

LVAD Handbook

LVAD team contact information:

LVAD Coordinator: Monday – Friday 8:00 am – 4:00 pm

Phone: (613) 696-7000 ext. 14973

Fax: (613) 696-7165

Pager: (613) 759-0443

Office H-4433

If it is after hours and there is an emergency, please call

(613) 696-7000, press 0 and ask to speak to the Nurse Coordinator

This handbook is intended to help you and your caregiver understand and feel more comfortable with living with your LVAD. It is not intended to replace your LVAD product manual. **You should read and be familiar with your product manual, including how to use and maintain your equipment, how to respond to alarms, and how to do a controller exchange.**

The University of Ottawa Heart Institute (UOHI) currently uses 2 different LVAD products. They are Heartmate 3 and HeartWare. Your surgeon will decide which device you receive.

Your LVAD was inserted because you have heart failure. Your LVAD indication depends on many other health factors. It can be for:

- Bridge to Transplant (BTT) – your LVAD was inserted to help keep you stable while you wait for a heart transplant.
- Bridge to Candidacy (BTC) – your LVAD was inserted to help keep you stable and to improve your candidacy conditions for transplant.
- Destination Therapy (DT) – your LVAD was inserted to improve your quality of life. You are not a heart transplant candidate.

The team that looks after you at the UOHI consists of:

Cardiac Surgeons

- Dr. Munir Boodhwani
- Dr. Marc Ruel
- Dr. Hadi Toeg

Heart Failure Cardiologists – we use a shared care approach, meaning you will be seen by any/all of our physicians.

- Dr. Sharon Chih
- Dr. Mariana Lamacie
- Dr. Lisa Mielniczuk
- Dr. Ellamae Stadnick

LVAD Coordinator

Perfusionists

Biomedical Engineer

Other Allied Health Professionals: including social workers, dieticians, psychologist, and physiotherapists.

When to call the LVAD Coordinator

- If you have new symptoms of the conditions listed in the Medical Concerns section of this handbook:
 - Heart failure
 - Bleeding
 - Stroke (after you've called 911)
 - Driveline infection
 - Clot formation in the LVAD
 - Accident
 - Arrhythmia
- If you feel light-headed or dizzy.
- If your blood pressure (MAP) is too high or too low.
- If you have a fever.
- If you are sick to your stomach and unable to take your pills.
- If you have any LVAD alarms.
- If you're concerned that your LVAD may be damaged.
- If you notice any changes in how the LVAD feels or sounds, or if you feel different.
- If you notice any trauma to the driveline.
- If you have been started on an antibiotic or other medication that could affect your INR.
- If you are going to have any procedures done.
- If you are going to have any dental work done (even cleaning) – you will need antibiotics.
- For your bloodwork results and Warfarin dosing.
- If you need more Hollister anchors.
- If you need refills for any of your medications that were prescribed by the heart failure team. Please prepare ahead and call before you run out of pills. You can also ask your pharmacy to fax a refill request to 613-696-7165. For medications that were ordered by another doctor (family doctor, specialist, etc.) please contact their office for refills.
- For health issues that do not pertain to your LVAD or heart failure you can still go see your family doctor or specialist.

When to call 9-1-1

For medical emergencies dial 9-1-1, and then call your LVAD coordinator to let them know what's going on. If you live in Ottawa ask them to bring you to the Civic Hospital emergency department.

If you live in another city go to the closest hospital. Once you are medically stable we can arrange transfer to the Heart Institute if needed.

It is important to explain to the paramedics and the hospital that you don't have a pulse and that your blood pressure is a MAP so that they can assess and treat you appropriately. Your caregiver should travel with you to the hospital as they know about your LVAD. They should bring your backup controller, batteries, charger and AC power adapter.

Emergency examples:

- LVAD not working
- Stroke
- Significant bleeding
- Suspected heart attack
- Loss of consciousness
- Seizure

Medical Concerns

Having an LVAD and being on blood thinning medication can put you at a higher risk of certain medical conditions. The following are medical conditions that you should be aware of and know how to spot. If you are concerned you may be experiencing any of them call your LVAD coordinator.

Heart Failure:

If you have increased signs of heart failure it could mean that your medications or LVAD need to be adjusted. Signs of heart failure include:

- Shortness of breath
- Swelling in your legs
- Swelling in your abdomen
- Fatigue/weakness
- Feeling lightheaded or dizzy
- Sudden weight gain of 5 or more pounds in a week

Bleeding:

Taking blood thinners means your blood cannot clot as fast as before. You should watch for signs and symptoms of bleeding and report them to the LVAD coordinator. If you are bleeding significantly you should call 911 as this can be life-threatening. It's important that **you should never be given Vitamin K or Tranexamic Acid** unless the doctor clears it with one of our heart failure doctors – this can cause clotting in your LVAD. Signs of bleeding can include:

- Dark (black) or bloody stools
- Rigid painful abdomen
- Nose bleeds/bleeding from gums
- Pink sputum
- Flecks of blood in your vomit
- Frequent new bruises
- Blood in the urine
- Any new blood

Stroke:

The earlier that a stroke is detected and treated, the better the outcomes. Call 911 right away if you suspect a stroke, even if you aren't sure. Having an LVAD can put you at risk of ischemic stroke (blood clot) and hemorrhagic stroke (bleed). To minimize your risk of stroke it's important to take your Warfarin and your Aspirin, and that your blood pressure is well controlled. Signs of stroke can include numbness or weakness (particularly on one side or area of your body), altered level of consciousness, or confused or garbled speech.

If you suspect a stroke you need to act **F.A.S.T. – call 911**

- **Face....is it drooping?**
Arms....can you raise both?
Speech....is it slurred or jumbled?
Time....to call 9-1-1 right away

Driveline Infection:

Your driveline exits your body and goes to your heart. It is very important that you don't get a driveline infection as this can cause an infection in your heart. Driveline infections need to be treated with antibiotics immediately. Notify the LVAD coordinator if you notice any signs of driveline infection, including:

- Fever of 38C or higher
- Redness around the driveline insertion site
- Warmth at the driveline site
- Foul odor at your driveline site
- Drainage
- Pain at your driveline site
- Skin pulling away from driveline
- Seeing white velour on driveline

Arrhythmias (irregular heart rate):

You will no longer feel your pulse because your LVAD flow is continuous, not pulsatile. Even though you can't feel it, your own heart will continue to beat and you'll still have a heart rate. Your LVAD will work best when your heart rate is regular because the LVAD will fill properly. If you feel palpitations or have an ICD shock you should call the LVAD coordinator and seek medical attention. You should also notify the pacemaker clinic if you've had a shock.

Clot Formation in the LVAD:

Clot formation in the LVAD is rare, but can be fatal. It's important to take your Warfarin and Aspirin as directed, and to call the LVAD coordinator if you suspect clot formation. Signs and symptoms of clot formation can include:

- Increased heart failure symptoms
- A rise in power (watts) on your LVAD of 2 or more above your normal value. Call the LVAD coordinator immediately.
- Urinating very dark urine (looks like Coca-Cola) – this can happen due to the destruction of red blood cells. Call the LVAD coordinator immediately.

Accidents:

If you are involved in a blunt-force event you should go to the emergency room to be checked out. Blunt force trauma can cause internal bleeding and should be ruled out. It is also possible that your VAD could become damaged. Blunt force accidents include car accidents, falls, and hitting your head.

Driveline Dressing Change

Your dressing change will be done by a home care nurse. Depending on where you live and the policies of your LHIN, the nurse may come to you or you may have to go to their office. If you/your caregiver are interested in learning how to change your own dressing you can speak with your home care nurse and LVAD coordinator. It may be possible to have the nurse change it one day a week, and you change it the other day.

Your driveline dressing should be changed 2x per week. If you develop a driveline infection this may need to be increased to 3x per week or even daily.

Your driveline dressing should be changed under sterile technique. This means that the nurse should wash their hands and then use sterile gloves. You or your caregiver should look at the driveline site every time the nurse changes your dressing. This way you will notice if there are changes that could suggest driveline infection. Let the LVAD coordinator know if you see increased redness, drainage, the skin is pulling away from the driveline, or you have pain at the driveline site. If you are concerned about the appearance you should take a picture and email it to the LVAD coordinator.

Your driveline should be well secured using a Hollister anchor (2 for Heartmate 3). This is to prevent it from being accidentally dislodged. The Hollister should be changed weekly, or more often if is loose or soiled. The Hollisters are provided by the hospital – ask the LVAD coordinator if you need more.

Scissors should never be used to remove any part of your dressing or Hollister. You don't want to risk damaging your driveline.

Avoid pulling, kinking or twisting your driveline or cables. This can cause them to fracture, which could cause your LVAD to stop working. If you think your driveline or cables have become damaged call the LVAD coordinator.

The best way to prevent infection is to practice good overall hygiene, including frequent hand hygiene.

Daily Life

- We encourage you to live a full and active lifestyle!
- You can go out and about as you would prior to having your LVAD with a few things to keep in mind. The following information is to assist you in living safely with your LVAD
- Your caregiver should remain with you for the first few weeks after returning home from your LVAD surgery. After this and once you are stable, you should eventually become more comfortable with being independent. You can discuss this with the heart failure doctor and LVAD coordinator at your first clinic appointment.
- It is important to remember that **you must always bring your backup controller and spare fully charged batteries with you any time you leave your house.**

Sleeping:

- You must switch to AC power for naps and overnight sleep. If you stay on batteries there is a risk that you may run out of power and may not hear the alarms.
- You should check all your connections before you go to sleep to make sure they're tight.
- You should have your backup controller, charged batteries and a flashlight near you when you sleep in case there is a power outage.
- Your controller can get too warm when it's covered with blankets, so try to keep it uncovered.
- It's recommended that you don't sleep on your stomach.

Power outages:

- In case of a power outage you need to go somewhere that has power. If you cannot stay with a friend/family member or at a hotel then you can go to the emergency room. Please call the LVAD coordinator for assistance with this.
- Keep a flashlight and fully charged batteries by your bed in case of power outage in the night.
- The LVAD manufacturers recommend that you do not use a back-up generator to power your LVAD.

Showering:

- You cannot ever have a tub bath or go swimming with an LVAD.
- You can shower once your driveline site has healed and the heart failure doctor has assessed you and says it's ok. Usually this is after you've returned home and after you've had one or two clinic appointments. This is to protect you from getting a driveline infection. Until then you can take sponge baths.
- You must keep your driveline site dry. Keep it covered with your dressing and cover your dressing with saran wrap and tape. Cut a piece of saran wrap that is bigger than your dressing and secure it with tape on all 4 sides. Make sure it's well sealed.
- If your dressing gets wet it must be changed.
- When you first start showering you should do so on the days that the home care nurse is going to change your dressing. That way if it gets wet your dressing will be changed soon after. Once you are confident that you can keep your dressing dry you can start showering when you choose.
- You must keep your controller and batteries dry by using the shower bag we provide you
- You must shower on battery power, not plugged in to AC power.
- If you have difficulty hearing then your caregiver should remain close enough to hear any alarms should they occur while you're showering.
- Make sure your shower is safe – get a non-slip mat, a grab bar and a shower chair.

Driving:

- You may not drive immediately after LVAD implant. You must wait until at least 2 months after surgery and for your heart failure symptoms to be minimal. Your heart failure cardiologist must give their approval prior to starting driving. You can discuss this with them in clinic

Dental work:

- You must take antibiotics prior to any dental work or cleaning. You can ask for a prescription in LVAD clinic, or you can call the LVAD coordinator you arrange this for you.

Travelling:

- You can travel with your LVAD once you are stable and feeling well. If you wish to travel we ask that you discuss this first with your heart failure doctor to decide if you are stable enough to do so.
- Please let the LVAD coordinator know when/where you are travelling. We can give you the information of the nearest VAD center in the event of emergency, as well as notify them that you will be in the area. For longer trips we may have to arrange for you to do bloodwork while you are away.
- You can travel by airplane with your LVAD, however this requires advance preparation. Please speak with the LVAD coordinator if you plan to take a flight. We can advise you how to travel with your equipment and give you a letter for airport security. It's important that you don't go through the x-ray scanner as this can cause electrical interference that may stop your LVAD. Also, if you are travelling to another country you may require a different plug for your equipment which we will need to arrange.

Electrostatic discharge (ESD):

ESD is the sudden transfer of electricity from one object to another. A mild shock to your skin is OK, however ESD to the controller could cause it to malfunction. It's important to avoid sources of ESD as this can cause electrical damage to your LVAD which may cause it to stop working. Sources of ESD that should be avoided include:

- Touching computer monitors or TV screens
- Scuffing your feet on carpets
- Vacuuming
- Taking clothes out of the dryer
- Electric blankets

Using dryer sheets and a humidifier in the house can help prevent ESD. If you think you've got ESD you should discharge it by touching a metal surface before handling your LVAD controller or power sources.

Sexual activity:

You can resume sexual activity 6-8 weeks after surgery, once your sternum has healed. Be mindful of where your controller is and that your driveline does not get pulled. You should not get pregnant with an LVAD. A growing fetus could cause your LVAD to become dislodged. Warfarin can cause birth defects. If you are a woman of child-bearing age please speak to your doctor about reliable contraception options.

Rehab, exercise and diet

- Going to rehab is required for all patients after getting their LVAD.
- The goal of rehab is to increase your strength and exercise tolerance in order to help you live a more capable and healthy lifestyle.
- Rehab is free!
- Rehab starts 6-8 weeks after surgery, once the doctor has assessed you and says it's ok.
- Rehab lasts for 12 weeks for destination therapy LVAD patients. If you are a bridge to candidacy or bridge to transplant patient we encourage you to stay in rehab while you wait for your heart transplant.
- Rehab at the Heart Institute is twice a week, for an hour each time.
- If you live in another city we can arrange your rehab there.
- You should exercise regularly, not just in your rehab class. Rehab will help teach you what exercises are safe.
- Many people tend to put on weight after they get their VAD. You will most likely be feeling better and therefore have a better appetite. It's important to continue to exercise and make healthy food choices. This should be a low sodium, heart healthy diet. If you would like to speak to a dietician please ask the LVAD coordinator to arrange this.
- In the beginning you may feel full quickly. This is because of the location of your VAD. Try eating smaller, more frequent meals. This feeling usually goes away.
- You may be asked to keep a fluid restriction. It's also important to drink enough so that you don't become dehydrated as this could impact how well your LVAD fills. If you aren't sure how much water to drink please ask your heart failure doctor or LVAD coordinator.
- Maintain a consistent amount of Vitamin K in your diet. Fluctuating amounts can affect your INR.
- Do not drink alcohol. Alcohol can impair your judgement and delay your ability to react safely in an emergency. Alcohol can also affect your INR. Alcohol is a diuretic and can also cause you to become dehydrated which can affect how your VAD operates. Drinking alcohol can increase your risk of bleeding in the gastrointestinal tract.
- Do not smoke and try not to expose yourself to second hand smoke.

Absolute DON'Ts with an LVAD:

- No swimming or baths – your LVAD cannot be submerged in water
- No MRI's
- Don't go through/near security screening equipment or metal detectors
- No contact sports or vigorous jumping (no trampolines)
- Never leave the house without a backup controller and batteries
- Avoid exposure to extreme heat or cold
- Do not become pregnant
- Keep your cellphone at least 20 inches away from your controller
- Don't undergo procedures that require high power electrical treatment or therapeutic ultrasound
- Avoid therapeutic ionizing radiation

Online LVAD resources:

- <https://www.heartware.com/patients-caregivers>
- <https://www.heartmate.com/healthcare-provider/heartmate-3-lvad>
- <https://www.mylvad.com/>
- <https://www.canada.ca/en/health-canada/services/drugs-medical-devices/warfarin.html>

Monitoring Your Health

Daily monitoring:

You should check and record your weight, temperature and MAP daily as well as your LVAD numbers. This should be done at the same time every day. Please email or fax your log sheets to the LVAD coordinator once a week, or input your recordings in MyChart.

Blood pressure (MAP):

Because your LVAD provides continuous flow to your aorta you will not have a pulse and your blood pressure will be a one number measurement, a mean arterial pressure (MAP), instead of two numbers (systolic/diastolic). Your MAP is obtained by using a doppler ultrasound and an automatic BP cuff. You will be taught how to do this before you go home from the hospital. You should check your MAP daily and record it on your log sheet. A normal MAP is:

- HeartWare: 65-85
- HeartMate 3: 65-90

It's important that your MAP is well controlled to reduce your risk of stroke and to ensure that your LVAD can provide good flow. If your MAP is too high or too low you should call the LVAD coordinator. If you are able to feel your pulse or are getting two numbers on your BP cuff let the LVAD coordinator know. It could mean that your LVAD speed needs to be adjusted.

Clinic:

- Clinic visits take about 1 hour.
- Our clinic is on the 2nd floor of the Heart Institute.
- Please bring your medication list with you at every visit.
- Your driveline dressing will be changed in the clinic.
- We may sometimes ask you to bring some of your equipment with you for maintenance checks.
- You will have an ECG before your appointment, and may need to have a blood sample drawn as well. This will all be done at the clinic.
- Clinic visits are every 1-3 months.

Regular testing:

- You will require frequent blood tests in the beginning. This could be twice a week. The goal is to get this to once every two weeks once you are stable. You will be given a standing order requisition for blood work when you leave the hospital. Blood tests can be done at the 2nd floor lab at the Heart Institute, or at an outside lab.
- You will have an ECG before each clinic visit.
- You will have echocardiograms once or twice a year. This is may be done as a regular echo, or as a speed optimization echo where we adjust the speed of your LVAD.
- If you are a BTC or BTT LVAD patient you will also require right heart catheterizations every 6 months and blood tests to check for antibodies every 3 months.

Anticoagulation

You must take Aspirin and Warfarin (also called Coumadin) daily when you have an LVAD. This is to prevent the LVAD from developing clots.

Your Aspirin dose will not fluctuate. It needs to be taken daily, usually in the morning.

Your Warfarin dose will be prescribed based on the results of a blood test called INR. The INR measures how long it takes your blood to clot. **Your goal INR range is 2.0-3.0.** Your INR will be checked every 2-3 days until it is stable and within range. After that it will be checked weekly. Once it has been stable for 3 weeks we will check it every 2 weeks. Your INR results will be monitored by the LVAD coordinator. If you do your blood work at the Heart Institute we will have your results the same day. If you do it at a lab in the community we usually have your results the next day.

Your Warfarin should be taken daily, at the same time. We recommend taking it at dinner time. If you miss a dose and don't remember till the next day don't take an extra dose. Call the LVAD coordinator.

Your dose of Warfarin may need to be adjusted frequently. You will be given a prescription for different strength pills. You should become familiar with the different strengths and how to combine them for your dose. The LVAD coordinator will tell you what dose to take, based on your INR results.

If your INR falls below 2.0 you may be asked to take enoxaparin. This is a subcutaneous injection that you give yourself every 12 hours. You will also continue taking your daily Warfarin. The enoxaparin keeps your blood thin while your INR is too low. Once your INR is above 2.0 the LVAD coordinator will tell you to stop your enoxaparin.

Some medications can affect your INR. Please tell the LVAD coordinator if you have been started on a new medication. Do not take probiotics.

Aspirin, Warfarin and Enoxaparin all affect your blood's ability to form clots. You need to monitor for signs of bleeding and take measures to stay safe from injury.

If you go for any invasive procedures or dental work you need to inform them you're taking blood thinners. Your blood thinners cannot be held, however we can work to ensure the safest INR range for your procedures.

Alcohol can affect your INR. It is recommended that you abstain from drinking alcohol when you have an LVAD.

You should never be given Vitamin K or Transeaxemic Acid without consulting the heart failure doctors. These medications make your blood clot and could cause clot formation in your LVAD.

Some foods contain Vitamin K. You can still eat Vitamin K foods, but it's important that you maintain a stable amount of them every day. That way your INR result will stay consistent.

Foods rich in Vitamin K that can be eaten, but eat a consistent amount:

- Green leafy vegetables (kale, spinach, swiss chard, green leaf or romaine lettuce)
- Parsley
- Broccoli
- Asparagus
- Coleslaw
- Brussel sprouts

These foods can be eaten, but not in large quantities:

- Flaxseed
- Garlic
- Cranberry juice
- Mango
- Ginger
- Green tea
- Avocado
- Soy (soy milk, tofu)
- Chamomile tea

Avoid eating:

- Natto (fermented soy)
- Grapefruit
- Seville oranges
- Tangelos

Enoxaparin Administration Instructions

PREPARE



Step 1
Wash and dry your hands thoroughly.



Step 2
Have your patient sit or lie in a comfortable position and choose an area on the right or left side of the abdomen, at least 2 inches from the belly button.



Step 3
Clean the injection site with an alcohol swab and let dry.

INJECT



Step 4
Remove the needle cap by pulling it straight off the syringe and discard it in a sharps collector.



Step 5
With your other hand, pinch an inch of the cleansed area to make a fold in the skin. Next, insert the full length of the needle straight down – at a 90° angle – into the fold of skin.



Step 6
Press the plunger with your thumb until the syringe is empty. Then pull the needle straight out and release the skin fold.

DISPOSE



Step 7
Point the needle down and away from yourself and others, and then push down on the plunger to activate the safety shield.



Step 8
Place the used syringe in the sharps collector.