

ENABLELVAD

CHARTING YOUR COURSE

A Guide for Caregivers of People Living with LVADs

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



INCREASED STRESS



INCREASED PHYSICAL SYMPTOMS

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.

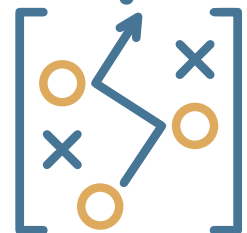
6

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

	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

	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

	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=extremely)

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

	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

	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

	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:

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?