood test straight away. We will contact you to complete an information session and a health screening and ask you to complete the health questionnaire. You may be asked to provide a blood test at a later date or you could move straight to the donation phase. Whatever the special circumstances, your DKMS coordinator will keep you informed.

Donation methods at a glance

Bone marrow collection



Medical assessment of the donor in collection centre

Duration: One day including travelling

Waiting period

After the medical assessment

Duration: One to two weeks

Collection

Bone marrow collection in collection centre

Duration: Three days

Possible side effects of anaesthesia

Sore throat, mild nausea and vomiting, a decrease in blood pressure, headache, tiredness

Possible side effects of bone marrow collection

Lower back pain, fatigue, stiffness, slight bleeding or infection at the site of incision

Returning to usual activities

Usually within one to two weeks



Peripheral Blood Stem Cell collection (PBSC)

Medical assessment of the donor in collection centre

Duration: One day including travelling

Waiting period

After the medical assessment

Duration: One to two weeks

Preparation

G-CSF injections

Duration: Four days

Possible side effects

Headaches, bone or muscle pain, nausea, fatigue, skin rash

Collection

PBSC in collection centre

Duration: One to two days


Possible side effects of PBSC

Slight bruising at the needle site, numbness or tingling, chills, a temporary decrease in blood platelet count, light-headedness, nausea. At the current state of research there are no long-term side effects documented

Returning to usual activities

Usually within two to seven days





Two ways to donate blood stem cells

It is important to read about the two methods used to collect blood stem cells as you will be asked to donate in one of these two ways. Learn about the steps involved before, during and after each method of collection and how we will support you along the way.

Opposite: **Richard Jones** donated his blood stem cells at The London Clinic'

1. Peripheral Blood Stem Cell collection (PBSC)

PBSC is an apheresis procedure, meaning your blood is removed with a needle from your arm and passed through a machine that separates your blood stem cells. Your remaining blood is returned to you through the other arm.

Before the collection

In order to ensure that you are able to donate enough blood-forming cells for the transplant, you will receive daily G-CSF (granulocyte-colony stimulating factor) injections for four consecutive days before your donation. If you agree, you will be trained at your medical assessment to self-administer these (usually into your stomach). Alternatively, they will be given to you by a healthcare professional at your home or work.

G-CSF is a naturally occurring growth factor that encourages your stem cells to move from your bone marrow, which is where they usually live, to your blood. G-CSF also stimulates the overall production of stem cells in the bone marrow of the donor.

DKMS would not ask a pregnant woman to donate as G-CSF has not yet been proven to be medically safe during pregnancy. We therefore suggest that, if possible, female potential donors use contraception, as required, in the lead up to donation and for a month after their injections.

During the collection

Blood is removed from a vein in your arm and is passed through a machine that collects your blood stem cells. The remaining blood components are returned to you through a vein in your other arm (apheresis). A donation takes between four and six hours. A second consecutive donation day could be necessary depending on the mobilisation of your blood stem cells. A stay over in a hotel would then be arranged by DKMS.

After the collection

You will be monitored by a healthcare professional until you are physically stable and ready to go home.

PBSC

- Will be scheduled on a weekday (usually Monday - Thursday).
- It is carried out at the hospital where you had your medical assessment.
- You can go home the evening of the donation if it is a one-day procedure
- We will follow up with you regularly to check on your recovery after donating.

Possible side effects of PBSC

PBSC is a very safe procedure. However, there are possible side effects which can vary from person to person. During this procedure there is a 24 hour call service available to you.

During your recovery

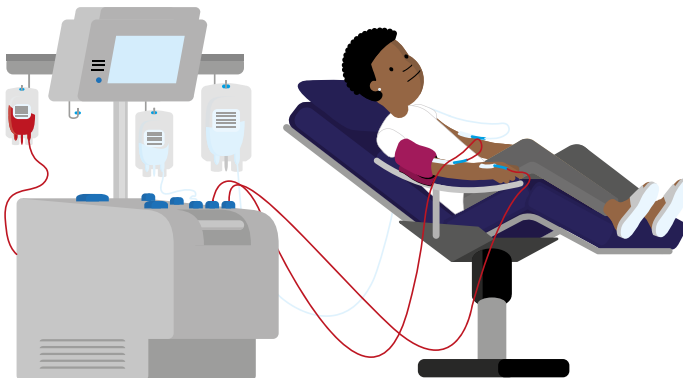
The possible side effects of G-CSF are comparable with flu-like symptoms. They usually disappear within 48 hours of donation. To ease any discomfort you can take painkillers such as paracetamol or ibuprofen. Most donors are able to return to usual activities within two days of donating. If your usual activities involve physical exertion, more recovery time may be necessary – possibly up to one week.

Possible side effects of PBSC

- Bruising at the needle site
- Numbness or tingling
- Chills
- Temporary decrease in blood platelet count
- Light-headedness
- In rare cases nausea has been reported

Possible side effects of G-CSF

- Headache
- Bone or muscle pain
- Fatigue
- In rare cases nausea and skin rashes have been reported
- Spleen enlargement



2. Bone marrow collection

Bone marrow collection is an inpatient surgical procedure carried out under general anaesthetic. Liquid marrow is removed from the pelvic bones. Some donors experience some short-term pain, bruising and stiffness after the collection. Most donors are able to resume usual activities within a week of the procedure.

Before the collection

You will have a general anaesthetic and may be under anaesthesia for one to two hours.

During the collection

The doctor will insert a needle through two small incisions in the skin at the back of the pelvic bones. The incisions are less than one centimetre and do not usually require stitches. The collection itself takes about 60 minutes, and you will be positioned lying on your front. The doctor will remove no more than five percent of your bone marrow. Four weeks after donation, your bone marrow will have recovered fully. The pelvic bones will have properly healed within six weeks.

Bone marrow collection

- Will be scheduled on a weekday (usually Monday - Thursday).
- It is collected at the hospital where you had your medical assessment.
- You will spend two nights in hospital, arriving in the evening prior to collection to meet the doctor, sign consent forms and spend the night after collection.
- We will follow up with you regularly to check on your recovery after donating.



Possible side effects of bone marrow collection

Bone marrow collection is a very safe procedure. However, there are known risks involved with anaesthetic and possible side effects, which can vary from person to person.

During your recovery

It is normal to experience some pain, bruising and stiffness for the first two to three weeks after your donation. You should avoid heavy lifting, bending and strenuous exercise for about two weeks after donating. We would recommend taking a week off after the procedure. If your usual activities involve physical exertion, more recovery time may be necessary.

Possible side effects of bone marrow collection

- Lower back pain
- Fatigue
- Stiffness when walking
- Slight bleeding at the site of incision
- Risk of infection

Possible side effects of anaesthesia

- Sore throat (caused by the breathing tube)
- A decrease in blood pressure
- Headache
- Tiredness
- In rare cases mild nausea and vomiting have been reported

Support after your donation

For both methods of stem cell collection we will provide support. We will contact you on a regular basis after your donation to check your recovery. It is also important to contact us directly if you have any concerns, or wish to discuss any symptoms you may experience. You should expect a phone call within a couple of days of your donation.

As part of your long-term after-care, we will be in contact with you on occasion for the next ten years giving you the option to have a follow-up blood test one month after donation. The blood test is optional but we recommend you have it to ensure your blood values have returned to normal.

Frequently asked questions

Here you will find all the questions we regularly get asked by potential donors. If you can't find the answer in this booklet, please feel free to call our donor support team on 020 8747 5660.

1. Where will my stem cells be collected?

Your blood stem cell collection will be scheduled at a specialist hospital in the UK.

2. Who covers the expenses?

There will be no cost to you. When a donor is a confirmed match with a patient, DKMS will cover the costs (including any travel, meals, or accommodation expenses that may be necessary). DKMS will also cover the costs for a companion to travel with you for your donation. A donor's health insurance will never be used. While it is rare to require follow up care, if it is ever needed, the donor's costs will also be covered by DKMS. Other than that we are not legally allowed to make any payments or rewards for the provision of donations including bone marrow or blood stem cells for transplantation.

3. Will I be compensated for the time I take off from work?

If you are not covered by your employer, DKMS has a financial assistance programme that deals with lost wage compensation. Your DKMS coordinator can provide more information.

4. Will I permanently lose my blood stem cells?

No. For either procedure, the amount of blood stem cells collected is only a fraction of the body's total amount. Your immune system is not weakened and your stem cells naturally replenish themselves within four weeks.

5. When will my donation take place?

In most cases you would be asked to donate one to three months after the confirmatory blood test. We will usually try to give you four to six weeks' advance notice. If there are any important dates when you cannot donate, we will always try to accommodate your schedule.

6. Will I be asked to donate again?

Sometimes the patient requires a second donation, eg because the immune system does not accept the new donor cells. If this happens we might get in contact with you again to ask you to consider a second donation, or a donor lymphocyte infusion, which for the donor is similar to the peripheral blood stem cell procedure, but without the stem cell stimulation injections.

Sean's story

Sean Parsons, 25, donated some of his blood stem cells by peripheral blood stem cell donation in 2014.

When did you first hear about blood stem cell donation?

The first time I heard about DKMS and blood stem cell donation was in 2014 through a friend who tragically lost a loved one through leukaemia. She talked to me about it and that evening, I visited the DKMS website and signed up.

How long were you on the register before you got the call to say you were a match for someone?

I was only on the register for two or three months. It was a strange feeling because I knew that someone, somewhere was seriously ill but I was also happy that I could donate my blood stem cells and potentially save that person's life.

How did you feel before your donation?

I felt nervous at first, but I was reassured by DKMS and all the medical professionals involved that there was nothing to worry about. On the day of the donation I didn't feel nervous at all.

What did your friends and family feel about you being a potential lifesaver?

After a lot of explaining about the donation process and the difference I could make to someone's life, my friends and family were elated that I could do something to help someone in need.

If you met your patient what would you say to them?

Just find out how they are getting on, see how their life has hopefully changed for the better, and also find out what they want to accomplish in their new life.

How did you feel after your donation?

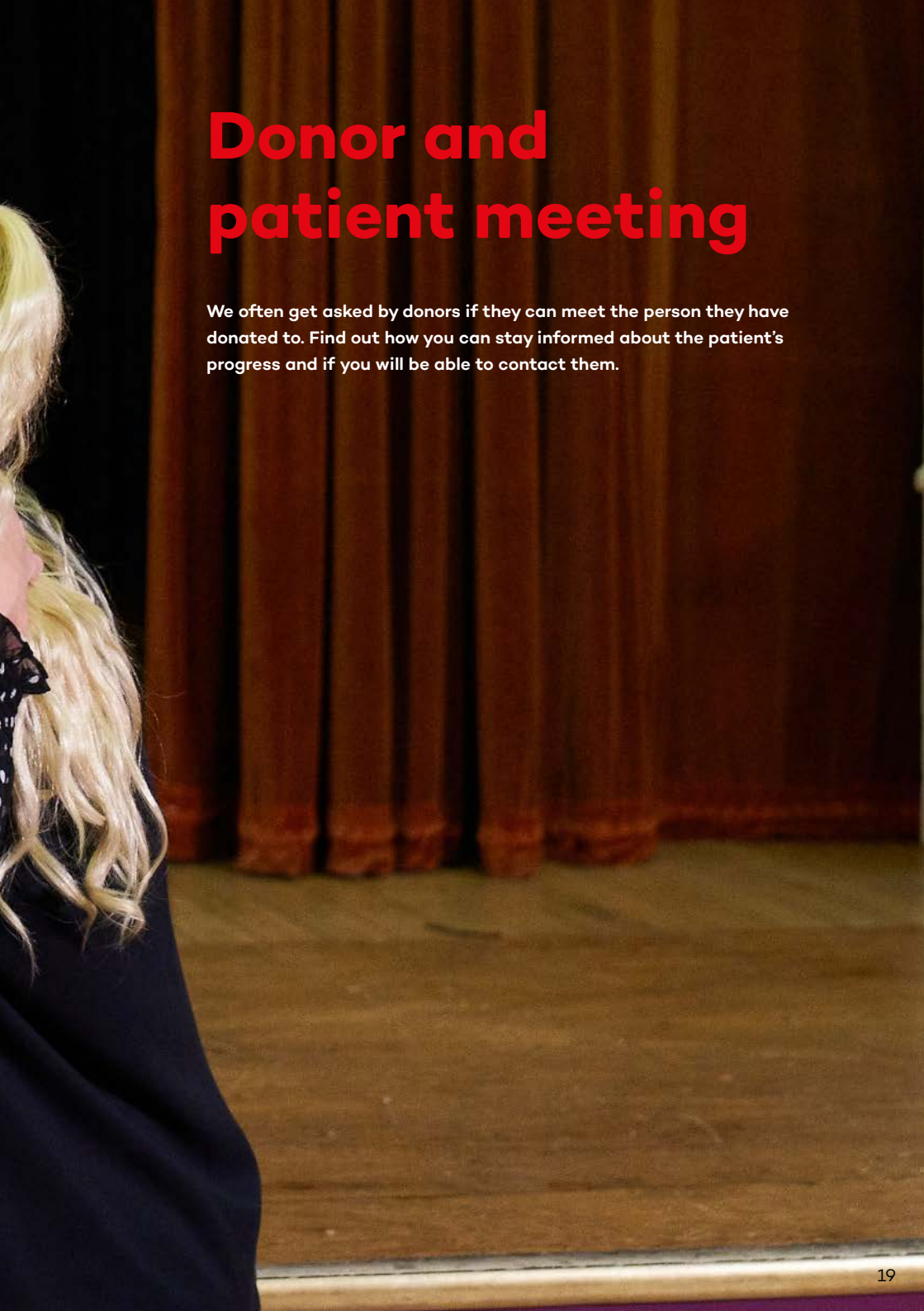
It's made me feel very happy. It is probably one of the most important things I'll ever do. I would 100% do it again!

“When I got the call to donate, I can say with hand-on-heart, it was one of the proudest moments of my life.”

Sean Parsons, blood stem cell donor





A woman with long, wavy blonde hair is seen from the side, looking towards a stage. The stage is covered with a brown carpet and has a backdrop of heavy, red curtains. The lighting is warm and focused on the stage area.

Donor and patient meeting

We often get asked by donors if they can meet the person they have donated to. Find out how you can stay informed about the patient's progress and if you will be able to contact them.

Updates about the patient

The patient's doctor can provide up to three updates within the first year after the donation. We will contact you once an update is available. It is important to note, because of confidentiality requirements that vary by country, some transplant centres cannot provide patient updates. You should be prepared for the possibility that you may not receive any updates on the patient's recovery. Your DKMS coordinator can provide further information on the policies of the country where the patient you are supporting is being treated.

Communicating with the patient: the first two years

Communication with the patient is managed by DKMS. Before the patient receives your blood stem cell donation, details of both parties will remain anonymous. After the patient has received your stem cell donation you are able to request some of the patient's details, eg age, gender and country the patient

received their treatment in. During the first two years after your donation, some transplant centres may allow you to send anonymous letters to the patient. This communication should not include any self-identifying information such as your name, address, city, or any other contact information. We can also supply you with social media guidelines on how to talk about your donation online.

Communicating with the patient: Longer-term

Two years after the donation, some countries may allow direct contact with the patient. Contact may only occur if both you and the patient agree to communicate. Some countries do not allow any communication, so you should be prepared for the possibility that you might not learn of the patient's identity or have any contact with them. Your DKMS coordinator can provide further information on the policies of the country where the patient is being treated.

Opposite: Mum, **Lorna**, on the left, meets **Christin** who donated her blood stem cells to **Alfie**.



Why patients need blood stem cell donations

Learn about the different types of blood disorders and what happens when someone's blood cells become dysfunctional, why blood cancer patients need donations of blood stem cells and how some of yours could save their life.

“A blood stem cell transplantation is still the only real hope for many patients.”

Dr Khaled El-Ghariani, Consultant haematologist and medical advisor to DKMS

Patients in need of a blood stem cell donation are fighting life-threatening diagnoses such as:

- leukaemia
- lymphoma
- myeloma

The patient's disease affects the formation and functioning of their blood cells. Blood cells are categorised into red blood cells, white blood cells and platelets. Patients with leukaemia, lymphoma or other blood disorders have a high number of immature or dysfunctional blood cells. In most cases it is their white blood cells that disrupt the normal production of cells.

A blood stem cell donation by an unrelated donor (allogeneic stem cell transplantation) can be a potentially lifesaving treatment option for patients who don't respond fully to conventional treatments such as radiotherapy or chemotherapy or who relapse after prior treatment. Before the patient can receive the donated stem

cells, they will receive high dosages of chemotherapy and possibly radiation therapy in order to completely remove all the diseased cells in their blood system.

This high dose of treatment removes their blood-forming cells in the bone marrow, to make room for the new stem cells and also weakens the patient's immune system so it cannot attack the donated stem cells. The donated stem cells move through the bloodstream to where they belong in the bone marrow and replace the patient's unhealthy blood stem cells. The donated stem cells settle into the bone marrow, where they begin to grow and produce red blood cells, white blood cells and platelets (engraftment).

Because the immune system and the blood system are closely linked and can't be separated from each other, allogeneic transplantation means that not only the donor's blood system but also their immune system is transferred. As a result there could potentially be some adverse effects for the recipient, such as immune rejection of the donated stem cells by the patient or immune reaction by the donor cells against the patient's tissues (graft-versus-host-disease).

The individual survival rate after a transplant depends on the age and health of the patient, the illness and the occurrence of complications. Between 40 to 80% of the transplants are successful.



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