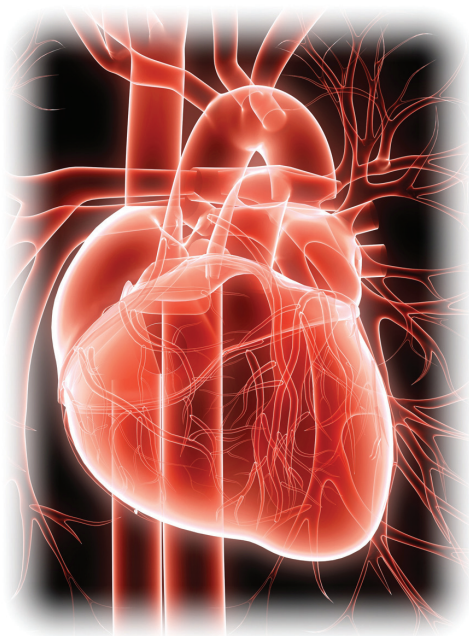




How you want to be treated.

Heart Transplant

A Brief Overview



HEART CENTRE

PROVIDENCE HEALTH CARE

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LEARNING THAT YOU MIGHT NEED a heart transplant can be very stressful. Whether you have been sick for a short or long period of time, it can be hard to imagine that this is happening to you.

You will have many questions.

This booklet briefly describes what a heart transplant involves.



Stages of a heart transplant

Up to 1 year (or more)

1 day to 1 year (or more),
usually around 6 months



Surgery

- you get the call
- you get your new heart



Waiting

- you are on the wait list
- you carry a pager



Transplant assessment

- a series of tests and interviews to determine if a heart transplant the right option for you



Recovery

- you stay in the hospital for 2 to 3 weeks
- you return home if you live locally, *or*
 - you will need to prepare to live in Vancouver for 3 months
- come to the Heart Transplant Clinic every week

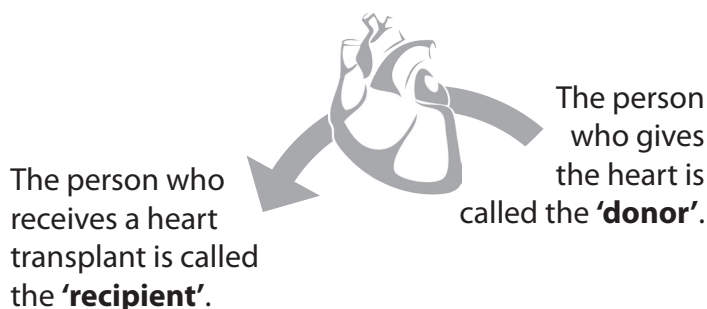


Living life

- gradually return to normal routine and daily life
- come to the Heart Transplant Clinic every month for a year, then once or twice a year
- live a heart healthy lifestyle
- take anti-rejection medications, antibiotics, nutritional supplements and other heart medications for life

About Heart Transplants

A heart transplant is when we replace a person's sick heart with a healthy one from someone who has died and whose organs have been donated. Organ transplants are only possible because of the gift of an organ from a donor and their family.



When is a heart transplant a good option?

A heart transplant might be an option for someone who has advanced heart failure but who is also in fairly good health.

A heart transplant can offer you a second chance at life and hope for the future. However, if you are a candidate for a heart transplant, you need to know that your life will be different after the transplant. You will have to make some major changes to your life. These changes give you and your new heart the best possible chance for a long and healthy life.

Heart Transplant – an Overview

There are five stages to a heart transplant.

1. Transplant assessment

The first step is to decide if a person is a good candidate for a heart transplant. Even though a heart transplant is one option, it is not always the best option.

You will see the pre-transplant team in the Transplant Clinic. You will have a number of tests, including some you probably have already had in the past. During this time, you will get lots of information on what it means to have a heart transplant.

If the team thinks a heart transplant is the right option, you and your loved ones will have a chance to talk with the team in detail about what will happen next. If the team thinks it is the right time to go on the transplant list and you agree, then you proceed to the waiting stage.

2. Waiting

Your name would be placed on a 'wait list' and then the search for a donor heart begins.

Your wait could be as short as one day or as long as a year or more. The average time is about 6 months.

We must be able to contact you at any time by phone or pager when a suitable heart is found. If you plan to travel, please talk to your nurse or the social worker. You will need to make a transportation plan to bring you to the hospital as quickly and safely as possible. We recommend you stay within the province.

Waiting, (continued)

If you are becoming sicker while waiting for a heart, the team will talk about options for treatment with you. One option might be for you to have a mechanical heart pump (called a “Ventricular Assist Device” or VAD). If you have any questions about options such as this, please ask the team.

3. The surgery

Once a donor heart that is a good match is found, we will call you to come to St. Paul’s Hospital. Normally, a person has between 4 and 6 hours to get to the hospital, but this is different for every situation. How soon you get to the hospital will depend on the time of day, the distance you need to travel, and the length of time we have to get you there. Long before you get the call, the social worker helps you make your travel plans.

Once you arrive at the hospital, you are prepared for your surgery. The surgery takes between 4 to 6 hours.

After your surgery, you stay in the Cardiac Surgery Intensive Care Unit (CSICU) for one or two days, or until you are well enough to move to the cardiology ward.

4. Recovery

How much time it takes you to recover depends on many things, especially how sick you were before the surgery.

Recovery, (continued)

Most people stay in hospital for 1 to 3 weeks. You spend this time learning how to care for yourself once you leave the hospital. (The chart on the next page shows an average recovery in hospital.)

Note: You and a caregiver will need to stay in the Lower Mainland for up to three months. You come to the Transplant Clinic often during this time. You should start thinking now about where you might live and who can stay with you. The social worker can help make these plans.





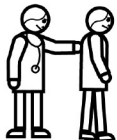
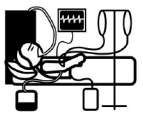
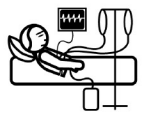
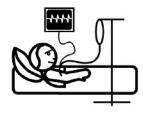
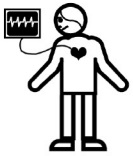
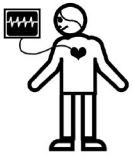
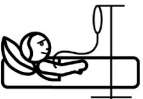









A test you will have weekly in these first three months after the transplant is a heart biopsy. A heart biopsy is done by inserting a thin, flexible tube into a vein in your neck and threading it into your heart. Tiny pieces of your new heart's tissue are removed for testing. We test to see if your body is rejecting the heart. (For more about rejection, see the section 'Frequently Asked Questions').

5. Living life

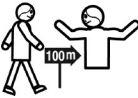
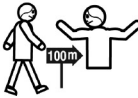





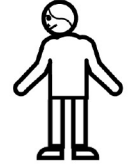
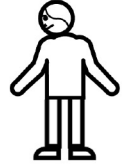















Everyone's recovery is different, but our goal is for transplant recipients to return to their normal lives and daily activities.

About four months after your surgery, your visits to the Transplant Clinic decrease to once a month. You continue to come to the Transplant Clinic once or twice a year after that. How often you come to see us depends on your health and progress.

Heart Transplant Average Recovery

	Day 0	Day 1	Day 2	Day 3	Day 4
Activity	 Asleep	 Asleep	 Sitting at edge of bed	 In chair, transfer to ward	 In chair, increase walks
Tubes	 IVs, heart monitor, tubes	 IVs, heart monitor, less tubes	 IVs, heart monitor & wires	 Heart monitor & wires	 Heart monitor & wires
Drugs	 IV medication	 IV medication	 IV medication, some pills	 Pills by nurse	 Learning pills
Diet	 No food or fluid	 No food or fluid	 No food, sips of fluid	 Some food, restricted fluid	 Food & restricted fluid

This is a guide only. Each patient recovers differently.

Day 5	Day 6	Day 7	Day 8	Day 9	Day 10
 Walking 3 laps of ward, shower	 Walking 5 laps of ward	 Walking stairs with physio	 Walking unaided	 Walking unaided	 Discharge
 Heart monitor off	 Pacemaker wires out	 No tubes	 No tubes	 No tubes	 No tubes
 Learning pills	 Learning pills	 Learning pills	 Taking own pills	 Taking own pills	 Taking own pills
 Food & restricted fluid	 Food & restricted fluid	 Food & restricted fluid	 Food & restricted fluid	 Food & restricted fluid	 Food & restricted fluid

If you have any questions, please talk to the doctor or nurse.

Your part in the transplant journey

The transplant team can do many things to get you ready for your heart transplant and help you recover afterwards, but it is you who is going to make the difference. You must be willing to look after yourself and your heart both before and after your heart transplant.

Here are just a few of the things you must do:

Medications

- get to know them
- take them exactly as directed on the label
- never change them unless your Transplant Clinic doctor or nurse asks you to
- report side effects to the Transplant Clinic
- **always check with the Transplant Clinic doctor or nurse before taking:**
 - any new medications
 - over the counter medicines (medicines that you can buy without a prescription)
 - vitamins, natural health or herbal products



Some of these products can interact with your transplant medications or cause side effects.

Lifestyle

- live a smoke-free life and do not use recreational drugs
- before you drink any alcohol talk with your transplant doctor or nurse. Alcohol and drugs can interfere with how some medications work
- join a cardiac rehabilitation program if possible or exercise regularly
- keep track of your health
- tell us if you are not well
- eat a healthy diet
- watch how much fluid and salt (sodium) you have in your diet

Appointments

- come to all your clinic and specialist appointments
- get blood work and other tests as directed

Frequently asked questions

How are organs matched?

When a heart becomes available, the recipient list is checked to find the best possible match. Organs are matched mainly by body size and blood type. We do not match by gender, race, or age.

Some people are harder to match because of their size or blood type, and they might have to wait longer. The transplant team makes sure the donated heart is a good match for the recipient. If there are two people who are equally matched to the donor heart, we choose the sicker of the two recipients.

For more information about organ donation, please visit the BC Transplant website at www.transplant.bc.ca.

What are the possible complications?

A heart transplant is a serious surgery. Like all surgeries, there are risks and possible complications. Your transplant team will go over these with you.

When you have a heart transplant, you are trading one set of problems for another. You will be 'immunosuppressed'. That is, you must take anti-rejection medications to suppress your immune system for the rest of your life. You must take these medications to reduce the chances of your body rejecting your new heart.

Common complications of any organ transplant are rejection and infection. Over the long term, there is an increased possibility of getting certain types of cancer.

What does it mean to suppress my immune system?

What is rejection?

Your body defends itself from foreign invaders such as germs and diseases with your immune system. Each time your body comes across a foreign invader, your immune system reacts and remembers how to stop it the next time it comes into your body.

Unfortunately, your immune system cannot tell the difference between foreign invaders that can harm you and those that are there to help you, such as your new heart. Your body's normal reaction to the new heart would be to try and destroy it or reject it.

If your immune system attacks your transplanted heart, it is called rejection. We give you anti-rejection medications to stop your body's normal response.

While helping your body accept your new heart, the anti-rejection medications will increase your chances of getting infections and certain types of cancer.

To prevent any damage to your heart, for the rest of your life you must:

- Take the anti-rejection medications as prescribed
- Watch for signs of rejection and call the clinic if needed
- Live an active and healthy lifestyle

How many medications do I have to take?

Most people with a heart transplant take between 10 and 12 different medications every day. Most of these medications help suppress your immune system. You must take these medications for the rest of your life.

There are possible side effects with anti-rejection medications. They range from mild short-term effects such as headaches, weight gain, or tremors to more serious long-term effects such as diabetes and kidney failure. Everyone is different and it is difficult to predict who will have get side effects and how serious they will be.

Can I get heart disease after a transplant?

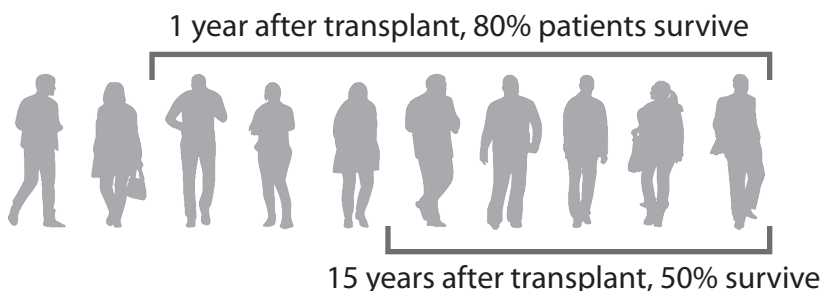
It is possible to develop a type of heart disease in the transplanted heart. This happens when the arteries supplying oxygen to your heart muscle narrow. If not treated, it could lead to a heart attack.

Usually this can be treated with medications and occasionally other treatments may be necessary. The doctor will discuss this with you if you have questions about it.

Will I live longer with a heart transplant?

Advances in science mean that people who have a heart transplant today are more likely to survive and live longer than in the past.

This picture shows an example of the chances of surviving a heart transplant in British Columbia. If 10 people have a heart transplant, 8 will be alive after one year (80%), more than 7 after five years (75%), and 6 after ten years (60%). After 15 years, 5 of the 10 transplanted people will still be alive. Our survival rate is among the best in the world.



These figures are averages, and everyone is different, so please ask the transplant team if you would like more information on your own chance of survival.

Living through the first year of a transplant is a critical time. If a person lives through the first year, that person has a very good chance of living for many years.

By taking good care of yourself, following the team's instructions and getting regular checkups, you can improve your chances of living longer with your new heart.

Advice from patients who had a heart transplant:

- 'You are your number one caregiver! Be responsible. Exercise and eat well.'
- 'Be positive! Enjoy life as much as you possibly can with family & friends - pursue and do things you enjoy.' (3.5 years post heart transplant)
- 'Keep positive and strong, wait for the big day.'
- 'If people were not afraid of living, they would not be afraid of dying. It is important to maintain a positive attitude, take to 'heart' how fortunate you are to have the opportunity for a transplant. Not everyone is so fortunate.'
- 'Go to the Healthy Heart program at St. Paul's Hospital. Continue to go before and after since your recovery will be faster.' (11 years post transplant)
- 'Make sure your caregiver has a support system or make him/her aware he/she has the resources at the hospital too. Not just the patient.'
- 'Listen up to the heart team.' (6 years post transplant)

Notes:

[illegible]

Heart Transplant Assessment (Workup)

This is a summary of what needs to be done to see if you may be a candidate for a heart transplant

We will organize the following tests for you (the nurse will check the ones you need):

- ☐ **Blood work**to look for how your body might react to a new heart and what treatments you might need after a transplant
- ☐ **Chest X-ray**to check for lung problems
- ☐ **CT scan**to look closely at internal organs (not all patients need this)
- ☐ **ECG**to look at your heart rhythm
- ☐ **Stool test**to test for blood in the stool which means you might need further tests to screen for bowel cancer
- ☐ **Urine test**to look for problems in the bladder and kidneys
- ☐ **Bone density test**to test for osteoporosis which may mean that you will need to see a specialist
- ☐ **Abdominal ultrasound**to look for abnormalities in your internal organs
- ☐ **Carotid Doppler**to look for blockages in your neck blood vessels
- ☐ **Vascular Doppler**to look for blockages in the blood vessels in your legs
- ☐ **Echocardiogram**ultrasound to look at your heart function
- ☐ **Right heart catheterization**to look at the blood pressure in the lungs – done in the “Cath Lab”
- ☐ **Lung Function test**a breathing test
- ☐ **Exercise test**a bike or treadmill test that tells us how much activity you can tolerate
- ☐ **Social worker visit**to make sure that if you get a transplant, you will be able to manage the stresses after the surgery
- ☐ **Psychology visit**to help you with managing stress
- ☐ **Dietitian visit**to help manage the diet restrictions and guidelines
- ☐ **Surgeon visit**a final step to see if a major surgery is the right thing for you

We would like you to talk with your GP and organize the following tests which are a requirement before we put any patient on the transplant list:

- ☐ **PAP smear**screening test for cervical cancer (women only)
- ☐ **Mammogram**screening test for breast cancer (women only)
- ☐ **Prostate exam**screening test for prostate cancer (men only)
- ☐ **Immunizations**we want to make sure your body is protected by vaccines against common diseases prior to undergoing a transplant
- ☐ **TB skin test**to make sure you do not have tuberculosis
- ☐ **Dental Exam**tooth abscesses can be dangerous after a transplant. Your dentist will need to do a thorough exam and send us a report

*** Please note:** Undergoing the transplant workup does NOT mean you are on the heart transplant list. If you are to be placed on the heart transplant list and be actively waiting for a donor heart, you will be formally informed by the transplant team and be given a pager.

Pre-heart Transplant Clinic Office:

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How you want to be treated.

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