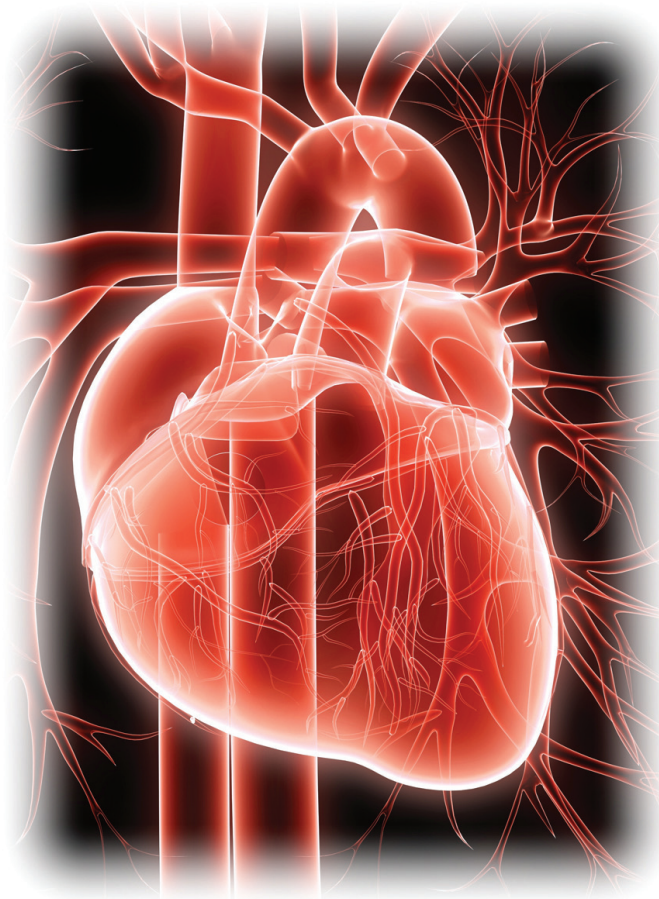


Living With a Heart Transplant



Bring this booklet with you
when you come for your transplant.



HEART CENTRE

PROVIDENCE HEALTH CARE

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*The information in this document is intended solely for the person
to whom it was given by the health care team.*

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About Heart Transplants

Introduction

LEARNING THAT YOU 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 this has happened to you. You may have many questions. This booklet will try to answer your questions and guide you through each stage of the heart transplant.



A heart transplant can offer you a second chance at life and hope for the future. Things will be different after your 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.

If you follow the transplant team’s advice and the tips in this manual, there is a very good chance you can have an active lifestyle, get back to your old activities, and return to work.

Science has advanced so that people who have a heart transplant are more likely to survive and live longer than in the past.

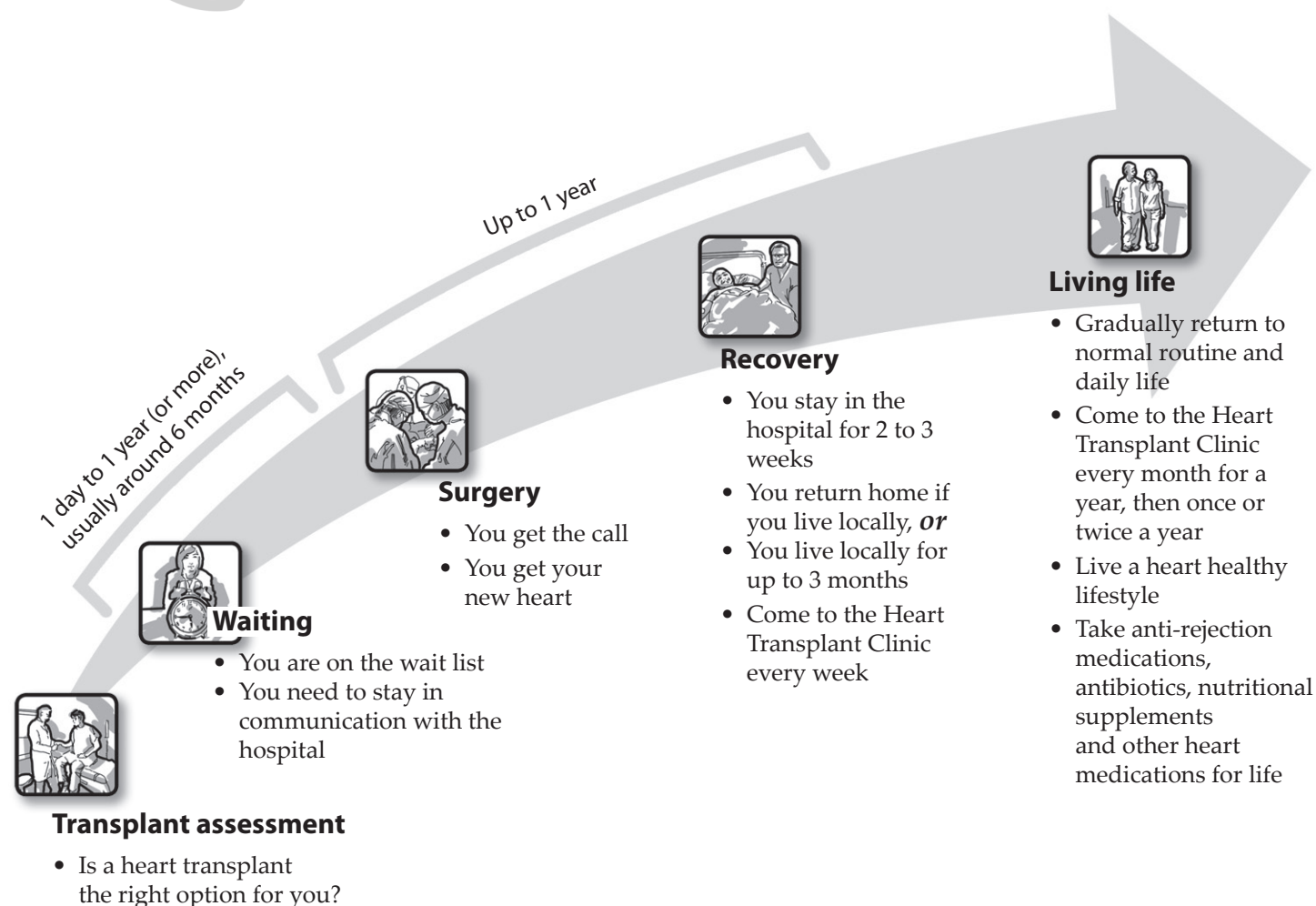
The first year after a heart transplant is a critical time. If a person lives through the first year, that person has a very good chance of living for many years.

The transplant team is here to support you and your family as you face the challenges of living with a new heart.

Note: *Appendix A explains many terms that you might hear while you are in hospital or in the clinic.*



Stages of a heart transplant



Waiting for your Heart

The Wait List

Once you and the transplant team have decided to go ahead with the heart transplant, your name is placed on the waiting list. The search for a suitable donor heart begins.



How long will you be on the wait list?

It is hard to predict how long you will wait. Some people are matched with a suitable heart within the month, while others could wait for over a year. The average wait time is 6 to 9 months.

How long you wait depends on a few factors:

- your blood type
- how serious your current heart condition is
- how easy you are to match

Blood Type	Average wait time
Blood Type A	3 months or more
Blood Type B	3 months or more
Blood Type AB	1 to 3 months
Blood Type O	9 months or more

The reason people with Blood Type O wait longer for a suitable heart is because this blood type is the most common of all blood types. Because it is the most common, that means there are more people on the list with the same blood type.

Waiting for the call

Hearts must be transplanted quickly and there is no warning of when a suitable heart will be found. Because of this, you will need a cell phone and you will need to be contactable at all times.

When a suitable heart is found, we will first try to contact you on either your cell phone or home phone.

✓ **You must carry your cell phone with you all the time**, even if you are at home. Always carry a spare charger with you in case the battery needs to be charged while you are out.

✓ Give us as many numbers of family and friends as you can, in case we can't contact you, perhaps they can help us find you to the nearest phone

✓ Always call the transplant coordinator when:

- You are going to be away from your home telephone for a period of time (such as vacation or visiting overnight).
- You are going to be travelling outside the cell phone's range (traveling outside the lower mainland). Contact your cell phone provider to find out what areas are out of range.

✓ Remember, if we are unable to contact you, there is a chance you could miss out on a possible heart that matches. It is your responsibility to make sure we can find you at all times, so always plan ahead.

Waiting for the call, *continued*

- ✓ Always call the transplant coordinator (or have someone call for you) if:
 - You feel more unwell
 - You are admitted to the hospital
- ✓ Have a plan for your travel to the hospital. We complete the *Transportation Planning Sheet* (Appendix H) with you.

Planning what to bring to the hospital

Pack your hospital suitcase and have it ready to go for when you get the call. Make a list of any items you need to add at the last minute.



Last minute items usually include things you use every day such as your glasses, toothbrush, or shaving supplies.

Try not to bring valuables as they may get lost during many transfers between wards etc.

Appendix E has a handy checklist to use when packing your bag.

Do not bring a lot of cash or valuables.

Planning to be away from home

Arrange for someone to look after your pets, water your plants, and pick up your mail while you are in the hospital. This person needs to be available on short notice – you never know when you will get the call.

Make a list of the people you need to tell that you are going for your heart transplant. The less you have to do when the call comes, the better.

Planning where to stay in the Lower Mainland after your surgery

If you do not live in the Lower Mainland, you will need to arrange to live locally for up to 3 months after your surgery (sometimes longer).

If you do not have a place you can stay, our social worker will work with you to help find a place.

A group of heart transplant recipients have formed a charity called “The Heart Transplant Home Society”. They sublet two apartments close to the hospital. One of these apartments might be available to stay in. These homes are not always available and are rented on a first come, first serve basis. So all patients should have a “plan B”.

TIP: Use the checklist in Appendix E to help you get ready for the call.

Keeping healthy during the wait

Stay positive

Most people find the waiting as the most difficult part of the heart transplant process. You will feel worried, anxious, uncertain, or other emotions. This is normal. While waiting can be frustrating, we encourage you to try to stay positive and hopeful. If you need support during this time, the transplant team psychologist and social worker are here to help you - just ask the clinic nurse.

Keep active and healthy

Stay as active as you can. Ask your doctor about what level of activity is best for you.



Exercise every day, even if only for a short period. Exercise is important for your heart and general health. Slow down if you get short of breath, have chest pain, or feel faint. Talk with your doctor about which activities are best for you.

If there is a cardiac rehabilitation program near you, the clinic nurse will work with you to join the group.

Do not smoke. Smoking is deadly both before and after the transplant. If you smoke, you will not be eligible for a heart transplant. You must have stopped smoking for at least 3 months before you will be considered for a heart transplant.



Eat healthy

It is important that you eat a healthy diet to prepare for the procedure. This gives you the nutrition you need to keep healthy and help you recover.

If the doctor has asked you to limit the amount of fluids and salt, continue to follow your doctor’s directions.

See the dentist

If you have your own teeth and you have not seen your dentist in the last 6 months, book an appointment. The transplant nurse will discuss the importance of having regular dental visits with you.

Checking your finances

The social worker can help you make a plan to manage your finances. We want to make sure you are on all the government programs that you qualify for and, if needed, approach other agencies with you.

Advance care planning

As long as you can understand and communicate with your care team, you make your own decisions about your care and treatment. However, there could come a time when you are not able to express your treatment wishes to us. Talk to your family now about the care you would agree to, or refuse, in case you cannot speak for yourself later.

By planning ahead, you can be sure your family, friends, and care providers know your wishes and use these wishes to guide your care and treatment.

Advance care planning, *continued*

To learn more about this, talk to our social worker and read the booklet (available online): *My Voice: Expressing My Wishes for Future Health Care Treatment* from the BC Ministry of Health (www.seniorsbc.ca)

Getting the call

Once you get the call:

- do not take any medication, but bring it with you. We will decide which pills you should take.
- arrange a ride to the hospital or airport by either asking a family member or friend to drive you, or take a taxi
- do not eat or drink anything.
- pack your last minute items into your hospital suitcase

Once at the hospital, come to ward 5A. At night, go through the Emergency Department and tell them you are here for a heart transplant.

We put an intravenous line into your arms so we can give you medications and monitor you during the surgery.

Going through a ‘dry run’

Sometimes a person is called to the hospital and prepared for surgery only to find the donor heart is not suitable and the transplant is cancelled. When this happens, we call it a ‘dry run’. Unfortunately, dry runs happen about 1 time out of 3 transplant calls.

If this happens to you, it can be very disappointing for you and your family. But it is better to go through a dry run than have a heart transplanted that is not a good match.

If the transplant is cancelled, usually you go home from the hospital the same day.

Whenever you get the call, always ask your family, or support person, not to leave the hospital, or to stay close by, until they know the transplant is going ahead.

If you have a ‘dry run’:

- You need to arrange a way to get a ride back home.
- For those with an implantable defibrillator in place, you will not be able to go home until it is turned back on. This is usually done during the day.
- For those taking Coumadin (or warfarin), you must wait until we give you instructions about the dose and extra blood work. This is because we could have given you medication to reverse the blood-thinning effects of Coumadin. This causes your INR tests to be too low.

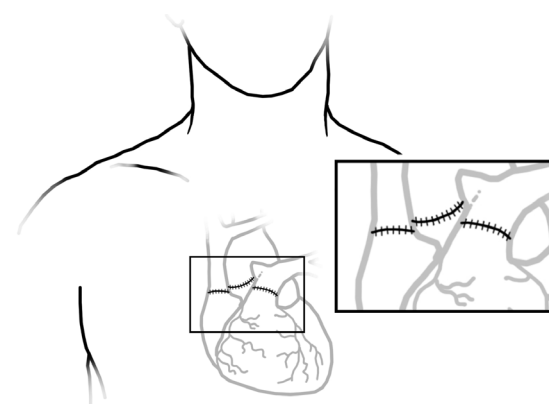
The Heart Transplant Surgery

Once we know for sure the donor heart is a good match for you, we go ahead with the surgery.

The transplant surgery takes about 4 to 6 hours, depending on your condition. It could take longer if you have a Ventricular Assist Device (VAD) in place.

To do the surgery, the heart surgeon opens your chest by cutting through your breastbone (or sternum). The surgeon connects you to a heart-lung machine. Your blood flow is routed through this machine and does the work of both your heart and lungs during the surgery.

The surgeon removes your old heart and attaches the new heart. The surgeon wires your breastbone together and sews or staples your incision closed.



Loss of nerve supply to the heart

The heart has many nerve connections. When your heart is removed, these nerves are cut.

Because of this, your new heart will beat a little faster and this is normal. Your new ‘resting heart rate’ will be around 90 to 110 beats per minute.

Your transplanted heart rate will not respond as quickly to such things as exercise, stress, or fear. It will also take longer for your heart rate to return to normal afterwards.

What to expect when you wake up

After the surgery, we move you to our Cardiac Surgery Intensive Care Unit (CSICU) on the 3rd floor to recover.

When you first wake up, you will hear voices, and the sounds of medical equipment around you. You will be very sleepy for several hours. You might be a bit confused and not sure what has happened or where you are. We remind you often where you are and what is happening.

You will have a bandage on your chest, and a number of tubes and lines connected to you.

Endotracheal tube

This plastic tube goes through your mouth and down into your windpipe. The tube is about the size of your little finger.

This ‘breathing tube’ keeps your windpipe open so we can give oxygen and help you breathe until you are fully awake. We connect this tube to a breathing machine called a ‘ventilator’. If you get a build-up of mucus in your lungs, we can easily clear this with a small suction tube passed down through the endotracheal tube.

What to expect when you wake up, continued

You cannot speak with the endotracheal tube in place. We will ask you “yes” and “no” questions so you can answer with a nod for “yes” and a shake of the head for “no”. We remove the tube within 24 hours of the surgery.

Breathing tube

A plastic tube goes through your mouth and down into your windpipe. The tube is about the size of your little finger.

This ‘breathing tube’ (medical term: endotracheal tube) keeps your windpipe open so we can give oxygen and help you breathe until you are fully awake. We connect this tube to a breathing machine (ventilator).

You cannot speak with the endotracheal tube in place. We will ask you “yes” and “no” questions so you can nod or shake your head to answer. We usually remove the tube within 24 hours of the surgery.

Heart monitor

The heart monitor gives us a constant display of your heart rhythm.

Pacemaker

Small pacemaker wires that were attached to your new heart during the surgery may be connected to a temporary pacemaker. The pacemaker helps regulate your new heartbeat for the first few days. We usually remove these wires a few days after your surgery.

Chest tubes

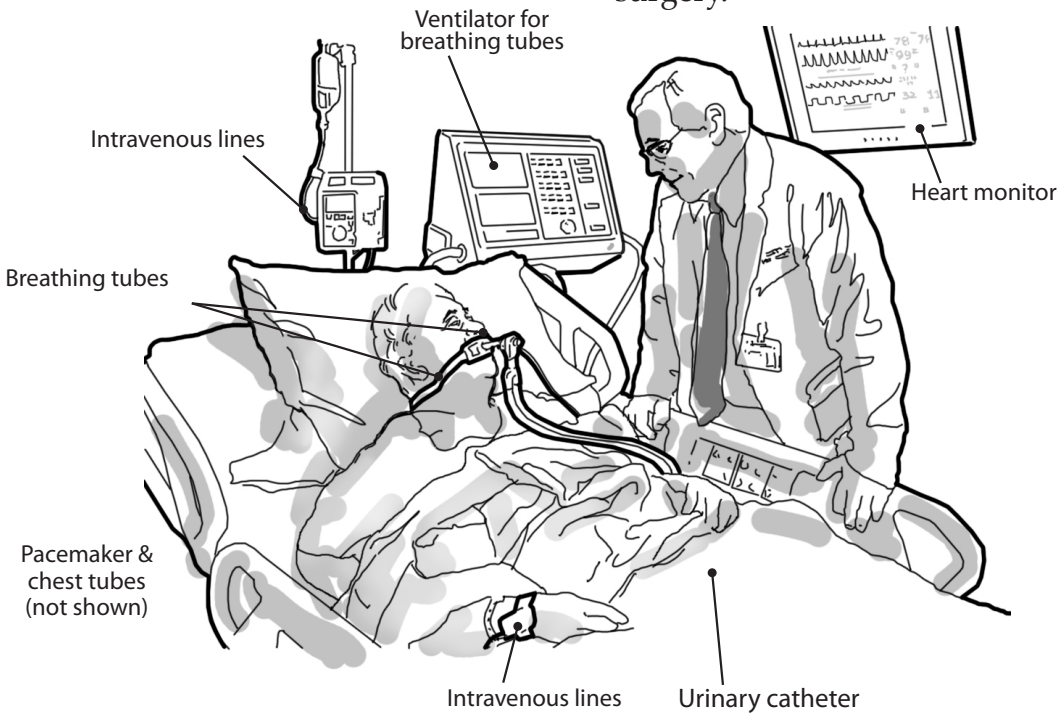
These plastic tubes are placed around the heart during surgery. They come out through small holes in the skin of your chest. They drain any blood from the site of the surgery. Once the tubes stop draining, we remove them. This is usually within 2 days of the surgery.

Intravenous lines

You will have intravenous lines (or I.V. lines) in your neck and arms. We use these to give you medications and fluids. We take out most of your intravenous lines within a week of your surgery.

Urinary catheter

This small tube goes into your bladder. It empties urine from your bladder until you are able to go to the toilet yourself. We usually remove this tube within a few days of your surgery.



Heart Transplant Average Recovery

Day 0	Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7	Day 8	Day 9	Day 10
Asleep	Asleep	Sitting at edge of bed	In chair, transfer to ward	In chair, increase walks	Walking 3 laps of ward, shower	Walking 5 laps of ward	Walking stairs with physio	Walking unaided	Walking unaided	Discharge
IVs, heart monitor, tubes	IVs, heart monitor, less tubes	IVs, heart monitor & wires	Heart monitor & wires	Heart monitor & wires	Heart monitor off	Pacemaker wires out	No tubes	No tubes	No tubes	No tubes
IV medication	IV medication	IV medication, some pills	Pills by nurse	Learning pills	Learning pills	Learning pills	Learning pills	Taking own pills	Taking own pills	Taking own pills
No food or fluid	No food or fluid	No food, sips of fluid	Some food, restricted fluid	Food & restricted fluid	Food & restricted fluid	Food & restricted fluid	Food & restricted fluid	Food & restricted fluid	Food & restricted fluid	Food & restricted fluid
Diet	Drugs	Tubes	Activity							

This is a guide only. Each patient recovers differently. If you have any questions, please talk to the doctor or nurse.

Activity

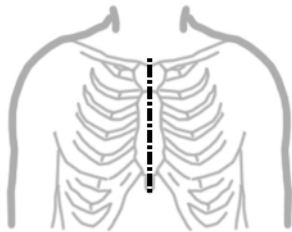
Usually, on the first day after your surgery, we get you sitting up on the edge of the bed.

About 2-3 days after your surgery, we move you back to our cardiology unit (5A). It is here where you begin to eat, move about, and get your strength back.

During this time, you will slowly increase your activity. This includes walking and doing exercises.

Your incision and pain

Your incision goes down the middle of your breastbone. We leave it covered with a bandage for about 2 days.



Your chest will hurt when you cough or move.

Your chest will feel bruised and it will hurt when you cough or move around. Coughing and moving are important to your recovery.

We regularly give you medication for the pain to make sure you are as comfortable as possible.

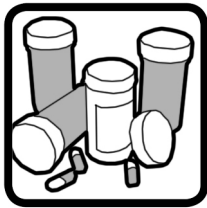
Eating and drinking

You will not be eating or drinking anything for the first day or so.

On the day after your surgery you can start eating small amounts of food and fluids.

Medications

From the time you have your new heart, you must take anti-rejection medications. We also give you medications to control your blood pressure and to manage extra fluid in your body.



Family and visitors

After your surgery, your family will be anxious to see you. Close family and friends can visit you in the CSICU at any time. Remember you will be tired and probably not feel like lots of visitors. It is best just to have close family and friends and only for short periods.



To keep all your family and friends informed, we ask you to appoint a contact person for the family.

The contact person:

- talks with the doctor and nurse regularly about your condition
- gives the details of your condition to other family and friends

Once you move to the cardiology unit (5A), your family and visitors are welcome to visit for short periods. Remember you will get tired easily and you need your rest.

We encourage you to ask at least one person to join you in learning about life after your transplant. Together, you will learn about your medications, what to watch for when you go home, and how to care for yourself at home. There is a lot to remember and having another person learn it with you will help in your recovery.

Getting ready to leave the hospital

You usually stay in the hospital for 2 to 3 weeks.

During this time, you will be learning what you need to know to live with your new heart.

We will encourage you to do more for yourself each day.

We will teach you:

- how to do your exercises
- how to monitor your blood pressure, pulse, and temperature
- how to take your medications
- what to look for and what to do if you are having problems at home

By the end of your stay in the hospital, you will be taking your medications on your own with a nurse or pharmacist watching you. This is a good time to review that medication and ask any questions you might have.

We also talk with you about returning home. If you do not live locally, the social worker will talk about where you will stay for the next few months.

The Transplant Clinic nurse will talk with you about your schedule for check-ups and blood tests.

TIP: If you need help, check the back page of this manual for important phone numbers.

Complications of a Heart Transplant

We want to focus on complications specific to your heart transplant, what to watch for, how to prevent them, and how we treat them. The main complications are:

- Rejection
 - Acute rejection
 - Chronic rejection
- Infection
- Cancer

Rejection: Acute Rejection

Acute rejection can happen any time after the transplant, but is most common in the first 6 months.

Your body's immune system reacts to the new heart and tries to get rid of it like it would if it was a virus or bacteria. This is a way that the body tries to protect itself from foreign invaders. If this protective process is not stopped, your heart could be damaged, even destroyed. This process is called rejection.

The best ways to fight rejection:

1. Stop it before it starts.
2. Recognize it when it happens.
3. Treat it early.

1. Stopping acute rejection before it starts

We give you a number of medications to weaken your body's immune system. These are called anti-rejection or immunosuppressant medications. These medications help stop the damage to your heart.

We closely monitor the medications and how much you are taking of each one. When you first start taking anti-rejection medications, the doses will be high. After a short period, as the risk of rejection decreases, the doses are lowered.

Your transplant doctor adjusts your medications so your body has just enough to protect your heart but not too much to stop your body from reacting to and fighting off infection.

You must take anti-rejection medications for the rest of your life or you will die.

2. Recognize acute rejection when it happens

Rejection episodes can happen even if you are taking your anti-rejection medications regularly and as directed.

For most people, if we catch it early and treat it right away, we should be able to reverse the rejection episode completely.

To prevent rejection episodes, take medications on schedule and as directed.

Signs of rejection

Most rejection episodes are mild. You might not notice any signs of rejection. You might only find out when it is detected with a biopsy.

Signs to watch for and report right away:

- decreased energy level
- reduced ability to exercise
- weight gain (more than 2kg (4lb) in a day or 2.5kg (5lb) in a week)
- shortness of breath while doing normal activities
- irregular heart rate or palpitations
- low blood pressure

You might notice you feel a bit like you did before your heart transplant.

If you notice any of these, **report them right away to the Transplant Clinic nurse or doctor**, anytime day or night.

Heart Biopsies

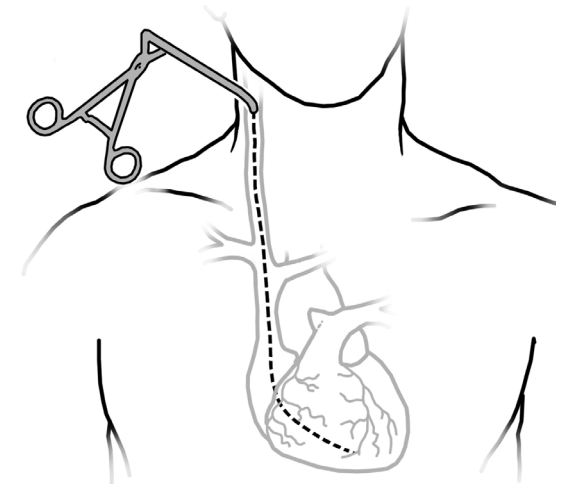
Currently, the most reliable way of detecting rejection early is with heart biopsies. This is a safe test. It takes about 10 to 15 minutes to do.

We arrange for your heart biopsies to be done once a week for the first few weeks after surgery, then once a month for the first five to six months. After the first year, generally you do not need heart biopsies.

Heart biopsies are also done after treatment of a rejection episode so we can make sure the rejection has been completely reversed.

To do a heart biopsy:

- you go to the radiology department.
- the doctor injects freezing (local anaesthetic) around where the biopsy goes through your skin
- the doctor threads a thin flexible tube through a vein and into your heart. You might feel some pressure as the tube is inserted.
- through the tube, the doctor inserts a small tool that can take tiny pieces of heart tissue. You might feel a gentle tugging in your chest as these tiny pieces are taken.



The pieces taken from your heart are so small the heart is not affected during or after your biopsy. However, it is possible the biopsy could cause some bleeding or bruising.

After a heart biopsy, if you notice any pain in the chest, shortness of breath, or heart palpitations, **report it to the transplant team immediately**.

3. Treating rejection early

Usually, we treat the rejection by increasing doses of prednisone (or steroids). You might get this medication through an intravenous or by taking pills. This treatment is usually enough to reverse the rejection.

There are different levels of rejection, called grades. Get to know these grades. After each heart biopsy, the transplant nurse will you know the grade of rejection.

Grade	Level of Rejection	Action
0	No rejection	
1R	Mild rejection	Usually not treated
2R	Moderate rejection	Usually treated with steroids by intravenous or pill
3R	Severe rejection	Treated with IV steroid Closely monitored either 5A or CCU depending on your condition

Rejection: Chronic Rejection

Chronic rejection is when the arteries of your transplanted heart become thicker. As the arteries get thicker, the blood flow to the heart muscle decreases. You might hear us refer to this as ‘Cardiac Allograft Vasculopathy’ (CAV).

Normally, a person would have chest pain as a sign the heart muscle is not getting enough blood. However, the nerves that allow you to feel the chest pain are often damaged during the transplant surgery. This means you might not feel any chest pain.

We do yearly tests such as an angiogram, or a special echo test called ‘dobutamine stress echo’ where we use special dye to see if your arteries are narrowing.

In most cases, the disease is mild and can be managed with medications.

Only the most severe cases may require major treatment such as angioplasty (a balloon to open the blockage), bypass surgery, or, rarely, a second transplant.

To help prevent chronic rejection, take your medications as prescribed, exercise and eat a heart healthy diet.

Infection

While helping your body accept your new heart, your anti-rejection medications weaken your immune system. A weakened immune system means your body cannot fight off infections the same way you could before taking these medications.

You are more likely to get infections after your transplant. As the doses of some medications are lowered over time, the risk of infection falls. The risk will be there for the rest of your life – as long as you are on medication.

As with rejection, the best ways to fight infection are to:

- 1. Stop it before it starts.
- 2. Recognize it when it happens.
- 3. Treat it early.

1. Stopping infection before it starts

Most infections are passed from hand to mouth. Other infections are carried in the air. Many infections are present in our bodies already and flare up when we take anti-rejection drugs.

The best ways to prevent an infection are:

- wash your hands often.
- ask others to wash their hands before touching you.
- try not to have ‘close contact’ with people who have a cold or infection.

That means:

- do not get very close to, or kiss, a person who is sick.
- if your spouse/partner has a cold, it might be best to sleep in another room until the coughing and sneezing stops.
- ask people with colds to cover their nose and mouth when coughing or sneezing.
- try not to visit people who are sick.

Others ways to help from getting an infection:

- Take your medications that are meant to help prevent common infections.
- Always tell your dentist you have had a heart transplant.
- Follow the food safety instructions outlined in this manual.
- Do not go into crowded, poorly ventilated areas.
- Keep your pets clean and do not allow them to lick your face. Wash hands after petting animals.
- If you have a cat, ask someone else to change the cat litter or wear a dust mask and gloves.
- Do not use public whirlpools or hot tubs.
- For the first 3 to 6 months after surgery, do not go into public swimming pools.
- Wear a dust mask when sanding paint, gardening in dry, dusty conditions, or when doing any other dusty activity.

Stopping infection before it starts, continued

- if you have birds or fish as pets, have others clean the cages or tank. Ideally, birds should not be in the house due to the dust they create.

2. Recognizing infection when it happens

It is important to catch any infection early.

What to watch for:

- Fever above 37.5°C (99°F) two times in 2 hours.
- Coughing up sputum, or a dry cough.
- Burning or stinging sensation when you urinate.
- Cold sores on the lips or cankers in the mouth.
- You notice redness, swelling, drainage, or pain around any cut or scrape.

- Throwing up (vomiting).
- Diarrhea.
- Pain in the stomach.
- Headache that does not go away with pain medicine.

If you notice any of these signs, report them right away to the Transplant Clinic nurse or doctor. See the phone numbers on the back cover.

3. Treating infection early

The medication we give depends on the type of infection and where it is. We might need to give you more than one medication.

If you are unwell, call the transplant clinic during office hours or the emergency number on the back cover.

If you or your loved one feels you are very ill, call an ambulance.

Cancer

When people take anti-rejection medications for a long time, they are more vulnerable to other disease, including certain types of cancer. The most common type of cancer is skin cancer.

Helping to prevent skin cancer

All transplant recipients are more prone to skin cancer.

To protect your skin:

- ✓ Wear sun block with a sun protection factor (SPF) of 30 or higher.
- ✓ Wear sunglasses when outdoors.
- ✓ Wear a hat with a wide brim.
- ✓ Wear protective clothing when outdoors.
- ✓ Never use a tanning booth.

Your doctor should refer you to a dermatologist to be checked at least every 6 months to a year, depending on your skin. If you prefer, the transplant doctor can refer you to a dermatologist at St Paul’s.

Signs of skin cancer

If you notice any new skin spot or change to a mole, report it to your doctor.

Other types of cancer

It is very important to have a family doctor that is committed to regular cancer screening for you.

Your family doctor should monitor you closely for other types of cancer for the rest of your life.

You should have regular PAP tests and breast exams if you are a woman.

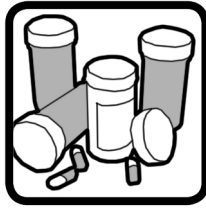
You should have regular prostate tests if you are a man.

Regular bowel screening is also very important for both men and women.

Report any sudden, unexpected weight loss or other unusual signs to your doctor.

Taking Your Medications

You are taking medications to help keep your transplanted heart working well and to keep you healthy. When you take all your medications as directed, you give yourself the best chance of having a healthy transplanted heart for a long time.



As you recover and gain your strength, we reduce the doses of your medications to a minimum level. Some will be stopped.

Where to get your medications

We give you a supply of your transplant medications (your anti-rejection medications) when you are ready to leave the hospital.

All your anti-rejection and some anti-virus medications are supplied by BC Transplant. This means you do not have to pay for them. However, you are responsible for the cost of all your other medications.

The key is to have a really good system to keep track of when you need to get refills. It can get confusing! The BC Transplant Pharmacy at St Paul's Hospital (located on the first floor of the Providence Building) needs at least 3 days notice if a refill is needed. The phone number is on the back cover.

Plan ahead. This will prevent many problems in the future.

Buy all of your other medications at your local pharmacy.

Tips for taking transplant medications

- NEVER stop taking any transplant medication unless the transplant doctor has told you to stop.
- Take your transplant medications at the same time in the same way every day. This keeps the amount of medication in your body the same throughout the day.
- Take your transplant medications exactly as directed on the label. Never change the dose of your medications without the go ahead from the transplant doctor.
- Report side effects to the Transplant Clinic.
- Men should not father a child without talking to the transplant doctor. Some of the drugs can affect the unborn baby.
- If you are a woman and could get pregnant, transplant medications can harm the unborn baby.
 - You must use birth control.
 - If you become pregnant while taking this medication, call the transplant clinic right away.

TIP *Never eat grapefruit, pomegranate, pomelo, or their juices.* These fruits and their juices can affect how anti-rejection drugs work.

Always check with the Transplant Clinic doctor or nurse before taking:

- any new medications,
- over-the-counter medicines (medicines you can buy without a prescription),
- ANY natural health or herbal products.

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

Taking other medications

In addition to your transplant medications, you will have a number of other medications you need to take regularly. Take each medication as directed.

Not everyone takes all these medications, but you will be taking some of them:

- Pain medication – usually stopped after 3-6 weeks
- Anti-bacterial medication called cotrimoxazole (Septra) to prevent severe pneumonia. This drug is usually stopped after 6 months
- Medication to lower your blood pressure - most people are on this for life.
- Medication to lower your cholesterol, usually for life

- Medication to prevent stomach ulcers, usually for the first 6 months
- Aspirin to help keep the blood from clotting too quickly, for life
- Vitamins and minerals, for the first 3-6 months
- Anti-viral medication (acyclovir or valganciclovir) to prevent herpes virus (very common after a transplant), or cytomegalovirus (CMV, a common infection similar to mononucleosis or mono), for 3-6 months
- Diuretics (water pills), can be stopped if fluid retention is no longer an issue for you. The doctors will check you regularly.

When you miss a dose of any medication

✓ If you miss a dose and it is **less than half the time** before you must take your next dose:

- take the missed dose,
- then take your next dose on schedule.

✓ If you miss a dose and it is **more than half the time** before you must take your next dose:

- skip the missed dose,
- then take your next dose on schedule.

Missing a dose of medication, continued

✓ **Never take 2 doses at the same time or take any extra doses** to make up for missed doses.

Example:

If you are to take a medication every 12 hours and you remember to take your medication within 6 hours of the time you were to take it, take the missed dose.

If it is more than 6 hours after the time you were to take it, skip that dose. Wait and take your next dose as scheduled.

Worried about missing a dose?

- Write down the time and date you missed the dose.
- Contact the post transplant nurse.

Know your medications

We know it will take time to learn all your different medications. The commons ones are described on the next few pages.

Use the list of questions in Appendix B to help you learn about all your medications.

Transplant Medications

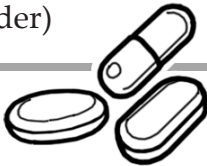
(Anti-Rejection Medications)

Mycophenolate *(my-ko-fen-oh-late)*

Other names: CellCept®
Novo-Mycophenolate
Myfortic®

Capsules: 250 mg (blue and dark orange)

Tablets: 500 mg (lavender)



What is it?

Mycophenolate is an anti-rejection medication.

How to take

- Keep the pills in the supplied container sealed until ready to take them.
- Take at the same time and the same way every day.
- Usually take one dose every 12 hours, in the morning and evening.
- Swallow the pill whole. Do not crush, break, or chew the pill.
- Wash your hands after touching the pill.

What to watch for

- This medication can cause birth defects.
- If you are a woman and could get pregnant:
 - use birth control before beginning, during, and for 6 weeks after taking this medication.

- call your doctor right away if you become pregnant.

- If you are a man:

-you should not father a child while taking this medication.

-use some form of contraception.

Tell your transplant team if any of these side effects bother you or do not go away:

- diarrhea
- loss of appetite
- headache
- rash
- trouble breathing
- chest pain or pressure
- dizziness or fainting
- very tired or no energy
- swelling of the hands, feet, ankles, or lower legs
- unusual bruising or bleeding

Other notes

- If other people handle the capsules, they must wash their hands.
- Store this medication in dry, dark place at room temperature.
- If you take antacids containing aluminium & magnesium (Maalox) or magnesium supplements, or calcium supplements, take them 2 hours before or 4 hours after taking this medication.



Examples of Mycophenolate (not to scale)

Note:

Numbers on tablet **do not necessarily** indicate the dosage.

Tacrolimus (*tah-crow-li-mus*)

Other names: Prograf®

Capsules: 0.5 mg (yellow), 1.0 mg (white)
5 mg (pink)



What is it?

Tacrolimus is an anti-rejection drug.

To work properly, this medication must stay at a certain level in your blood. If the level is too low, your body can reject your heart. If the level is too high, it can damage your kidneys or liver.

Over time, we allow the levels to get lower. Although the doses will be dropped to a minimum over 12 months, you will be on this drug for the rest of your life.

How to take

- Take at the same time and the same way every day.
- Usually take one dose every 12 hours. You should take this medication the same way and same time every day.
- **Do not eat grapefruit, pomegranate, pomelo and their juices.** These fruits can change how this medication works.
- Swallow the pill whole. Do not crush, break, or chew the pill.



Examples of Tacrolimus
(not to scale)

What to watch for

Most side effects either go away with time or when the dose is reduced.

Tell your transplant team if any of these side effects bother you or do not go away:

- vomiting
- diarrhea
- headaches
- feeling dizzy
- high blood pressure (over 140/85)
- increased blood sugar
- tremors (shaking) in the hands or feet
- trouble sleeping
- rash, hives or skin blisters
- swelling of the mouth, face, lips, tongue, or throat
- very hoarse voice or sore throat
- trouble breathing
- chest pain or pressure
- swelling of the hands, feet, ankles, or lower legs

Tacrolimus, continued

- very thirsty
- painful or difficult urination
- passing only small amounts of urine
- unusual bruising or bleeding

Other notes

- Store this medication in dry, dark place at room temperature.
- On the day you are scheduled for blood tests:
 - write down the last time you took your medication and bring this with you.
 - **Do Not** take your morning dose of Tacrolimus until after your blood is drawn.
 - take your medication as scheduled, unless told differently.
- If you take antacids, take them 2 hours before or 4 hours after taking this medication.

Prednisone (*pred-ni-zone*)

Other names: Apo-prednisone®, Novo-Prednisone, Winpred™

Tablets: 1 mg, 5 mg, 50 mg

Liquid: called Prednisone



What is it?

Prednisone is also sometimes called 'steroids'. It is an anti-rejection drug. This drug starts at a high dose and is slowly lowered down over 4-6 months. In most people we are able to stop it after that time. Some people will take it for the rest of their lives.

How to take

- The dose of this medication can change often. Always take the dose ordered for you.
- Take this medication with food or a glass of milk to keep from getting an upset stomach.
- At first, this medication is taken twice a day. After your condition stabilizes, the doctors will ask you to take this medication once a day.
- Prednisone tablets can be cut in half either by hand or with a pill cutter. Sometimes you will have to take ½ tablets as your prednisone doses are slowly dropped down.

Prednisone, continued

What to watch for

This medication has many side effects that depend on how much and how often you take it. Some patients suffer from diabetes after the transplant, even if they didn't before. Blood sugar levels are much higher while on Prednisone. You may have to take insulin for a while.

People who are already diabetic will notice their sugar levels are more difficult to control.

We will refer diabetic patients to a specialist if they don't already have one to help them manage. The diabetes will change as the doses of Prednisone changes, so you must be very careful about measuring and treating your sugar levels.

Tell your transplant team if any of these side effects bother you or do not go away:

- more hungry than normal for you
- weight gain
- vomiting
- mood swings
- feeling anxious or paranoid
- pimples (acne)
- bruise easily
- pain in joints
- trouble sleeping
- headaches
- swelling of the hands, feet, ankles, or lower legs
- feeling dizzy or unwell
- weak muscles
- mouth sores

- trouble breathing
- trouble thinking (confusion)

Other notes

- Weigh yourself every day at the same time. Empty your bladder before you weigh yourself. Keep a record of your weight.
- Make sure you know your correct dose because this dose will change often.
- Store this medication in a dry place at room temperature.
- If you take antacids, take them 2 hours before or 4 hours after taking this medication.
- Limit the amount of sweets you eat or drink, such as candy, pop, desserts, and jams. Look for sugar-free substitutes.



Examples of Prednisone
(not to scale)

Note:
Numbers on tablet **do not** necessarily indicate the dosage.

Living With Your New Heart

Recovery - The first weeks and months

Keeping safe

You need to have someone stay with you for at least the first month after the transplant. You will need help with managing at home for the first while.

Monitoring your heart

- ✓ **Check your blood pressure:**
- once a day. for the first 3 months
 - if you feel dizzy or have a headache

Check your blood pressure while sitting down.

- ✓ **Check your pulse:**
- once a day
 - if you feel dizzy, feel a pounding or fluttering in your chest, or you feel your heart skipping beats

- ✓ **Check your temperature:**
- once a day for the first 3 months
 - any time you do not feel well

Always wait 20 minutes after eating or drinking anything hot or cold before taking your temperature.

If your temperature is more than 37.5°C (99°F), take your temperature again in one hour. If it is still high, call the transplant team.

- ✓ **Check your weight:**
- every morning at the same time (empty your bladder first)
- If you gain more than 2 kg (4 lb) in 2 days, or 2.5 kg (5lb) in a week, contact the transplant clinic (see back cover for numbers).

Use the Vital Sign Record in Appendix D to keep track of your readings.

Activity

- ✓ Rest often for the first few weeks. Save your energy.
- ✓ Do your deep breathing and coughing exercises frequently. Remember to protect your breastbone.
- ✓ Go for short walks.
- ✓ Start attending the Healthy Heart Program. The nurse will arrange this for you.

Protect your breastbone

Your breastbone takes 6 to 8 weeks to fully heal.

- ✓ Brace your chest when coughing or sneezing, especially for the first 2 weeks.
- ✓ Report any severe pain to the transplant doctor or nurse.
- ✗ Do not lift more than 8 pounds.
- ✗ Do not push or pull with your arms such as when moving in bed and getting out of bed.
- ✗ Do not drive for at least 6 weeks after the surgery. After that, ask the transplant doctor if you are allowed to drive.

Your incision and pain

You will have pain on the surface of your chest. As your incision heals, expect to feel itching, burning, or tingling along your incision. You might find your skin around your incision feels numb or sensitive to touch.

Contact the transplant doctor or nurse if you have any of the following signs of infection:

- redness around the incision
- swelling around the incision
- yellow or green drainage from the incision
- severe pain around the incision
- a fever above 37.5°C (99°F)

Continue to take pain medication when you need it. Make sure you take pain medication at least one hour before you do any activities or exercises. Remember, it is important to keep moving. It helps you recover.

Eating and drinking

You must continue to limit the amount of fluids you drink for the first few weeks. We check this each time you visit the Transplant Clinic.



You will have learned by now how many calories you can eat and how much fluids, salt, fats, cholesterol, and carbohydrates you can have.

If you find some of your medications make you feel sick to your stomach:

- make sure you have some food in your stomach before taking your pills (unless the instruction specifically says to take a certain pill on an empty stomach).
- eat small amounts frequently.
- take small sips of diluted juices, clear low salt soups, or diet-carbonated drinks such as diet ginger ale.

Sleeping

You might have some trouble sleeping when you first get home. This can be from the medications, discomfort from your chest incision, changes in your daily routine, or worry about being out of the hospital.



Talk to the transplant doctor or nurse if you continue to have trouble sleeping.

Transplant Clinic Visits

- ✓ You must visit the Transplant Clinic 2 times a week for the first few weeks.
- ✓ Your clinic visits can include:
 - blood tests
 - heart biopsies
 - a visit with the Transplant Clinic nurse
 - an examination by the transplant doctor
 - a session with the physiotherapist in the Healthy Heart Program
 - meetings with other transplant team members

The Transplant Clinic nurse needs to be able to contact you with instructions after these tests are done. Make sure you leave the correct contact details with the clerk.

Living life - Staying healthy

The best way to stay healthy is to:

- take your medications correctly
- get your health checked regularly by your GP or Family Doctor
- eat a healthy diet
- get plenty of exercise
- protect yourself from illness

Get your health checked regularly

- ✓ Arrange to see your family doctor every 6 to 12 months. Your family doctor is the person who oversees all your health care needs.



- ✓ See your dentist every 6 months to get your teeth checked and cleaned.
 - Remind your dentist that you are a transplant patient and are taking anti-rejection drugs.

Eat healthy

- ✓ Continue to follow your diet, eating healthy foods.

Get plenty of exercise

- ✓ Attend the Healthy Heart Program.
 - This program will get you exercising regularly.
 - Nurses, doctors, and exercise specialists are there to keep track of your progress and help you if needed.
- ✓ Make time for exercise every day.

Get plenty of exercise, *continued*

- ✓ Take time to warm up before exercising. Warming up will help to slowly increase your heart rate.
- ✓ Take time to cool down after exercising. This will help your heart to slowly return to its normal rate.

Protect yourself from illness

- ✓ Regular handwashing (both you and your loved ones) is the best way to protect yourself from infections.
- ✓ Stay healthy by **preparing food safely** and avoid getting food poisoning.
 - Always wash your hands before preparing food and before eating.
 - Always wash and sanitize the surfaces you use to prepare food.
 - Read 'Food Safety: Easy Steps to Make Food Safe' (HealthLinkBC Health File Number 59a).
 - Follow "boil water" alerts issued by local health authorities.
- ✓ Prevent **disease**.
 - Get a tetanus vaccine every ten years. You were given one before your transplant.
 - Get a flu vaccine each year.
 - Always check with the Transplant Clinic before getting any other vaccines.

- ✓ **Don't smoke.** If you used to smoke and are finding it difficult to stay off them, speak with the transplant nurse. They will be able to link you with some programs to keep you free of smoking.



- ✓ **Before you drink any alcohol or use recreational drugs,** talk with your transplant doctor. Alcohol and drugs can interfere with how some medications work.

Medical Alert

Let everyone know you have had a heart transplant and are taking anti-rejection medications.

- ✓ Wear a medical alert bracelet or necklace.
- ✓ Carry a medical alert card in your wallet next to your photo identification.



Living Life – Returning to daily life

We encourage people to resume a normal life as soon as they are well enough

Understanding your emotions

It is common for a person who has had a heart transplant to feel a range of emotions, from high to low. This can last from days to months.

These feelings can be from the stress your body has gone through, from the stress of living with a health condition and the medications, and/or from the side effects of the medications you are taking.

If you are finding it hard to deal with these emotions, let your transplant team know. We can arrange for you to see a psychologist or psychiatrist. They can help you deal with your emotions and find ways to live life to the fullest.

Sex and pregnancy

It is fine to have sex after your heart transplant. How soon you return to having sex depends on how you feel and how much energy you have. To give you an idea of the energy needed, sex can take about as much energy as climbing two flights of stairs.

For 6 weeks after your transplant:

- choose a position you are comfortable in.

Don't forget that sexual contact is a possible way of getting an infection. If you do not have a regular sexual partner, use condoms to decrease your chance of getting an infection.

Some men have trouble getting or keeping an erection, both before and after a heart transplant. Talk about this with your transplant doctor. There are a number of treatments available to help.

Women must not get pregnant for the first year after transplant. Any planned pregnancy should be discussed with the transplant doctor as the medications may affect the unborn child.

Men should not father children until discussed with the transplant doctors. Some of the medications can affect the unborn child.

Going back to work

About 3 months after your transplant, you should be able to get back to work. However, this depends on how you are doing and what kind of work you do. You might need to start slowly and work part-time until you build up your strength. Talk with your transplant doctor about what works best for you.



Travel

As you recover and return to your daily life, you might want to go on a vacation or travel for longer periods. Once the transplant doctor has told you that your body has adjusted to your new heart and you do not need blood tests as often, you can start planning.



It is best not to travel to places where sanitation is a concern. This is because there is a greater chance you could get an infection and the health services you would need might not be available.

- ✓ Check with the Transplant Clinic first. We will let you know if it is safe to travel.
- ✓ Get a travel letter from the Transplant Clinic. This letter has:
 - a list your current medications (useful when crossing borders)
 - recent blood work results
 - Transplant Clinic phone number
 - phone number for the BC Transplant Society answering service where you can contact your transplant doctor 24 hours a day
 - contact details for the closest transplant centre where you are travelling
- ✓ **Buy travel health insurance.** Make sure it covers pre-existing illnesses. If you have trouble getting travel health insurance, contact the social worker.
- ✓ Keep all **medications** in their original containers. Make sure the medication name is clearly marked. This is very important when crossing borders.
- ✓ Carry twice the amount of **anti-rejection medication** you will need. Keep half with you at all times and put the other half in your luggage. That way, even if your luggage or handbag is stolen or lost, you have enough medications to get you through the trip.

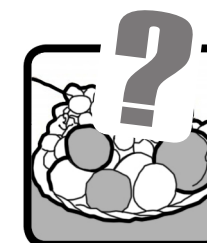
- ✓ Take enough of the rest of your medications to last your whole trip plus some extra, in case of an emergency or a delay.
- ✓ If travelling to a different time zone, ask the Transplant Clinic nurse if you should adjust your medication times, and if so, how.
- ✓ Get your regular blood tests done before you go away.
- ✓ Check with the transplant doctor before getting any vaccinations, or taking any tropical disease medication.

Nutrition after heart transplant

This gives you general information on eating a healthy diet. Before you leave the hospital, your dietician gives you information specific to you.

Certain fruits and transplant medications don't mix

Certain fruits and their juices can make the blood levels of your anti-rejection medication too high.



Do not eat grapefruit, pomegranate, pomelo and their juices

Protect yourself from infection

Raw or undercooked foods can carry harmful bacteria. With a lower immune system from your transplant medications, there is a greater chance you could get very ill.

- Always fully cook meat, fish and eggs.
- Choose dried deli meats such as salami and pepperoni. Make sure they are low salt.
- Do not eat uncooked hot dog wieners.
- Eat and drink only pasteurized dairy products such as hard cheeses and yogurts. Most products sold in stores are pasteurized.
 - do not eat unpasteurized dairy products, including soft and semi-soft cheeses such as Feta, Camembert, Brie, and blue-veined cheese.

- Choose pâtés, meat spreads, and smoked seafood or salmon sold in cans or choose those that do not need to be kept in the refrigerator until after you open them.
- Never take chances with your food. Remember, foods may not look or smell bad so *when in doubt, throw it out*.

For more information on making food safe, read Food Safety: Ten Easy Steps to Make Food Safe (#59a) from HealthLinkBC

Eat a diet high in protein

You need a diet high in protein for about 4 to 6 weeks after your heart transplant.

Protein helps your body heal from surgery.

Limit the amount of fluid you drink and eat

Right after your heart transplant, your body will still hold extra water.

Usually, people with a heart transplant are limited to 1500 mL (6.5 cups) of fluid in a day. You might be able to drink more fluids once your body stops retaining water – check with the transplant team before you do so.

Follow a low salt diet

High blood pressure is common for people with heart transplants. Too much salt in your diet increases the chances of you holding extra water in your body. You will need to follow a low-salt diet for the rest of your life.

Limit the amount of salt or sodium in your diet to 2000 mg or less.

One teaspoon of salt contains 2300mg of sodium!

Control your blood sugar

The medication prednisone could cause your blood sugars to increase. If you become diabetic (which happens sometimes after a transplant), the dietitian will talk to you in detail.

To help keep your blood sugar within normal range:

- eat at least 3 meals a day with regular snacks.
- eat foods high in fibre and whole grains.
- limit foods that contain simple sugars like sweetened drinks, regular pop, dried fruits, and ice cream.

Calcium and Bone Health

When a person takes prednisone for a long time, it can cause their bones to become thin and breakable (called osteoporosis).

- For at least the first 3 months after your surgery, you must take a calcium and Vitamin D supplement to make sure you get enough calcium in your body.
- Eat 4 servings of food high in calcium each day.
- If you find it hard to eat 4 servings of foods high in calcium each day, talk to your dietitian.

Weight Gain and High Cholesterol

Transplant medications can cause you to gain weight and give you high cholesterol.

If you put on too much weight, it could cause:

- high blood pressure
- hardening of the arteries
- problems with controlling blood sugar, especially if you already have diabetes

To control your weight:

- eat 3 meals a day.
- eat a snack if your meals are more than 4 to 6 hours apart. This helps control your hunger and help you to not overeat at mealtime.

- eat more high fibre foods such as vegetables, fruits, whole grains, and beans. They are naturally low in fat and can help you from feeling hungry.
- choose lean cuts of meat, fish, and poultry.
- choose non-fat dairy products.
- limit how much animal fat and saturated fats you eat.
- exercise regularly - an excellent way to control your weight, improve your cholesterol levels, and to keep your bones strong.

Your Donor

You are alive today because someone decided to be an organ donor and give the gift of life. You might receive a letter or card from the donor’s family, telling you something about the donor.

You are welcome to write and thank the donor family. There is no time limit on when to write. You can write at any time.

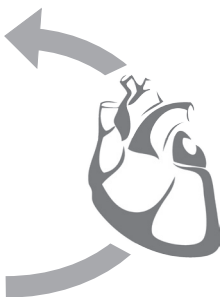
If you choose to write to the donor family, do not put details about yourself in the letter that could identify you, your family, where you live, or where you work.

Send or bring your letter to the Transplant Clinic. The social worker will forward it to BC Transplant who will then send it to the donor family.

The BC Human Tissue Gift Act protects the identities of donors, recipients and their families. This means you will not know who your donor was, and the donor's family will not know who you are.

The person who receives a heart transplant is called the ‘recipient’

The person who gives the heart is called the ‘donor’



Your Clinic Schedule

If you live outside of the lower mainland, you may be transferred to a clinic closer to home. BC Transplant has post transplant clinics in the Interior and Victoria.

Clinic Visit and Biopsy Schedule

- Weekly for the first month on a Thursday morning
- Once every two weeks for a month
- Monthly until 6 months
- Nine months
- One year (an angiogram and echo tests will be done to monitor your heart). No more biopsies will be done after one year unless you are sick
- Every six months

When to get help

Call 9-1-1 for any of the following:

- Chest pain or pressure
- Feel faint or very dizzy for more than 5 minutes
- Have really bad stomach pain
- Severe bleeding
- All the normal reasons you would call an ambulance

Contact the Transplant Clinic nurse or doctor, anytime day or night (see back cover for phone numbers) for any of the following:

- Signs of rejection:
 - decreased energy level
 - reduced ability to exercise
 - weight gain of two kilograms (4lb) in 2 days or more, sometimes with swelling of the ankles
 - shortness of breath while doing normal activities
 - irregular or fast heart rate
 - low blood pressure
- Signs of problems following a heart biopsy
 - pain in the chest
 - shortness of breath
 - heart palpitations
- Signs of infection
 - temperature above 37.5°C (99°F) for 2 hours in a row
 - coughing up sputum
 - a dry cough that does not go away
 - a burning or stinging sensation when you urinate

- sores anywhere on your body, including cold sores
- redness, swelling, drainage, or pain around your incision or around any cut or scrape
- diarrhea
- pain in your stomach

(See Appendix C for contact phone numbers)

Contact your family doctor for any of the following:

- Any health concerns not related to your heart or transplant medications
- Any prescriptions for drugs that you were on before your transplant for conditions not related to your heart.
- With time, your family doctor will become responsible for more and more of your health concerns. Especially when you are only coming to our clinic twice a year.

If in doubt, ask the clinic staff, they will spend time with you to answer any questions.

Appendices

Appendix A

Terms you might hear

Acute

Something that happens early or suddenly.

Anemia

Sounds like ‘an-ee-me-ya’. When you don’t have enough red blood cells in your body.

Antibiotics

Medicines used to treat or control infections caused by bacteria or other organisms.

Antibody

Sounds like ‘ant-ee-bod-ee’. A protein made by your immune system to fight infection and foreign invaders.

Arteriogram

Sounds like ‘arh-t-ear-ee-oh-gram’. A special xray to look at arteries. We inject a special dye into an artery and watch the dye flood through the arteries in your body.

Biopsy

Sounds like ‘bye-op-see’. A procedure that removes a small amount of tissue from the heart (or another part of the body). The small tissue is examined closely for signs of rejection, infection, or disease.

Catheter

A small flexible tube that goes into or out of the body.

When put into a vein or artery, it can be used to give fluids, nutrition, and medications; or to take measurements or blood samples.

Can be used to drain fluid from the body such as a when one is placed into your bladder to remove urine (urinary catheter).

Chest Tube

A large flexible tube put in through between the ribs into the chest. The end sits at the operation site. We use a chest tube to remove fluid from around the operation site.

Chronic

When a person has a disease for a long time, or it can get worse over time. Does not go away, but can be treated to lessen the impact of the disease.

CT Scan

CT stands for Computed Tomography (may also be called a CAT Scan). A CT Scan is a special xray test using a computer. The scan detects many conditions that do not show up on regular xrays.

Crossmatch

A blood test that checks to see if your blood is a good match for the donor’s blood.

Diastolic

The bottom number of blood pressure. This is the time when the heart is at rest and filling with blood.

Diuretic

Medicine that helps to remove excess fluid from your body.

Echocardiogram

‘Echo’ meaning using sound waves, ‘cardio’ meaning heart, and ‘gram’ meaning a print out.

An echocardiogram (also called an echo) is an ultrasound test. High-pitched sound waves are bounced off different parts of the heart, creating pictures. This test allows us to look at the heart muscle, the valves of the heart, and the blood flow through the heart.

Edema

Sounds like ‘eh-dee-ma’. Swelling of body tissue. Seen around an injury or wound.

Can also be from too much fluid in the body. This edema is seen in the feet, ankles, legs, belly, and hands. Fluid can also build up in your lungs, causing you to have trouble breathing.

Electrocardiogram (ECG)

‘Electro’ meaning electrical activity, ‘cardio’ meaning heart, and ‘gram’ meaning a print out.

An electrocardiogram is a test that checks the electrical activity of the heart. The heart’s electrical activity is represented as lines printed on paper. The test can show problems with the heart’s natural electrical system.

Extubate

This is when we take the breathing tube out.

Fluid

Any food or drink that is liquid at room temperature. This includes water, ice cubes, milk, juices, soft drinks, hot drinks, alcohol, soups, gelatin desserts, ice cream, popsicles, and liquid nutrition supplements (such as Ensure® or Boost®).

Hypertension

Sounds like ‘hi-per-ten-shun’. High blood pressure

Immune System

A special system of body cells that helps protect your body from infection, disease, and other foreign matter such as a new organ.

Immunization

Sounds like ‘ih-mew-ni-za-shun’. When you are given a vaccination to protect you from a certain disease.

Immunosuppressed

Sounds like ‘ih-mew-no-suh-prest’. When your immune system is weakened or blocked from working by medication.

Incision

The cut made in the skin with a scalpel (a very sharp surgical knife). An incision is made as part of a surgery to expose the organs under the skin. An incision is closed with suture, skin staples, or wire. Sutures (commonly called stitches) can dissolve over time or need to be removed at a later date.

Terms you might hear, continued

Intravenous (IV)

An intravenous is commonly called an IV. ‘Intra’ meaning into, and ‘venous’ meaning vein.

We give most medications through the intravenous because they might not be able to be given in any other way, or they work faster than pills.

Isolation

Some infections are easily spread. Critically ill patients have a greater chance of becoming infected with germs and put their health at greater risk. For this reason, we may ‘isolate’ patients. This involves keeping patients separate from other patients and using extra equipment and clothes (such as an isolation gown, gloves, and maybe a face mask) to protect everyone.

Magnetic Resonance Imaging (MRI)

A special kind of x-ray, commonly refer to this as having an ‘MRI’. Uses a large magnet, radio waves, and a computer to look inside the body. Creates clear pictures or images of bones, organs, and soft tissues. Does not use xrays or radiation.

Nausea

Sounds like ‘naw-zee-yah’. You feel sick to your stomach or feel like you are going to throw up.

Pacemaker

A device that helps the heart to beat regularly. Small electrical leads are threaded into the heart and attached to the heart muscle. When triggered, the pacemaker sends a small electrical charge into the heart muscle. This triggers the heart to beat. A pacemaker can be either temporary or permanent.

Pneumonia

Sounds like ‘new-moan-yah’. Pneumonia is an infection of one or both lungs. Three common causes of the infection are bacterial, virus, and fungi.

Pre-Transplant

Means before the transplant.

Post-Transplant

Means after the transplant.

Pulmonary

Sounds like ‘pull-mon-air-ee’. Means anything to do with the lungs.

Recipient

The person receiving the donor organ.

Rejection

When your body attacks the transplanted organ. If not treated, it can result in damage to the transplanted organ.

Renal

Refers to the kidney.

Sepsis

Sepsis is a serious infection in the blood or body tissues.

Sternum

Your breastbone.

Systolic

The top number of blood pressure. This is the time when the heart is pumping blood around the body.

Trachea

Your windpipe.

Urine, urinary, urinate

It means to ‘pee’. Some people refer to this as ‘passing water’.

Ventilator (breathing machine)

A machine that helps you breathe, either when you are not strong enough to breathe, or when you are not able to breathe. The machine is attached to an breathing tube. It may also be called ‘life support’.

Vital Signs

The measuring of a person’s temperature, heart rate, blood pressure, and breathing rate.

Vomit

Sounds like ‘vaw-mit’. Means to throw up.

Wean

When we slowly reduce or take away something such as a medication

Appendix B

Know your medications

It is good to ask yourself these questions often:

- ☐ Do I know the names of each medication?
- ☐ Do I know why I am taking each medication?
- ☐ Do I know what each of my medications looks like?
- ☐ Do I know when to take each medication?
- ☐ Do I know how to take each medication?
- ☐ Do I know how long I am to take each medication?
- ☐ Do I know what to do if I have any side effects?
- ☐ Do I know which medications have special instructions such as taking on an empty stomach or taking with food?
- ☐ Do I know what to do if I am late taking a dose, miss a dose, or forget to take a dose?
- ☐ Do I know how and when to re-order my medications?

If you answered ‘no’ to any of these questions, ask us to review your medication during your next Transplant Clinic appointment.

Appendix C

My Transplant Team Contact Sheet

Pre-Heart Transplant Clinic
8:30 am to 3:30 pm, Monday to Friday
Appointments 604-806-8374

Post-Heart Transplant Clinic
8:30 am to 3:30 pm, Monday to Friday
Appointments 604-806-8374
Clinic Nurse Pager 604-252-4843

Outpatient Pharmacy 604-806-8151

For emergencies

Outside of clinic hours
and days:



- 1. Call BC Transplant 604-877-2240
or 1-800-663-6189
- 2. Ask for the ‘Heart Transplant
Cardiologist on call’.
- or, if urgent -
- 3. Call 911.

	Name	Phone	Email
Transplant clinic			
Social worker			
Pharmacist			
Psychologist			
Dietitian			

Appendix D

My Vital Signs Record

Normal Values:

Weight (Wt) _____

Heart Rate (HR) _____

Date	Time	Wt	HR	BP	Temp
				/	
				/	
				/	
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Blood Pressure (BP) _____

Temperature (Temp) *Less than 37.5 °Celsius*

Date	Time	Wt	HR	BP	Temp
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Check List - Getting ready for the call

Get a dental check up

☐

Make an Advance Care Plan

☐

Cell phone and charger ready

☐

Pack suitcase:

In suitcase

Add last minute

Toothbrush.

☐

☐

Toothpaste

☐

☐

Dentures with case

☐

☐

Shaving supplies

☐

☐

Comb or brush.

☐

☐

Slippers (with non-slip soles) ☐ . . .

☐

☐

Glasses

☐

☐

Glasses case

☐

☐

Hearing aid(s)

☐

☐

Hearing aid case.

☐

☐

Spare hearing aid batteries . ☐ . . .

☐

☐

Something to read.

☐

☐

Underwear

☐

☐

Loose-fitting shirt

☐

☐

Loose-fitting pants

☐

☐

Socks

☐

☐

Supportive walking or running shoes

☐

☐

Cane or walker

☐

☐

Heart Transplant booklet. . . ☐ . . .

☐

☐

☐

☐

☐

☐

☐

☐

In my wallet:

BC Services Card / CareCard . .

☐

Photo Identification

☐

Small amount of cash (\$15-20)

☐

Arrange for someone to care for my pet(s)

☐

Make a list of people to call, before I go to the hospital, with phone numbers

☐

Arrange for a place to stay for 3 months after surgery

☐

Make my plan for travelling to the hospital (Transportation Plan) with the social worker . .

☐

☐

☐

☐

☐

☐

☐

☐

☐

Check List - Getting ready to go home

I know how to:

weigh myself

☐

take my blood pressure . .

☐

take my temperature. . . .

☐

check my blood sugar . . .

☐

do my exercises.

☐

I know:

the signs of rejection

☐

the signs of infection.

☐

the names of all my medications, how much I take, when I take them, and why I must take them

☐

I can take my medications correctly with little or no help from my nurse

☐

I have my schedule for appointments at the Transplant Clinic and blood tests.

☐

how to contact the Transplant Clinic if I have questions or concerns.

☐

when to get help

☐

I have:

a supply of all my transplant medications . . .

☐

prescriptions for all my other medications . . .

☐

someone to drive me from the hospital

☐

someone who can get my prescriptions filled. .

☐

someone to stay with me

☐

a place to stay for the next 3 months.

☐

I have where I am staying:

an answering machine or voicemail .

☐

a blood pressure machine.

☐

weigh scales

☐

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This material has been
reviewed and approved by
patients, families and staff.

