



Considering a Left Ventricular Assist Device (LVAD)

A Guide for Patients and Caregivers

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About this Booklet

If you are reading this booklet, your health care team has probably suggested that a Left Ventricular Assist Device (LVAD) may be an option for you. You will need to decide whether you would like to have an LVAD or continue to manage your heart failure with medication.

This booklet is designed to provide you and your loved ones with information to think about what is most important for to as you consider if an LVAD is right for you. It is important that you also talk with your health care team as you consider the options for management of your heart failure with or without an LVAD.

Before you make a decision, it is important to understand:

- What each option means;
- How each option would impact your life; and
- The risks, benefits and challenges of each option.

This decision will be made by you and supported by your family and health care team.

As you read this booklet, take time to think about:

- What is most important to me about my life?
- How do I want to live the rest of my life?
- What are my hopes and my worries?
- What are my options?

Getting an LVAD is not a complete solution, and you will require additional therapy in the future. There is a lot of information to take in and understand; but knowing and understanding what can happen will help you feel prepared and comfortable with your decision. A worksheet to write down your thoughts as you reflect on your options is found on pages 17-19 of this booklet.

Why you may need an LVAD

You have been living with heart failure, a condition where your heart is weak, and is unable to pump enough blood to meet the needs of your body. You have probably felt shortness of breath, tiredness or fatigue and noticed swelling because of your heart failure. You may have been in and out of the hospital often, and the quality of your life has been getting worse.

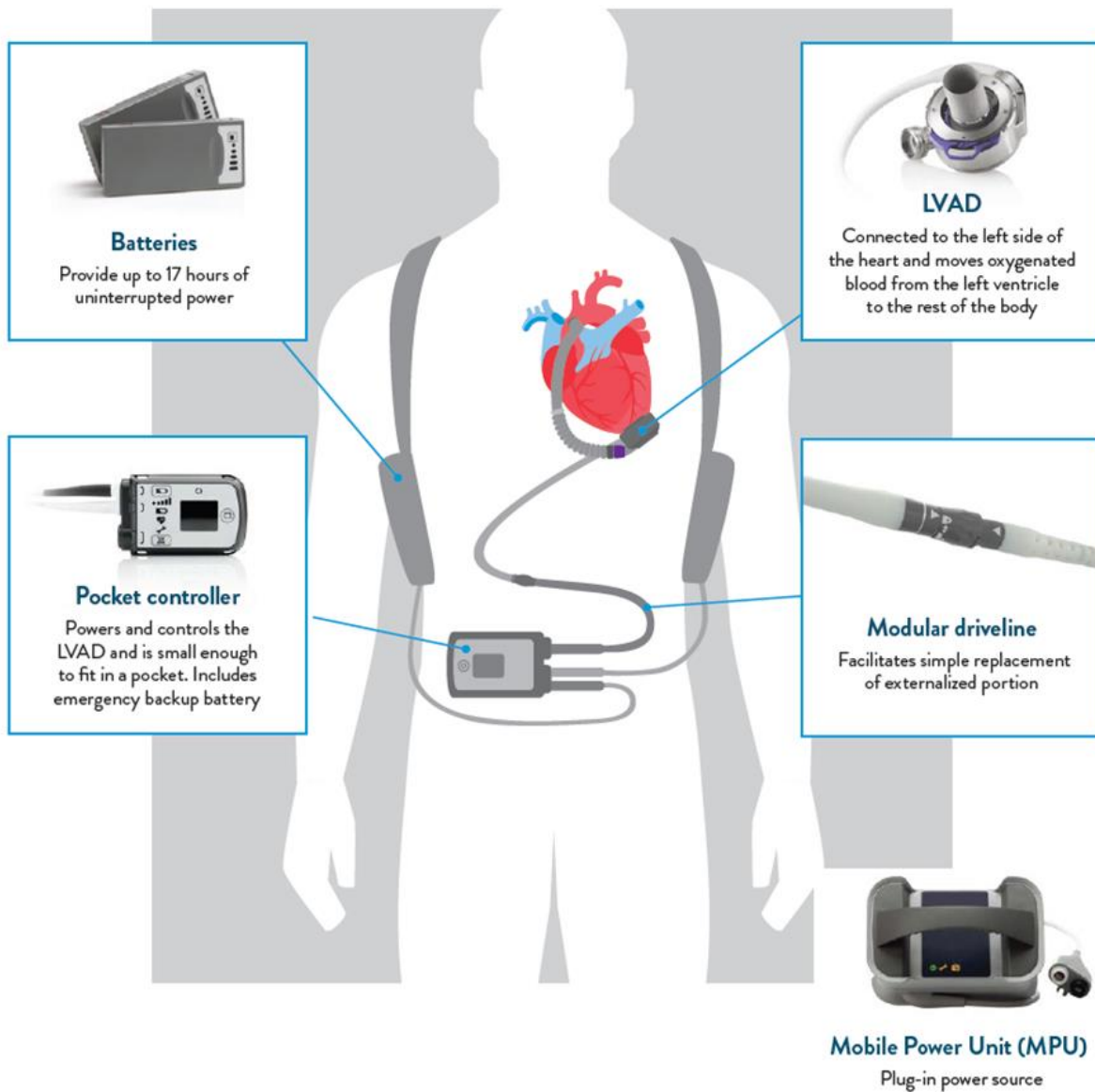
You now have *end-stage heart failure*. This means that the medications and other treatments that were helping you feel better, are no longer able to keep you feeling well. You may feel OK sometimes, but your heart will not get better, and it will likely become weaker over time.

People with end-stage heart failure have options. Depending on each person's circumstances, these might include:

1. Receive an LVAD (a mechanical pumping device attached to your heart)
2. Receive a heart transplant (a human donor heart)
3. Continue with medical therapy

What is a left ventricular assist device (LVAD)?

An LVAD is a mechanical pump that is attached to your heart and helps your heart pump blood throughout your body. The LVAD is surgically implanted, which means you would need to have major surgery. The LVAD is meant to improve your symptoms of heart failure and help you live longer (than if you did not receive the LVAD).



(Adapted for publication with permission.)

Indications for an LVAD

There are 3 main reasons why someone may need an LVAD:

1. Temporary therapy for people on the list for a heart transplantation

Some patients with end-stage heart failure may be candidates for heart transplantation. Sometimes a patient, on the list for a donor heart, may need a temporary LVAD until their heart transplantation can happen. When they receive their new heart, the LVAD is no longer needed and is removed.

2. Permanent therapy for people not eligible for a heart transplantation


For other patients with end-stage heart failure who are not eligible for heart transplant, they may be eligible to have an LVAD implanted permanently, for the remainder of their lives (called “destination therapy”).

3. Temporary or permanent therapy for people who still don’t know if they are eligible for a heart transplantation

Sometimes, patients might be too sick, and are not immediately eligible for a heart transplantation, but if they can get a little stronger, they might become eligible. In these cases, an LVAD can be implanted to see if it can help a patient get a little stronger, to become eligible for a heart transplantation (called “bridge to candidacy”). This is not an option for everyone.



What is involved in getting an LVAD?

- You will need to have major open-heart surgery.
 - Like other major heart surgery, getting an LVAD has risks, and recovery will feel difficult at times.
 - You will need to stay in hospital for a few weeks. If you have any complications, you may need to stay longer.
 - You and your caregiver(s) will learn about the device and equipment before you go home from the hospital.
- 
- After you are discharged from the hospital, the healthcare team will want to closely monitor your condition. If you live far from the LVAD hospital, you and your caregiver may need to stay close to your LVAD hospital to allow the team to closely monitor your condition before you can return to your home.
 - You will need to continue to have regular follow-up with your physicians and LVAD team. If you live very far from an LVAD centre, your local physicians, with support from the LVAD centre cardiologists will provide regular checkups.
 - You will have someone to call if you have questions or need help once you are home. The LVAD centre has a help line that is available 24 hours/day, 7 days a week.

Centres in Ontario that Implant LVADs

There are currently 3 hospitals that implant LVADs in adults in Ontario. These are the same 3 hospitals that provide heart transplantation for adults and include:

- University Health Network-Toronto General Hospital
- London Health Sciences Centre
- University of Ottawa Heart Institute

What is it like to live with an LVAD?

This section provides some general information about living with an LVAD. For more detailed information, please talk with the members of your LVAD team.

Term	Definition
Power Source	You will need to ensure you always have a power source (i.e. batteries or wall outlet). Charged batteries can last from 8 to 12 hours. If power supply to the pump is interrupted, the pump will stop, your heart failure symptoms will come back and you may die.
Carrying Equipment	You must always carry the controller and batteries on your body. The equipment can weigh 1.5 to 3 kg (3 to 6.5 lbs.). You must carry extra battery packs and an extra controller; in case they need to be changed.
Caring for the Driveline	You will need to clean the skin around the driveline site and change the bandage at least a few times a week. If this area is not regularly cleaned, this could cause a serious driveline infection.
Lifestyle Changes	It may take up to 3 months to recover from surgery, establish a daily routine, and resume normal activities. You and your caregiver may or may not be able to return to work. It is important to think about how this major change can affect your lives. Participation in a cardiac rehab program can help you return to normal activities and provide support as you deal with a major life change.
Water Precautions	You will no longer be able to swim, or bathe (no immersion under water) due to the equipment and driveline site. You can take regular showers, but need to take precautions, like placing the controller in a special shower bag and covering up your driveline site to keep it dry.

Sleep	You will not be able to sleep on your stomach. You will need to sleep in positions that do not cause the driveline to become tangled.
Sex	Patients living with an LVAD can still have sex, but you may feel differently about your body after getting an LVAD. Some patients report changes to their sex life.
Medications	Once you have the LVAD, there may be some adjustments to your heart failure medications. You will need to take blood thinners for the rest of your life.
Follow up appointments	Regular blood tests and follow up visits with the LVAD team are needed. Sometimes extra tests are needed. The LVAD team will explain their specific routines and schedules.
Cost	You could be responsible for some costs associated with having an LVAD, such as the cost of the driveline bandage supplies, medications, as well as travel and accommodations costs when you return to the hospital where you received your LVAD for follow up visits.
Emotions	Getting an LVAD is a big change, and you might feel worried, overwhelmed, depressed or anxious about the equipment and the changes to your life. Taking care of your mental health will be important.
Travel	You will still be able to travel with an LVAD but plan ahead to make sure you can travel safely. For example, power source availability, hospitals close by for emergencies, and travelling to places where LVAD experienced care is available.

Hospital Stays	During the first 2 years of living with an LVAD, most patients need to return to the hospital at least once for a complication. This can include infection, bleeding, stroke, blood clots, recurrent heart failure and other issues.
Compatibility with other Treatment	LVADs are compatible with other treatments, cardiac and non-cardiac, including implantable cardioverter-defibrillators (ICDs). CT scans, ultrasounds and x-rays tests are fine with an LVAD in place. You cannot have an MRI scan done if you have an LVAD.

Speak with members of your health care team to learn more about the LVAD and help you figure out if an LVAD is right for you.

Ask if they can connect you with patients who have an LVAD or with caregivers to learn about their experiences.



**You may find the following American websites helpful.
These websites have more information about LVADs
as well as patient and caregiver stories.**

**www.patientdecisionaid.org
www.lvaddecisionaid.com**

Benefits, Risks and Challenges to Think About

	Getting an LVAD	Not Getting an LVAD
Benefits	<p>The LVAD can help you live longer than if you did not get the LVAD.</p> <p>8 out of 10 patients who get an LVAD are alive after 1 year.³</p> <p>The LVAD can help you feel better (less short of breath, less swelling, and be able to do more activity).</p>	<p>You will not have to be dependent on a mechanical pump to live.</p> <p>You will not have to go through the complications and risks of surgery and having an LVAD.</p>
Risks and Challenges	<p>The surgery itself and living with an LVAD comes with risk of complications like stroke, infection, and bleeding. This can mean more hospital visits and longer hospital stays. These risks can also cause permanent damage to your health and well-being.</p> <p>Readjusting to life with new routines, limitations, burdens and worries. Patients report the first few weeks and months as the most difficult.</p>	<p>You will have a lower chance of surviving the next year, than if you had an LVAD.</p> <p>3 to 5 out of 10 patients without an LVAD are alive after 1 year.⁵</p> <p>You will continue to have moderate to severe heart failure symptoms (short of breath, tired, swelling). You may need to go to the hospital often to deal with those symptoms.</p> <p>If you need an LVAD to be eligible for heart transplantation, not getting an LVAD will prevent you from getting on the waitlist for transplantation.</p>

A Look at the Numbers – Life with an LVAD

Although each person's experience will be unique and unpredictable, the following numbers can give you an idea of what to expect if you have an LVAD.

Benefits after first year

Survival



8/10

people will be alive after 1 year.

Living well at 1 year



6/10

people living with LVAD will not experience any major complication related to LVAD.

Quality of Life

The majority of people notice improvement in their symptoms of heart failure and quality of life 6 months following LVAD surgery.

Risks during first year

Re-hospitalized for any cause



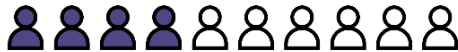
7/10

Stroke



1/10

Bleeding in the stomach or intestines



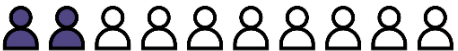
4/10

Bleeding requiring surgery



1/10

Major infection (sepsis or driveline infection)



2/10

Any infection (major or minor)



8/10

Ongoing heart failure



2/10

About 1/100

people need their LVAD replaced from device malfunction.

(Adapted from McIlvennan et al., 2014)⁴⁻⁷

How will your caregiver's life change?

The caregiver for someone with an LVAD will need to:

- Learn how to operate the LVAD (i.e. battery care, equipment maintenance, responding to alarms).
- Help the patient with their medical care (i.e. managing medications, attending follow up appointments).
- Help the patient with their care needs every day (i.e. sponge bathing or showering, cooking, running errands, driving, housework). More care may be needed for the first few months after surgery.
- Clean and change the bandage of the driveline site every day or as needed and check for infections.

Being a caregiver to someone with an LVAD – being able to help a loved one - can be rewarding. Being a caregiver to someone with an LVAD can also be life-changing and needs serious thought and consideration. It is important that everyone involved has a realistic understanding of what life with an LVAD will be like for you, and the impact of this on the caregiver's life as well.

In Ontario, people who get an LVAD must have a committed caregiver, i.e. someone to help you every day with your care. While in hospital, the patient and caregiver receive extensive training with the LVAD, but they will also need to show proficiency with certain tasks such as battery and controller changes before the patient is discharged home.

As you recover from your surgery and have a regular routine, caregiver responsibilities may get easier over time. If a patient experiences any complications due to the LVAD, the caregiver's life may become more challenging. Daily routines and activities, finances, emotional, physical and psychological health are some things that may impact a caregiver's life.

Every person's experience of living with an LVAD can be different. There is no way to predict which patients will experience complications before the surgery which makes it very hard for your LVAD team to prepare you for what to expect. Caregivers tell us that this is the hardest part of the decision – not knowing what complications to expect after the surgery.

These same things can also impact the life of a caregiver of someone who does NOT get an LVAD.

**You can read or listen to stories by caregivers
by visiting the following American websites:**

www.lvaddecisionaid.com
www.patientdecisionaid.org

Palliative and Supportive Care

Whether or not you decide to get an LVAD, you might also have needs for palliative or supportive care. It is important to speak with your health care team now about:

1. Palliative and Supportive Care

Many people living with heart failure have needs such as managing pain and symptoms, emotional support, assistance with decision-making and support for caregivers. Your health care team can provide much of this support; however, a palliative care practitioner may also be helpful.

Palliative care is aimed at promoting patient's quality of life through attention to symptoms, support and promoting shared decision-making. All of this can improve your feeling of control over the remainder of your life.

2. Advance Care Planning

Advance Care Planning has 2 main parts:

a) **Choosing a Substitute Decision Maker.**

Your Substitute Decision Maker (SDM) is someone who makes health care decisions on your behalf if you are incapable of health care decision-making. They make decisions based on your prior expressed wishes, or if unknown, in your best interest.

To learn more about the role of an SDM, please visit the website for the Canadian Hospice Palliative Care Association at www.chpca.net. They have several resources available on the website. Resources specific to Ontario can be found on the websites www.speakuontario.ca and Hospice Palliative Care Ontario (www.hpco.ca)

b) **Reflecting on your values, priorities, fears and beliefs with your SDM.**

This will help your SDM be prepared to make decisions for you in the future if needed. This is especially important for people with an LVAD as there may come a time in the future when you would want your health care team to turn off the LVAD and allow death.

3. End of Life Considerations

With an LVAD, most patients feel better and live longer. Some patients may feel worse or develop other health problems. Others may feel well for months or years and then experience symptoms or complications.

Turning off your LVAD

If things continue to worsen you may wish to discuss the option of turning off the LVAD pump with your healthcare team. For example, some people may want to turn off their LVAD if they have a stroke or are unable to communicate or care for themselves. It is important to talk to your doctors and loved ones ahead of time about your values and what makes life meaningful to you.



Without an LVAD, you will continue to manage your heart failure with medication, but your heart will continue to weaken. You may feel worse, and you may not live long. It is important to have access to palliative and supportive care, either through your current health care provider or from a specialized palliative care team. These providers can make sure you receive good pain and symptom management, emotional support and caregiver support.

Other Resources to Consider

Work with your health care team to identify where you can get help and resources for:

1. Nursing care support
2. The cost of medication and medical supplies
3. Social support
4. Finances
You can start by visiting: <https://www.canada.ca/en/services/benefits.html>.
5. Travel and accommodation options near the LVAD hospital
6. Legal support (will, power of attorney)
7. Palliative and Supportive Care
You can visit: www.virtualhospice.ca OR www.hpco.ca
8. Support for the caregiver

Reflection Worksheets

Now that you know more about LVADs and what your life might be either with or without an LVAD, take some time to answer these questions:

1. How do I want to live the rest of my life? (Check a box on the scale)

<p>I want to live longer, even if it means having a major surgery, being dependent on the LVAD, and at the risk of some serious complications.</p>	<p>I want to live with whatever time I have left. I do not want to go through a major surgery, risk serious complications, or be dependent on the LVAD.</p>
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2. What is most important to me about my life?

3. How do I want to live the rest of my life?

4. What do I hope for if I get an LVAD?

5. What do I hope for if I do not get an LVAD?

6. What worries me about getting an LVAD?

7. What worries me about not getting an LVAD?

References and Resources

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Acknowledgements

CorHealth Ontario would like to gratefully acknowledge the contributions of the patients, family members, caregivers, and health care professionals who provided their valuable thoughts and insight to the creation of this resource.

This guide was adapted by CorHealth Ontario from the I DECIDE: LVAD patient decision aid, entitled “A decision aid for Left Ventricular Assist Device (LVAD): A device for patients with advanced heart failure”, developed by the Colorado Program for Patient Centered Decisions at the University of Colorado School of Medicine (© 2018)², available at patientdecisionaid.org. Changes were made by CorHealth Ontario to represent the experiences of patients and their family members in Ontario.

Disclaimer

This publication is for informational purposes only and is not intended to be considered or relied upon as medical advice or a substitute for medical advice, a medical diagnosis or treatment from a physician or qualified health care professional. You are responsible for obtaining appropriate medical advice from a physician or other qualified health care professional prior to acting upon any information available through this publication.