ENABLE LVAD

CHARTING YOUR COURSE

A Guide for Caregivers of People Living with LVADs

INTRODUCTION:

Background to the Resources

School of Medicine
UNIVERSITY OF COLORADO
ANSCHUTZ MEDICAL CAMPUS

UAB SCHOOL OF NURSING
The University of Alabama at Birmingham

WELCOME

Living with an LVAD can be stressful... and not just for the patient but also for caregivers, families, and loved ones.

We can help you take steps to lower stress and make the best of things. We want to provide you with coaching and guidance to navigate the challenges you currently face and prepare for those that lie ahead.

The resources provided will help address different aspects of caregiving. The four parts can be viewed on their own and contain activities to help you get the most out of the content.

Summary of Booklet's Contents

Introduction: Background to the Resources

Part 1: How to Handle Problems

Part 2: Taking Care of You

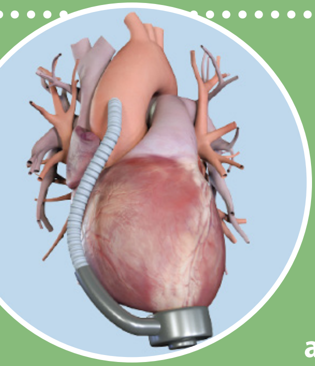
Part 3: Being a Partner in Symptom Management

Part 4: Talking About What Matters Most and Making Choices

WHAT IS SUPPORTIVE CARE?

- Supportive Care is specialized care for people with serious illness. It provides an extra layer of support. It focuses on providing individuals with the highest quality of life possible for as long as possible—whatever the diagnosis.
- It is appropriate at any age and at any stage in a serious illness.
- It can be provided at the same time as heart failure care.
- Want to learn more? Visit: ***getpalliativecare.org***

WHAT DOES CARING FOR SOMEONE WITH AN LVAD LOOK LIKE?



Caregiving for someone with an LVAD means learning new skills and changing your way of life. Caregiving duties can be different for everyone, depending on how well the person does with the LVAD. For some, caregiving is a full time commitment that will last for many months or years. Along with using existing caregiving skills for heart failure management, caring for an LVAD also requires learning the controller alarms and response, battery care, and driveline dressing changes. And if complications occur, even more responsibilities can arise. All of this can be a lot for someone to take in.

However, you are not alone. These resources can help you learn how to engage people around you with what you are going through. Your family, friends, and your loved one's health care team all want to be there for you and your loved one.

HOW DO THESE RESOURCES WORK?

1. THE TOOLS

This guide has four parts. Each part has information about topics that can help you take control of your situation. Topics include:

- How to stay healthy and take care of yourself.
- How to manage your loved one's symptoms.
- How to link with community resources in your area.
- How to cope with serious illness and solve problems.
- How to make decisions that take into account what matters most to you and your loved one.
- How to communicate with health care providers and family members about your loved one's health.

Activities within each part can help you think through each topic. Practice the activities, discuss them with others.

2. THE COACH

At some programs, a specially trained coach may work with you to go over the topics in this guide. They may invite you to share your own thoughts and experiences. They can help you work on challenges you are facing, no matter how big or small. These interactions may occur one-on-one over the phone or through in-person or virtual support group settings.

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PART ONE:

How to Handle Problems

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WHAT DOES IT MEAN TO BE A CAREGIVER?

YOU ARE NOT ALONE. You are part of a huge network of people from all walks of life who provide care for a family member or friend. There are more than 65 million people who are caregivers each year, and about 6 million of those care for someone with heart failure. Like many people, becoming a caregiver may have come to you unexpectedly. Even with this new job, all your previous responsibilities still demand your attention. Because of this, many caregivers feel overwhelmed, distressed, or discouraged.

YOU CAN HAVE A BIG IMPACT ON YOUR LOVED ONE'S SUCCESS. People with an LVAD may have a hard time managing all of the new responsibilities and life changes. When caregivers like you are involved, making these difficult adjustments is often much easier. To be the best caregiver you can, you may need to master new skills, develop new ways of relating to your loved one, and make tough decisions. You are an active partner in the long haul of living with an LVAD.

Chronic Stress Can Hurt Your Body

TAKING CARE OF YOURSELF IS ONE OF THE MOST IMPORTANT THINGS YOU CAN DO. Given how hard caregiving can be, taking care of yourself is essential.

The goal of this booklet is to help caregivers learn about problem solving methods to help manage issues in a way that can reduce stress. Thinking about how to cope with stress and how to do problem solving in a stepped way may help you have a more positive experience of caregiving.

COPE: START WITH A POSITIVE ATTITUDE

Problems happen to everyone. Problems can get better or worse depending on the attitude we have. A more positive approach to solving problems is called COPE.

C CREATIVITY

Many of the problems you face with your loved one's LVAD can be new to you, so the solutions you come up with may also be new. Be creative and think of things you have not thought of before.

Some ways to be creative:

- See your problem from someone else's point of view. What would they do if they were in your shoes?
- Ask yourself: "What has worked for similar problems I've had in the past?"
- Ask other people for ideas (e.g. family, friends, neighbors, health care team, other people dealing with the same problem).
- Are there smaller parts of the problem you can do something about?

O OPTIMISM

Optimism means having a positive attitude about solving problems which will increase your chance of success.

Some ways to be optimistic:

- Know that solving problems takes energy and time.
- Notice the good things that surround you each day and talk to people who can provide you with encouragement.
- Remember that a partial solution to a problem is better than no solution.

P PLANNING

Planning means thinking about solutions to a problem in clear, concrete steps. It also means coming up with goals and solutions that are reachable.

Some ways to plan:

- Write down your plan; get ideas out of your head and onto paper.
- Keep track on paper of how your plan is going.
- Evaluate your plan and make changes; remember that most plans are not perfect the first time around.
- Separate what you know from what you do not (be honest) and then get the facts you need.

E EXPERT INFORMATION

- Have you ever thought about what makes someone an expert?
- Some people are experts because they have spent years in formal education while others are experts because they have jobs where they spend all day assisting people who have problems.
- Experts can be helpful. Remember you have expert resources all around you, including your coach.

THE SEVEN STEPS OF PROBLEM-SOLVING

Problem solving is a structured method for dealing with stressful and upsetting life experiences that can occur during caregiving. Big problems often have no "right" answer. However, by taking small steps to try to solve your problem, you might feel better. The 7 steps of problem solving are helpful when you face complex problems.

THE SEVEN STEPS ARE:

1. Identify & clarify the problem
2. Establish a goal
3. Brainstorm possible solutions
4. Look at the pros & cons of each possible solution
5. Pick the solution that seems the most realistic
6. Create and implement a plan of action
7. Review how it worked

1 IDENTIFY & CLARIFY THE PROBLEM

Write down a clear description of your problem. Know that problems can come from all aspects of your life.

Some ways to clarify your problems:

- Make the problem specific.
- Make the problem objective (apart from your feelings about the problem). Write your problem in a way that gives you control.
- Think about the problem in terms of when, where, why, who, and how.

2 ESTABLISH A GOAL

The goal is what you plan to do to help address the problem.

Some ways to set your goal:

- Make the goal measurable.
- Make the goal achievable (can realistically be done).
- Make the goal action-oriented.
- Make the goal general (allowing for multiple solutions).

3

BRAINSTORM POSSIBLE SOLUTIONS

List as many solutions as you can. Remember to be creative.

Some ways to brainstorm:

- Think about ways to change yourself.
- Think about ways to change your environment.
- Think about ways to change how you do an activity.

4

LOOK AT THE PROS & CONS OF EACH POSSIBLE SOLUTION

Each solution has advantages (or pros) and disadvantages (or cons).

Some ways to think about the pros:

- "Compared to the other solutions I have listed, what makes this solution a good one?"

Some ways to think about the cons:

- How much time will it take? How much effort will it take? How much money does it take?
- Will it make me or others feel bad?
- How much assistance from other people will it require?

5

PICK THE SOLUTION THAT SEEMS THE MOST REALISTIC

Compare the pros and cons of the solutions you listed. Choose the solution or solutions that seem best.

Some ways to pick a realistic solution:

- Choose a solution that you have the resources to carry out.
- Choose a solution that you have the energy and motivation to carry out.

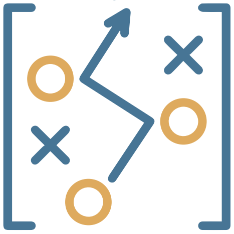
6

CREATE & IMPLEMENT A PLAN OF ACTION

Write down clear steps to achieve the solution within the coming week.

Some steps to create a plan of action:

- What will I do this week?
- Where will I do it?
- When will I do it?
- Who is going to help me?
- What things might get in the way?
- What is my "Plan B" if things don't work out?



7 REVIEW HOW IT WORKED

Check on your progress from week to week.

Some ways to review how it worked:

- Ask yourself "Was I able to achieve what I set out to do?"
- If it didn't work, ask yourself "Was the goal too big?" Or "Was I not motivated?"
- Write down what things seemed to get in your way. What can you do this week to try to overcome these obstacles?

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

ACTIVITY: *Giving the Seven Steps a Shot*

Use the worksheet provided at the end of this booklet to work through the seven steps. Your coach will assist you. The next two pages provide two examples for you to review before completing the worksheet yourself.

1. My problem is: I have trouble sleeping - especially falling asleep

2: Goal: I will use one strategy everyday to improve sleep

3. My solutions are: See below

A.

Write down my "to do" list and my "worry" list

A. Pros(+) What makes this a good choice

1. Get thoughts out of my head
2. Helps me avoid forgetting things

4. Cons (-)

	A Little	Medium	A lot
EFFORT	✓		
TIME	✓		
MONEY	✓		
EMOTIONAL IMPACT	✓		
INVOLVING OTHERS	✓		

Other cons: One more thing to do

B.

Take a warm bath before bed

B. Pros(+) What makes this a good choice

Would be relaxing

4. Cons (-)

	A Little	Medium	A lot
EFFORT		✓	
TIME		✓	
MONEY	✓		
EMOTIONAL IMPACT	✓		
INVOLVING OTHERS	✓		

Other cons: Wasting time I could spend w/ family

C.

Exercise regularly, try walking even when I don't feel like it

C. Pros(+) What makes this a good choice

Will have more energy

4. Cons (-)

	A Little	Medium	A lot
EFFORT		✓	
TIME		✓	
MONEY	✓		
EMOTIONAL IMPACT		✓	
INVOLVING OTHERS	✓		

Other cons: Finding time/motivation, too many hills

5. Circle choice of solution(s) list above: B. Warm Bath

6. My action plan for this week is:

A. Preserve one hour before bedtime

B. Turn off ringer on phones so I won't be interrupted

C. Purchase a bath salt or soap with relaxing scent

7. Review Progress: How satisfied am I with my efforts (on a scale from 0-10) this past week to implement my action plan? (0=not at all, 10=extemely)

5

What things have gotten in the way of my plan?

1. Some days I just forget
2. I kept getting phone calls in the evening before I could even get into the bath

What will I do to overcome any obstacles I've had?

1. I will set an alarm to remind me to take my bath
2. Will put my cell phone on silent in the evening

1. My problem is: When friends & family invite me to events or get-togethers, I say no to avoid other people.

2: Goal: I will get involved in at least one social activity a week.

3. My solutions are: See below

A.

Go out to lunch with a friend

A. Pros(+) What makes this a good choice

1. Would be nice to catch up with this particular friend of mine

4. Cons (-)	A Little	Medium	A lot
EFFORT	✓		
TIME	✓		
MONEY		✓	
EMOTIONAL IMPACT	✓		
INVOLVING OTHERS	✓		

Other cons: Having to go somewhere expensive

B.

Have my friends and family over for dinner

B. Pros(+) What makes this a good choice

1. Would make me so happy to see my kids and grandkids each week

4. Cons (-)	A Little	Medium	A lot
EFFORT			✓
TIME	✓		
MONEY	✓		
EMOTIONAL IMPACT	✓		
INVOLVING OTHERS		✓	

Other cons: Someone would have to help me cook

C.

Go to the donut and coffee social after church on Sunday

C. Pros(+) What makes this a good choice

1. Might help me also get involved in other activities

4. Cons (-)	A Little	Medium	A lot
EFFORT	✓		
TIME	✓		
MONEY	✓		
EMOTIONAL IMPACT	✓		
INVOLVING OTHERS	✓		

Other cons: Don't know anyone

5. Circle choice of solution(s) list above: B. Have my friends and family over for dinner

6. My action plan for this week is:

A. Call my family tonight to agree on a night when we can have dinner each week

B. Look for an easy dinner recipe I can make...maybe spaghetti?

C.

7. Review Progress: How satisfied am I with my efforts (on a scale from 0-10) this past week to implement my action plan? (0=not at all, 10=extemely) 7

What things have gotten in the way of my plan? Nothing yet! I scheduled dinner at my house for Tuesday nights starting next week

What will I do to overcome any obstacles I've had? I will set a weekly alarm on my cell phone to remind me to cook dinner

1. My problem is:

2: Goal: dfdfdfdf

3. My solutions are:

A.

A. Pros(+) What makes this a good choice

4. Cons (-)	A Little	Medium	A lot
EFFORT	☐	☐	☐
TIME	☐	☐	☐
MONEY	☐	☐	☐
EMOTIONAL IMPACT	☐	☐	☐
INVOLVING OTHERS	☐	☐	☐

Other cons:

B.

B. Pros(+) What makes this a good choice

4. Cons (-)	A Little	Medium	A lot
EFFORT	☐	☐	☐
TIME	☐	☐	☐
MONEY	☐	☐	☐
EMOTIONAL IMPACT	☐	☐	☐
INVOLVING OTHERS	☐	☐	☐

Other cons:

C.

C. Pros(+) What makes this a good choice

4. Cons (-)	A Little	Medium	A lot
EFFORT	☐	☐	☐
TIME	☐	☐	☐
MONEY	☐	☐	☐
EMOTIONAL IMPACT	☐	☐	☐
INVOLVING OTHERS	☐	☐	☐

Other cons:

5. Circle choice of solution(s) list above:

6. My action plan for this week is:

A.

B.

C.

7. Review Progress: How satisfied am I with my efforts (on a scale from 0-10) this past week to implement my action plan? (0=not at all, 10=extemely) ☐

What things have gotten in the way of my plan?

What will I do to overcome any obstacles I've had?

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PART TWO:

Taking Care of You

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"Taking care of you"

means looking after yourself in a healthy way.

It includes any activity to maintain your physical, emotional, social, and spiritual health.

PHYSICAL

- Develop habits that keep you physically healthy such as exercising, eating healthy foods, and getting adequate rest and sleep.
  - *What does my body need to feel nourished, well rested, and strong?*
- Make healthy lifestyle choices, such as quitting smoking.
  - *What unhealthy or unhelpful activities do I need to avoid?*
- Remember your own health care needs.

EMOTIONAL

- Take time out for yourself to relax or engage in hobbies.
  - *What is a healthy distraction or hobby for me when I need to take a break and recharge?*
- Attend to your emotions.
  - *Are there positive, constructive ways I can deal with my emotions?*

SOCIAL

- Find the right balance of solitude and social interaction.
  - *Who can I turn to for support and comfort? Who should I avoid?*
  - *What responsibilities do I need to quit doing so I can attend to my needs?*

SPIRITUAL

- Find time to connect spiritually.
  - *What spiritual practices connect me to God or another higher power I believe in?*

When you take care of yourself, everyone benefits.

HEALTHY EATING AND NUTRITION

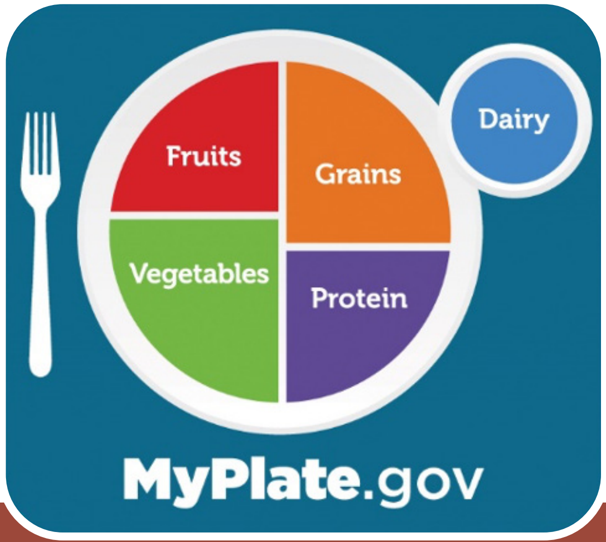
Healthy eating means eating foods that help you feel strong and energetic. The foods you eat can also sharpen your memory and stabilize your mood.

Healthy eating doesn't have to be impossible.

You can take small steps to eat healthier for you and the person you care for.

One such example of healthy eating is from **myplate.gov**.

- Focus on eating a variety of fruits, vegetables, grains, dairy or fortified soy alternatives, and protein foods.
- Make half of your plate fruits and vegetables.
- Change to low-fat or fat-free dairy.
- Make half your grains whole grains.
- Vary your protein routine.
- Choose foods and beverages with less added sugars, saturated fats, and sodium.



Healthy Eating for People with Heart Failure and LVADs

Many caregivers share their meals with the person they care for, so cooking for heart failure and LVAD diet considerations is important.

People with heart failure should usually avoid high salt or added salt in their food. An example of a low salt diet is the DASH diet.

- The DASH diet encourages you to eat a variety of foods rich in nutrients that help lower blood pressure.
- The DASH diet also focuses on reducing the sodium (Na+) in your diet. The best way to do this is to decrease the amount of salt in your food.

Tips for eating on a low salt diet can be found at: **https://www.cdc.gov/salt/reduce_sodium_tips.htm**

People with an LVAD are usually on Warfarin (blood thinning medicine), which means certain foods could affect the function of the medicine. These foods should be avoided or limited.

- Foods with Vitamin K, such as kale, spinach, brussel sprouts, collard greens, broccoli, and asparagus, should be eaten in only small amounts.
- Certain drinks, such as cranberry juice and alcohol, should also be consumed in small amounts.

Tips for eating on Warfarin can be found at: **https://www.nutrition.va.gov/docs/UpdatedPatientEd/WarfarinAndDiet%202016.pdf.**

PHYSICAL AND EMOTIONAL HEALTH

Your Health Care

- Even though you may be busy caring for your loved one, it's important to continue to take care of your own health too.
- Remember to keep up with your own regular medical visits.
- Continue to track and adhere to your own medications.

Quitting Smoking

- Smoking harms nearly every organ of the body and diminishes overall health.
- Quitting smoking improves the body's ability to heal and respond to medical treatments. The benefits of quitting smoking are great and start instantly.
- Want help quitting? Contact UAB's Tobacco Consult Service at (205) 934-0411.

Exercise

- Exercise has been shown to improve mood and other symptoms, increase energy levels, and improve sleep.
- To achieve the maximum benefits of exercise, the recommendation is 20 to 30 minutes per session, at least five times per week. However, as little as five minutes of exercise a day may be beneficial.
- Gradually increase your activity level if you have not been exercising regularly.
- Stick with it. If you exercise regularly, it will become part of your lifestyle. Finding someone to exercise with will help you stay motivated.

Relaxation

- Stress and tension impact your whole body. Take some time each day to relax, rest, and restore.
- Relaxation techniques are useful to help relieve tension, decrease worry, and improve sleep. Your coach will discuss these techniques with you.
- Make time for activities you enjoy, whether it be going on walks, playing games, knitting, or watching your favorite TV show. Taking time for yourself can also reduce stress and anxiety.

ACTIVITY: *Simple Ways You Can Relax*

In the below table are some techniques to help guide relaxation and meditation. These proven practices can help people focus on themselves and relieve stress. Please try some to see if any feel right for you.

NAME	GOAL	TECHNIQUE
Relaxed (Diaphragmatic) Breathing	**Promotes relaxation, improves physical and mental health**	• Sit in a chair or lie down on your back. • While breathing through your nose with mouth closed, gently expand your belly to fill it with air. • Imagine you are filling a small balloon inside your belly with air each time you inhale. • Breathe out through your mouth, empty your belly while pursing your lips like gently blowing on a candle. • If you become dizzy or light-headed, take smaller breaths and slow down.
Muscle Relaxation	**Trains you to be aware of tension in your body and control tight muscles**	• Get in a comfortable position, calm yourself with relaxed breathing. Take 4 slow, deep breaths. • Relax your body from face to toe, muscle by muscle. (face, jaw, tongue, eyes, forehead, shoulders, neck, arms, hands, fingers, back, chest, abdomen, legs, feet, toes) • For the next minute let your entire body relax.
Imagery / Visualization	**Uses your imagination to create mental pictures. Engages your 5 senses**	• Get in a comfortable position, calm yourself with relaxed breathing. Take 4 slow deep breaths. • Picture yourself in a quiet, special place that feels peaceful and safe. • Picture yourself in this quiet, special place as vividly as you can, using all of your senses. Look around. Notice what you see, hear, smell. Feel the warm or cool air against your skin. • Allow yourself to relax even more deeply.
Meditation	**Decreases your heart rate, slows your breathing, and eases your mind**	• Find some place private where you won't be disturbed for 10 to 15 minutes. • Sit comfortably in a chair with your feet flat on the ground and your hands resting on your thighs. • Breathe in through your nose and out through your mouth, loud enough that someone sitting next to you would hear you. • Close your eyes or maintain a soft focus on a spot on the floor 4 feet in front of you. • Take 10-12 slow deep breaths. Feel the weight of your body against the chair and the contact of your feet against the floor. • Let your breathing return to a normal rhythm. Begin scanning your body, just noticing how it feels without thinking about it too much or judging it. Start with your head and move down to your toes. • Begin counting your breathes with every inhalation and exhalation. When you reach '10', start over with '1'. • Your mind will wander and this is normal. When you notice that it has, gently return your focus to counting your breaths. • Maintain meditation only as long as it is comfortable, a few minutes per day. With practice, extend your time.

GETTING THE SUPPORT YOU NEED

Asking for help can be hard. Many people take pride in their independence. Some people may feel embarrassed, needy, and weak when they ask for help. Yet, asking for help is a vital life skill. It is a sign of strength, not of weakness. Most people do it every day without thinking about it. And many of the obstacles brought on by heart failure can't be tackled alone. Having others help can ease the burden of an LVAD. Plus, loved ones often like to help by making your life easier.

Having a back-up caregiver early on can also be very helpful. Ask someone that you trust and who can learn how to do the caregiving tasks.

How to ask for help:

- ***Step 1:*** **Tell yourself you need help (this is the hardest step).**
- ***Step 2:*** **Figure out exactly what you need help with and when.**
- ***Step 3:*** **Look for someone who can help.**

ACTIVITY: *Identify People Who Can Help*

Step 1: Who Makes Up Your Support Team

We encourage you to consider the support network that could help you, and the time that it might take them to complete the tasks. The following table helps you to make a list of helpful things that others might do for you currently or in the future.

Step 2: How Can They Help?

Who Currently Helps? Or Who Could Help?	*What Do You Need Help With?*	*When Do You Need Help With This Task?*	*Planned? (Yes/No)*
EXAMPLE: George, my neighbor	**EXAMPLE: Mow the lawn**	**EXAMPLE: 1hr/week**	**EXAMPLE: YES**

WORK TOWARDS A ROUTINE

Working toward a daily routine that includes positive lifestyle choices can help improve both your physical and emotional health. Small steps can have an influence. Pick one thing at a time that you want to work on and try adding it to your daily routine. This could be:

- **Spend 20 minutes outside walking or exercising a few days a week.**
- **Have 10 minutes of uninterrupted time before bed.**
- **Spend 30 seconds a day thinking about something you're grateful for.**
- **Take 10 minutes to mediate a few days a week.**
- **Work toward making one meal a day healthier.**

You can slowly work toward a healthier routine. Pick one healthy habit to focus on in a week and see if it can become part of your regular life. Then focus on another habit during another week.

Take small steps so that changes are manageable with your busy schedule. And do what feels and works best for you.

ADDITIONAL RESOURCES

For more information on any of these topics, talk with your health care team, read the resources, or visit the sites listed below:

- **Heart Failure Society of America's "Module 4 – Self-Care: Following Your Treatment Plan and Dealing with Your Symptoms"**
  - *hfsa.org*
    Telephone: 301-312-8635
- **DASH diet - Mayo Clinic's**
  - *mayoclinic.com/health/dash-diet/HI00047*
- **American Heart Association- "Getting Healthy"**
  - *heart.org/HEARTORG/HealthyLiving/Getting-Healthy_UCM_001078_SubHomePage.jsp*
- **Healthy Weight – Healthy Eating – Centers for Disease Control (CDC)**
  - *cdc.gov/healthyweight/healthy_eating/*
- **DASH Plan and Reducing Sodium Intake**
  - *https://www.nhlbi.nih.gov/health-topics/dash-eating-plan*
- **Exercise Guidelines - National Institutes of Health (NIH)**
  - *nlm.nih.gov/medlineplus/ency/patientinstructions/000094.htm*
- **Smoking Cessation**
  - *smokefree.org*
    Local and state telephone quitlines: 1-800-QUIT-NOW
- **Stress Management and Your Heart – Cleveland Clinic**
  - *my.clevelandclinic.org/heart/prevention/stress/stressheart.aspx*
- **American Heart Association's "Recognizing Advanced Heart Failure and Knowing Your Options"**
  - *heart.org*
- **UAB Heart Failure Guide**
  - *https://www.uabmedicine.org/patient-care/conditions/heart-failure*

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

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PART THREE:

Being a Partner in Symptom Management

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BEING A PARTNER IN SYMPTOM MANAGEMENT

In supporting someone who has an LVAD, you may need to help this person manage his or her symptoms. In addition, it is normal for you, too, to experience a variety of symptoms and other feelings as you run the caregiver marathon. Symptoms are feelings or experiences that can be your body's way of saying that something isn't quite right. Symptoms can affect how you feel physically, emotionally, socially, and spiritually.

Ask the person you care for which symptoms are most bothersome.

Keeping track of symptoms can help you gain some control. Communicating with the health care team about bothersome and new symptoms will help them figure out how to help.

PHYSICAL AND EMOTIONAL HEALTH

Physical symptoms such as pain, fatigue, swelling, cough or congestion, difficulty breathing, dizziness, and loss of appetite can impact your loved one's ability to do the things he or she normally does.

You should call your health care team if the person you care for:

- Has pain
- Has trouble catching their breath even while resting
- Suddenly gets an irregular or very fast heartbeat that causes dizziness or nausea.
- Gains 3 pounds or more in two to three days
- Is coughing up foamy pink spit
- Has new chest pain or pressure
- Falls and has an injury
- Is seriously considering stopping medical care

Specific symptoms to look for in people with an LVAD:

- Bleeding: black, tarry stools, red blood during a bowel movement, coughing or vomiting blood, nosebleeds
- Infection: redness or discharge around the driveline, confusion, fever
- Stroke: trouble with balance or coordination, trouble with speaking, sudden numbness or weakness, changes in vision

ACTIVITY: *Help Your Loved One Identify and Track Symptoms*

One way to identify and track symptoms is to use a log like the one below. Practice filling out the log with recent symptoms your loved one may have had.

Date/Time	*Symptom*	*When did it start and stop?*	*What things made this symptom better or worse?*	*Medical information at time of symptom*
EXAMPLE: 8/17/2020 8:30 AM	EXAMPLE: Shortness of breath	EXAMPLE: 2 days ago, still a problem	EXAMPLE: Better: Sitting up with pillow Worse: Walking up stairs	EXAMPLE: Blood pressure, weight, glucose, INR

There are also great apps and online resources to track symptoms. One recommended app is the Heart Failure Society of America Heart Failure Storylines available for free on Apple (https://apps.apple.com/us/app/heart-failure-health-storylines/id1062725794) and Google (https://play.google.com/store/apps/details?id=com.selfcarecatalyst.healthstorylines.hf&hl=en)

How to Talk to Your Loved One's Health Care Team About Their Symptoms

- Encourage your loved one to communicate their symptoms to their doctors and nurses.
- Make lists of questions and concerns before you visit the doctor or nurse. Have those lists with you during your visit.
- Write down what the doctor or nurse says or bring a tape recorder.
- When describing symptoms to doctors and nurses, here are a few tips on what to say:
  - Give them a basic description of the problem—one to two sentences should do it.
  - Tell them when and how often your loved one experiences the symptoms.
  - Let them know if anything makes the symptoms better or worse.
  - Tell them if your loved one has ever experienced the symptoms before.

EMOTIONAL, SOCIAL, AND SPIRITUAL SYMPTOMS EXPERIENCED BY YOU AND YOUR LOVED ONE

Emotional symptoms such as anxiety, depression, and grief are all things commonly experienced by people with heart failure and their caregivers.

For people with an LVAD, other symptoms may affect their daily life such as:
- Body image issues
- Acceptance of the LVAD as part of them
- Regret with decision to get an LVAD
- Adjustment to a "new normal"

These symptoms commonly occur after implant and lessen over time, but may continue for some patients the entire time with an LVAD.

ANXIETY

- Anxiety is a common and normal response to new or stressful situations.
- Caregivers of patients with LVADs have reported very high levels of anxiety in some studies.
- When someone is anxious, they may also feel physical symptoms like upset stomach, trouble breathing, fast heart rate, headaches, or sweaty palms.
- Anxiety may not go away completely. But, people can learn things to manage anxiety so that it is not seriously decreasing their quality of life.

DEPRESSION

- When a person is sad, discouraged, gloomy, or hopeless for several weeks or months – and when these feelings interfere with being able to manage day-to-day affairs – we say that he or she is suffering from depression.
- When someone is depressed, they may feel symptoms like difficulty sleeping, lack of energy to do things, difficulty paying attention, and changes in eating (more or less).
- Some depression is a normal response to the stresses that come with illnesses.
- People can reduce and manage depression so that it is not seriously decreasing their quality of life.

You should call your health care team *if you or your loved one is having anxiety and/or depression that is interfering with daily activities or is very upsetting to you or your loved one.*

You should call your health care team or 911 immediately if you or your loved one are thinking of harming yourselves or others.

SYMPTOMS EXPERIENCED BY CAREGIVERS

Caregivers can experience physical symptoms related to their caregiving responsibilities.

Be sure to take care of yourself so that you are able to take care of your loved one. This includes ensuring enough sleep, good nutrition, taking time for yourself, and seeing your own health care team.

Burden

Burden is a major challenge experienced by caregivers. Burden can be due to many things like:

- **Increased responsibilities and tasks**
- **Social isolation**
- **Financial strain**
- **Loss of former identity**
- **Decreased quality of life**

Rewards

Caregiving can cause a lot of negative symptoms, but caregivers of people with LVADs have also reported positive symptoms such as feelings of accomplishment, satisfaction, and meaning.

Grief and Loss

- **Grief is a natural response to loss. It's the emotional suffering someone feels when something or someone you love has been taken away. The more significant the loss, the more intense the grief can be.**

- **Feelings of grief can be due to things besides the death of a loved one, including: loss of the ability to do things you could do before, loss of health, loss of a job, loss of a friendship, and a loved one's serious illness.**

- **Everyone grieves differently. There is no "normal" timetable.**

ACTIVITY: *Identifying Losses, Strengths, and Resources*

It is sometimes helpful to recall earlier significant losses in your life to help you cope with a new loss. Allow yourself to remember the feelings around those experiences as you list them. Then list the resources that you depended on in order to cope with those losses.

Fill in the chart below with some of the new losses you are experiencing as a caregiver, and provide some strengths and resources for coping with those losses.

Losses	*My Strengths and Resources*
EXAMPLE: Time to myself	EXAMPLE: Calling friends and family to help with my loved one so I can do an activity I enjoy

Change in Relationship

People with LVADs and their caregivers have reported relationship changes. These can be normal in the process of becoming a caregiver and adjusting to a new way of life.

Some common changes experienced:

- Communication challenges
- Suppression of symptoms and feelings
- Conflict or resentment
- Effects on relationship quality - can be strengthened or stressed
- In couples, changes in sexual relationship

Spirituality

Spirituality is a broad concept that includes all the ways we look to find meaning in life. It is an expression of how a person relates to a larger whole, be it God, a higher power, family, or an aspect of nature.

- **Communicating with the health care team about your loved one's spiritual beliefs can help them understand preferences, concerns, and wishes.**
- **Be aware of your feelings around spirituality and how it affects caregiving.**
- **Taking time to think about the 'Four R's' can help bring meaning to life:**
    - **REMEMBERING: Reflect on your life and its events, accomplishments, relationships.**
    - **REASSESSING: See your life as a whole.**
    - **RECONCILING: Forgive yourself; be at peace with yourself.**
    - **REUNITING: Be at peace with loved ones.**

ADDITIONAL RESOURCES

- **Animation of Heart Failure (AHA):**
    - *https://watchlearnlive.heart.org/index.php?moduleSelect=hrtflr*

      A short animation on the pathophysiology of heart failure for patients and caregivers.

- **Self Check Plan for Heart Failure Management (AHA):**
    - *https://www.heart.org/-/media/files/health-topics/heart-failure/hf-symptom-tracker.pdf?la=en*

      A 1-page PDF which provides green, yellow, and red zones for patients' symptoms.

- **Healthier Living with Heart Failure: Managing Symptoms and Reducing Risk (AHA):**
    - *http://ahaheartfailure.ksw-gtg.com/publication/?m=46677&i=461880&p=1*

      50-page interactive web-based PDF that includes 7 chapters:
      1. Understanding Heart Failure
      2. Heart Failure's Effects on the Body
      3. Making Healthy Eating Choices
      4. Making Health Lifestyle Changes
      5. Treating Heart Failure: Taking Medications
      6. Other Heart Failure Treatment Options
      (small paragraph on LVADs on page 41)
      7. Living Well with Heart Failure

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

ENABLE LVAD

CHARTING YOUR COURSE

A Guide for Caregivers of People Living with LVADs

PART FOUR:

Talking About What Matters Most and Making Choices

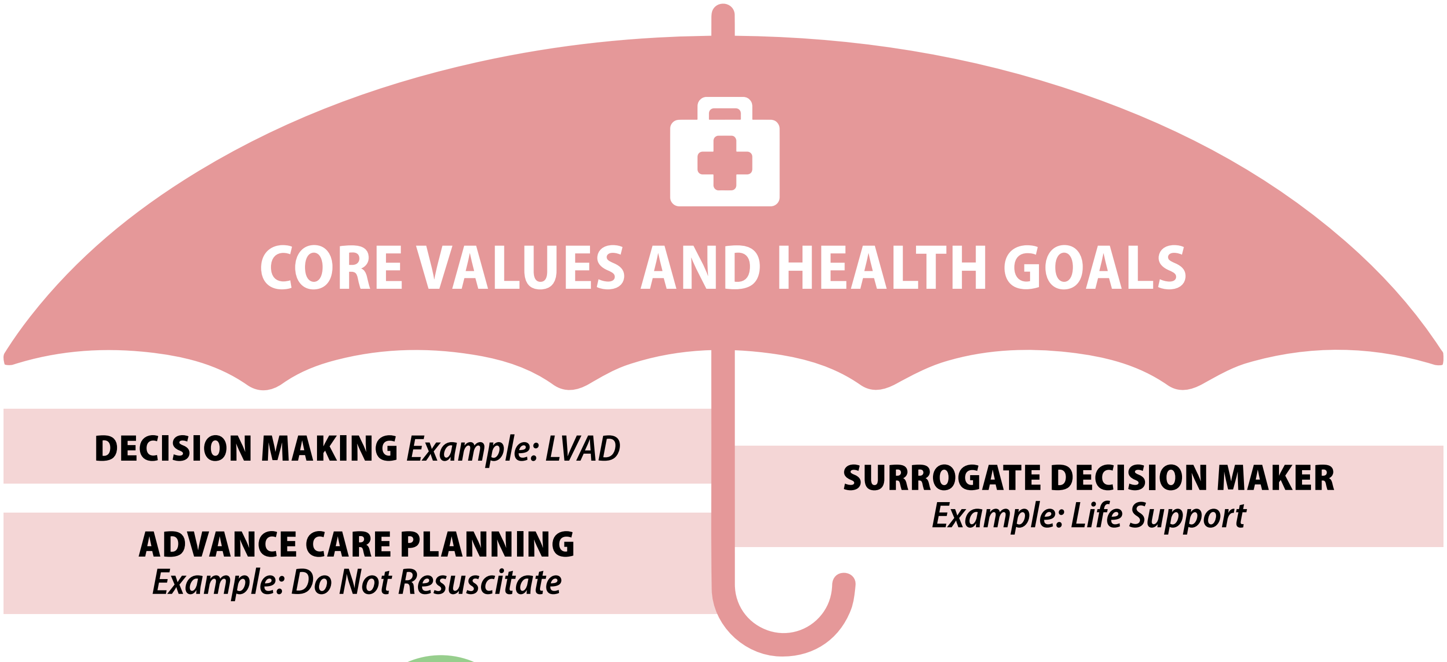
School of Medicine
UNIVERSITY OF COLORADO
ANSCHUTZ MEDICAL CAMPUS

UAB SCHOOL OF NURSING
The University of Alabama at Birmingham

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.



CORE VALUES AND HEALTH GOALS

DECISION MAKING *Example: LVAD*

ADVANCE CARE PLANNING
Example: Do Not Resuscitate

SURROGATE DECISION MAKER
Example: Life Support

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
- FRIENDS
- SIGNIFICANT OTHER
- RELIGION SPIRITUALITY
- COMMUNITY
- HEALTH
- DIGNITY
- MANAGING SYMPTOMS
- INDEPENDENCE
- PRODUCTIVITY
- PERSONAL GROWTH
- RECREATION

Mary Tineţti, Aanand Naik, Lilian Dindo. Conversation Guide for Patients and Caregivers for Identifying Their Health Priorities. Patient Priories Care. 2018. https://patientprioritiescare.org/wp-content/uploads/2018/11/Conversation-Guide-for-Patients-and-Caregivers-for-Identifying-their-Health-Priorities.pdf

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.

Ottawa Personal Decision Guide

For People Making Health or Social Decisions

❶ 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

❷ 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?	☐ Yes ☒ No	☐ Yes ☒ No	☐ Yes ☒ 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?	☒ 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**
Knowledge If you feel you do NOT have enough facts	☒ Find out more about the options and the chances of the benefits and risks. ☐ List your questions. ☒ List where to find the answers (e.g. library, health professionals, counsellors): Ask cardiologist and internist about current healthcare needs, regimens, potential treatments
Values If you are NOT sure which benefits and risks matter most to you	☐ Review the stars in step two ② to see what matters most to you. ☐ Find people who know what it is like to experience the benefits and risks. ☐ Talk to others who have made the decision. ☐ Read stories of what mattered most to others. ☒ Discuss with others what matters most to you.
Support If you feel you do NOT have enough support	☒ Discuss your options with a trusted person (e.g. health professional, counsellor, family, friends). ☐ Find help to support your choice (e.g. funds, transport, child care).
If you feel PRESSURE from others to make a specific choice	☐ Focus on the views of others who matter most. ☐ Share your guide with others. ☐ 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.) ☐ Find a person to help you and others involved.
Certainty If you feel UNSURE about the best choice for you	☐ Work through steps two ② and four ④, focusing on your needs.
Other factors making the decision DIFFICULT	List anything else you could try:

COMMON TERMS TO KNOW

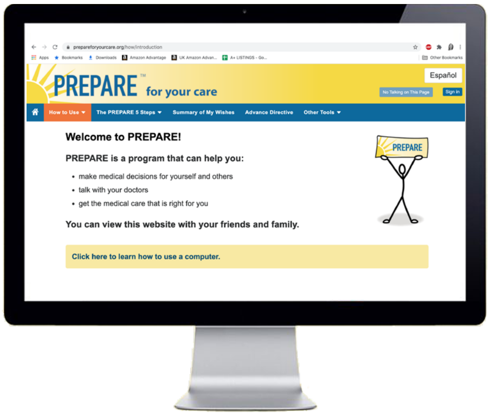
COMMUNITY

- **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



Welcome to PREPARE!

PREPARE is a program that can help you:

- make medical decisions for yourself and others
- talk with your doctors
- get the medical care that is right for you

You can view this website with your friends and family.

Click here to learn how to use a computer.

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

❶ 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

❷ 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.

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.

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Decision making needs	✓ **Things you could try**
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Other factors making the decision DIFFICULT	List anything else you could try: