

CHARTING YOUR COURSE

A Guide for Caregivers of People Living with LVADs

PART FOUR:

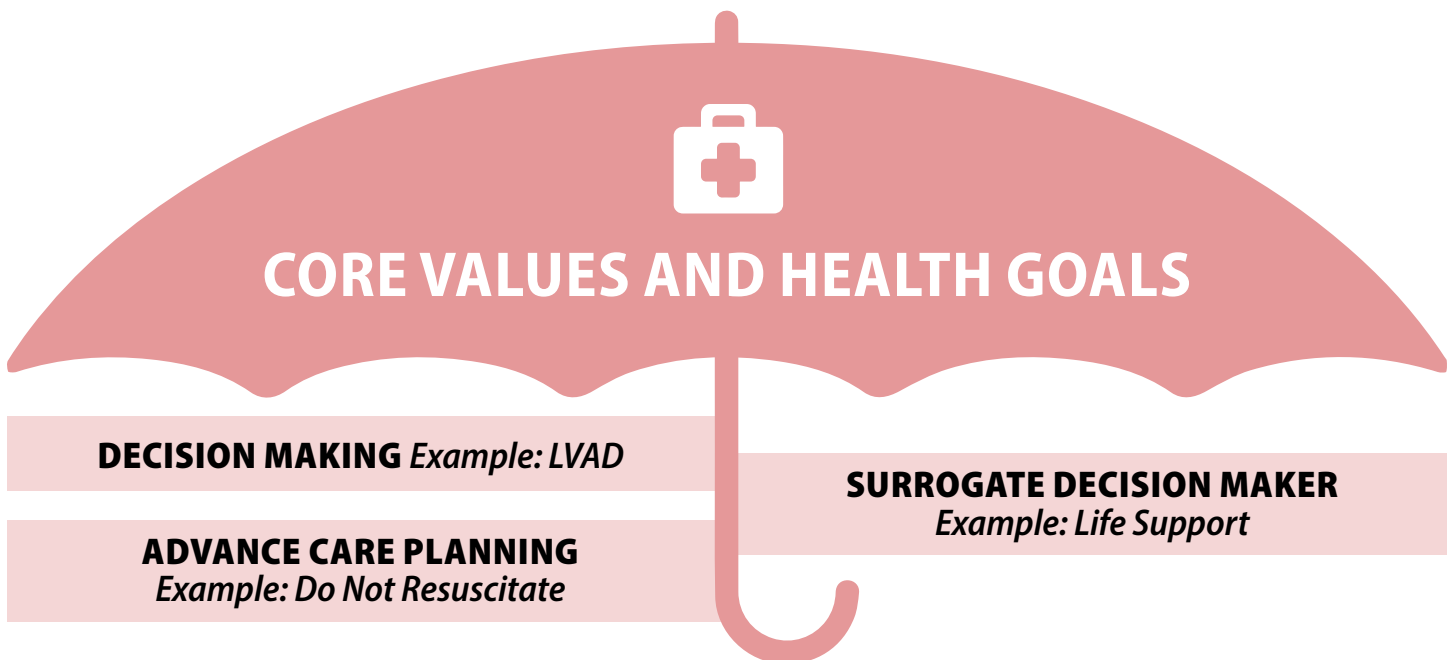
*Talking About What Matters
Most and Making Choices*



CORE VALUES AND GOALS:

What Matters Most

When caring for someone with a life-limiting illness like heart failure, some issues and decisions can be hard to talk about. Our values and goals play a large role in having this conversation and making decisions about the health care of the person you care for. This section will help you think about the core values that matter most to you and the person you care for.



SOME TIPS TO IDENTIFY YOUR CORE VALUES:



- What are you passionate about?
- What makes life worth living?
- What drives you to be better at something you love to do?
- Are there values you are unwilling to live without?

What Matters Most & Making the Best Choices for You

Every day we make decisions. Most of our decisions are simple. We decide what we want to wear, what we would like to watch on TV, or what we would like to eat for lunch. Other decisions are not so simple. Some decisions have longer lasting consequences because the stakes are higher. These decisions require more thought, planning, information, and time.

Values and goals play a role in decision making. Core values impact all aspects of our lives, including: relationships, political leanings, hobbies/passions, religious and/or spiritual connections, and where you live. Knowing your values is important when it comes to making choices.

ACTIVITY: *Thinking About Your Core Values and Goals*

Below is a small list of core values. Read each one. Circle the ones that ring true for you. How will you uphold your core values as you care for someone with heart failure? What activities or behaviors will you commit to doing to honor each value?

WHAT IS MORE IMPORTANT TO YOU? 4 IMPORTANT PARTS OF YOUR LIFE:
CONNECTING • **ENJOYING LIFE** • **FUNCTIONING** • **MANAGING HEALTH**

FAMILY (Icon: Family group)

FRIENDS (Icon: Two people standing)

SIGNIFICANT OTHER (Icon: Wedding rings)

RELIGION (Icon: Hands in prayer)

COMMUNITY (Icon: Group of people)

HEALTH (Icon: Heart with cross)

DIGNITY (Icon: Handshake)

MANAGING SYMPTOMS (Icon: Person with magnifying glass)

INDEPENDENCE (Icon: Person standing)

PRODUCTIVITY (Icon: Gears and clock)

PERSONAL GROWTH (Icon: Person climbing stairs)

RECREATION (Icon: Person on a bench)

DEEP DOWN WHAT MATTERS MOST TO YOU?

DECISION AIDS:

Making Choices That Are Right For You

Decision aids are tools that can help you and your loved ones make specific medical decisions by helping you think about available options (including the option not to do anything). Decision aids can come in different forms such as pamphlets, worksheets, online programs and videos. You can find examples of decision aids at: PatientDecisionAid.org.



ACTIVITY: *Ottawa Personal Decision Guide*

The Ottawa Personal Decision Guide helps you assess your needs and your loved one's needs for making a decision, planning your next steps, and keeping track of your progress. The next two pages show you an example of a completed form. Then, you can use the blank form at the end of this booklet to work through a decision you are facing. Your coach may go through the decision guide steps with you.



1 Clarify your decision.

What decision do you face? Additional care for my loved one

What are your reasons for making this decision? My loved one's health needs have increased; My comfort in providing care

When do you need to make a choice? 1 month

How far along are you with making a choice? Not thought about it Thinking about it Close to choosing Made a choice

2 Explore your decision.



Knowledge

List the options and benefits and risks you know.



Values

Rate each benefit and risk using stars (★) to show how much each one matters to you.



Certainty

Choose the option with the benefits that matter most to you. Avoid the options with the risks that matter most to you.

	Reasons to Choose this Option Benefits / Advantages / Pros	How much it matters to you: 0★ not at all 5★ a great deal	Reasons to Avoid this Option Risks / Disadvantages / Cons	How much it matters to you: 0★ not at all 5★ a great deal
Option #1 Care at home with part-time home health aide or nurse	Loved one stays home longer	*****	Cost	*****
	You can be part of care	***	You can be sure of needs met	***
	Professional help/advice	***	Still may have little time to self	**
Option #2 Care at home with full-time home health aide or nurse	Loved one stays home longer	*****	Cost (++)	*****
	Caring for your own health	**	Loved one's reluctance	****
	Professional help/advice	***	You can be sure of needs met	***
Option #3 Assisted living	In-center activities and groups	***	Cost (+++)	*****
	Safe and structured environment	****	Loved one's reluctance	****
	Relief from stress of caregiving	***	Guilt of not providing care	*****

Which option do you prefer? Option #1 Option #2 Option #3 Unsure







Support



Who else is involved?	Loved one	Home health agencies/assisted living	Loved one's healthcare providers
Which option do they prefer?	Part-time help	No opinion	Any of the 3 options
Is this person pressuring you?	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
How can they support you?	Participate in decision	Provide possible services	Provide opinion on health needs

What role do you prefer in making the choice? Share the decision with... Decide myself after hearing views of... Someone else decides...
Loved one








3 Identify your decision making needs.

Adapted from The SURE Test © 2008 O'Connor & Légaré.

	Knowledge	Do you know the benefits and risks of each option?	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> No
	Values	Are you clear about which benefits and risks matter most to you?	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> No
	Support	Do you have enough support and advice to make a choice?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
	Certainty	Do you feel sure about the best choice for you?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No

If you answer 'no' to any question, you can work through steps two  and four , focusing on your needs. People who answer "No" to one or more of these questions are more likely to delay their decision, change their mind, feel regret about their choice or blame others for bad outcomes.

4 Plan the next steps based on your needs.

Decision making needs	Things you could try
 <p>Knowledge</p> <p>If you feel you do NOT have enough facts</p>	<input checked="" type="checkbox"/> Find out more about the options and the chances of the benefits and risks. <input type="checkbox"/> List your questions. <input checked="" type="checkbox"/> List where to find the answers (e.g. library, health professionals, counsellors): <div style="border: 1px solid gray; padding: 5px; margin-top: 5px;">Ask cardiologist and internist about current healthcare needs, regimens, potential treatments</div>
 <p>Values</p> <p>If you are NOT sure which benefits and risks matter most to you</p>	<input type="checkbox"/> Review the stars in step two  to see what matters most to you. <input type="checkbox"/> Find people who know what it is like to experience the benefits and risks. <input type="checkbox"/> Talk to others who have made the decision. <input type="checkbox"/> Read stories of what mattered most to others. <input checked="" type="checkbox"/> Discuss with others what matters most to you.
 <p>Support</p> <p>If you feel you do NOT have enough support</p> <p>If you feel PRESSURE from others to make a specific choice</p>	<input checked="" type="checkbox"/> Discuss your options with a trusted person (e.g. health professional, counsellor, family, friends). <input type="checkbox"/> Find help to support your choice (e.g. funds, transport, child care). <input type="checkbox"/> Focus on the views of others who matter most. <input type="checkbox"/> Share your guide with others. <input type="checkbox"/> Ask others to fill in this guide. (See where you agree. If you disagree on facts, get more information. If you disagree on what matters most, consider the other person's views. Take turns to listen to what the other person says matters most to them.) <input type="checkbox"/> Find a person to help you and others involved.
 <p>Certainty</p> <p>If you feel UNSURE about the best choice for you</p>	<input type="checkbox"/> Work through steps two  and four  , focusing on your needs.

Other factors making the decision DIFFICULT

List anything else you could try:

COMMON TERMS TO KNOW

COMMUNITY



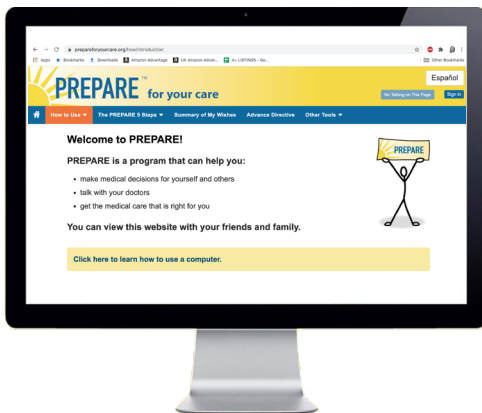
- **COMFORT CARE:** When curative care is not likely to help, medication or other non-invasive options are used to keep you pain free and comfortable.
- **PALLIATIVE CARE:** Specialized medical care focused on providing an extra layer of support and providing patients relief from symptoms, pain, and stress of a serious illness. The goal is to improve quality of life.
- **HOSPICE CARE:** Same principles of palliative care but usually provided in the home for people who are estimated to have six months or less to live.

ADVANCE CARE PLANNING



- **ADVANCE CARE PLANNING:** A process of learning and preparing for the decisions that might need to be made in future.
- **ADVANCE DIRECTIVES OR “LIVING WILLS”:** Legal documents that allow patients to provide instructions for their medical care in case they cannot make decisions on their own.
- **DURABLE POWER OF ATTORNEY FOR HEALTH CARE:** A legal document allows patient to choose a person to make medical decisions on their behalf if they are unable to make decisions on their own.
- **DO NOT RESUSCITATE (“DNR”):** This physician’s order to not use resuscitative measures is authorized by you or your health care agent.
- **MEDICALLY ADMINISTERED (ARTIFICIAL) NUTRITION AND HYDRATION:** Fluid and nutrients delivered by IV or a tube that goes into your nose and down to your stomach.

ADVANCE DIRECTIVES



An advance directive is a legal document that puts one’s values and wishes for your loved ones and the health care team in writing. It allows one to express desires for medical care if one were critically ill and could not make decisions for oneself. They are also called living wills. To get a copy of any state’s advance directive form, please visit this website: <https://prepareforyourcare.org/how/introduction>.

If you do not have access to the internet, you can call toll-free 1-800-658-8898 and request a copy of the advance directive for any of the states in the U.S. or ask your coach to mail you a copy to your home.



SOME TIPS ABOUT ADVANCE DIRECTIVES:

- You can get an advance directive form from any health care provider.
- Advance directive forms differ slightly from state to state.
- You can typically designate someone to be your durable power of attorney for healthcare in an advance directive.
- You do not need a lawyer to set one up. You only need two witnesses.
- You should give copies of your advance directive to your health care team, family, friends, and your lawyer.
- You can change your advance directive at any time and as often as you want.
- Talk with your loved ones, especially your durable power of attorney for health care, about what you have put in your advancedirective. Explain why you want the care you have decided on.

► SURROGATE DECISION MAKING

Sometimes, your loved one won't be able to make decisions for themselves. In this case, their "surrogate" decision maker – sometimes referred to as a health care agent – will make the decision for them.

It's best to identify the person you want as the surrogate decision maker before this time comes, otherwise, how this person is identified can vary by different state laws.

The job of the surrogate is to speak for the patient and to make a decision that their loved one would make. Thus, the surrogate's role is not to make a decision that they would make for themselves. This requires an understanding of their loved one's values and goals.



► TURNING OFF AN LVAD & END OF LIFE

SOME IMPORTANT QUESTIONS TO DISCUSS WITH YOUR LOVED ONE AND THEIR CLINICIAN:

- Is it okay to turn the pump off?
- Who should make the decision to turn the pump off?
- Who should turn the pump off?
- What will this process look like?
- Where (hospital, home) can the pump be turned off?

Turning off the LVAD: An LVAD is a life-saving treatment that people may choose to have turned off at any time. This does not mean the person with an LVAD needs to wait until the end of life. For example, some people have chosen to turn off the pump if the pump is not meeting their expectations around quality of life. Make sure to talk with the person you care for about instances in which they would want their LVAD turned off.

End-of-Life Care: Having an LVAD requires thinking about different aspects of end of life care. Most people with an LVAD will need to have the pump turned off at the end of life. This is something you will want to discuss with the person you care for prior to that time in case they are too sick to make the decision for themselves at that time.

COMMUNICATION TIPS

In order to inform your family and your loved one's health care team of what matters most to them, as you look forward into the future and to end of life care, good communication is essential. Talking with your loved one will help you both think further about your values and wishes in relation to medical care.

1. TALKING WITH YOUR LOVED ONE

Good communication involves both talking and listening.



Some tips for good communication with your loved one:

- When in doubt about what the person you care for is thinking, ask questions.
- It's common for individuals to avoid wanting to have these discussions. Don't be surprised or upset. Keep trying.
- Be honest about your own thoughts, concerns, and feelings. Use statements such as "I feel," "I believe," "I would want."
- Don't be afraid of the "D" words: death and dying.
- Understand that it's normal for you and/or your loved one to become upset and tearful during these conversations.
- You may find that you and your loved one disagree. That's okay. It's important that this is brought out in the open before a real crisis occurs.
- Nothing is set in stone during these conversations. You and your loved one can always change your minds.

2. TALKING WITH YOUR LOVED ONE'S HEALTH CARE TEAM

Good communication will ensure that your loved one's health care team will address his/her concerns. It is important to encourage the person you care for to communicate with the health care team.



Some tips for good communication with your loved one's health care team:

- Remember, you and your loved one are the experts about what matters most. Write a list of the biggest concerns and questions.
- Make a list of all the medicines, herbal and nutritional supplements that your loved one is taking. Don't leave without asking what the next steps are in your loved one's care.
- Ask for written information about medications, condition, and treatment: "Would you write this down for me?"
- Your loved one's clinician expects to answer "tough" questions.
- Make sure you tell the clinician if you and your loved one don't understand or can't hear what is being said: "I don't understand—can you explain it in a different way?"
- Tell the health care team about important milestones you and your loved one hope to make (the birth of a grandchild, a family member or friend's wedding or graduation, etc.).

▶ *For more caregiver support resources, including a discussion board to connect with other caregivers and ask questions, visit: <https://patientdecisionaid.org/lvad-caregiver-support/>*

Ottawa Personal Decision Guide

For People Making Health or Social Decisions



1 Clarify your decision.

What decision do you face?

What are your reasons for making this decision?

When do you need to make a choice?

How far along are you with making a choice?

Not thought about it
Thinking about it

Close to choosing
Made a choice

2 Explore your decision.



Knowledge

List the options and benefits and risks you know.



Values

Rate each benefit and risk using stars (★) to show how much each one matters to you.



Certainty

Choose the option with the benefits that matter most to you. Avoid the options with the risks that matter most to you.

	Reasons to Choose this Option Benefits / Advantages / Pros	How much it matters to you: 0★ not at all 5★ a great deal	Reasons to Avoid this Option Risks / Disadvantages / Cons	How much it matters to you: 0★ not at all 5★ a great deal
Option #1				
Option #2				
Option #3				

Which option do you prefer?

Option #1

Option #2

Option #3

Unsure



Support

Who else is involved?

Which option do they prefer?

Is this person pressuring you?

Yes

No

Yes

No

Yes

No

How can they support you?

What role do you prefer in making the choice?





Share the decision with...

Decide myself after hearing views of...

Someone else decides...

3 Identify your decision making needs.




Adapted from The SURE Test © 2008 O'Connor & Légaré.

	Knowledge	Do you know the benefits and risks of each option?	Yes	No
	Values	Are you clear about which benefits and risks matter most to you?	Yes	No
	Support	Do you have enough support and advice to make a choice?	Yes	No
	Certainty	Do you feel sure about the best choice for you?	Yes	No

If you answer 'no' to any question, you can work through steps two 2 and four 4, focusing on your needs. People who answer "No" to one or more of these questions are more likely to delay their decision, change their mind, feel regret about their choice or blame others for bad outcomes.

4 Plan the next steps based on your needs.

Decision making needs Things you could try

 <p>Knowledge</p> <p>If you feel you do NOT have enough facts</p>	<p>Find out more about the options and the chances of the benefits and risks.</p> <p>List your questions.</p> <p>List where to find the answers (e.g. library, health professionals, counsellors):</p>
 <p>Values</p> <p>If you are NOT sure which benefits and risks matter most to you</p>	<p>Review the stars in step two 2 to see what matters most to you.</p> <p>Find people who know what it is like to experience the benefits and risks.</p> <p>Talk to others who have made the decision.</p> <p>Read stories of what mattered most to others.</p> <p>Discuss with others what matters most to you.</p>
 <p>Support</p> <p>If you feel you do NOT have enough support</p> <p>If you feel PRESSURE from others to make a specific choice</p>	<p>Discuss your options with a trusted person (e.g. health professional, counsellor, family, friends).</p> <p>Find help to support your choice (e.g. funds, transport, child care).</p> <p>Focus on the views of others who matter most.</p> <p>Share your guide with others.</p> <p>Ask others to fill in this guide. (See where you agree. If you disagree on facts, get more information. If you disagree on what matters most, consider the other person's views. Take turns to listen to what the other person says matters most to them.)</p> <p>Find a person to help you and others involved.</p>
 <p>Certainty</p> <p>If you feel UNSURE about the best choice for you</p> <p>Other factors making the decision DIFFICULT</p>	<p>Work through steps two 2 and four 4, focusing on your needs.</p> <p>List anything else you could try:</p>