

# A Roadmap for Living with Heart Failure



The goal of this roadmap is to help you think about how you want to *live with and treat* heart failure.

By thinking about your personal, community, and cultural values, goals, and preferences, you will be prepared to have better conversations with your doctors and nurses. This will also help you make choices about the type of health care you want.

“This roadmap reminds me that I have choices, that I can approach my life how I want to keep living it.”  
-Patient with heart failure



## Step 1: Before your visit (pages 2-9)

- ✓ Learn about heart failure
- ✓ Think about your values, goals, and decision making style



## Step 2: Annual Heart Failure Visit with your doctor (page 10)

- ✓ Share what you want your care team to know about you
- ✓ Talk to your doctor about your treatment options

## Step 3: After your visit (page 11)

- ✓ Talk to your family, friends, and extended support network
- ✓ Create an Advance Care Directive (ACD)



# Preparing for your Journey

*What to think about before you begin*

Living with heart failure and making decisions about treatment is difficult. We've found doing the following things can be helpful as you live with this disease.

## Recognize your illness or health challenges

Sometimes, people don't want to think about being sick. It can feel easier to deny the fact that you have heart failure to protect your loved ones or because you don't want to be a burden to your family or community. However, people who accept their heart failure are able to proactively manage their illness better and feel better than those who don't.



## Focus on what you can do from day-to-day

Managing your heart failure can be a big task. By focusing on daily actions you can take for your health, like daily exercise, taking your medications, and watching your sodium and fluid intake, you can prevent your heart failure from getting worse. Remember to celebrate the hard work you are doing each day to take care of yourself!



## Make health decisions when needed

Decisions about your heart failure treatment can be very difficult, and you never want to feel rushed when making a choice. However, sometimes putting off a big decision, like whether or not to get a surgery or take a new medication, will end up making your heart failure worse. It is important that you talk with your care team and loved ones to sort through your values and goals. Then you will be ready when big decisions do come.



## Advocate for the help you need

For many people, getting the diagnosis of heart failure can be scary and overwhelming. Your life, routines, and day-to-day responsibilities will change with this disease. Talk to your care team to get resources for the help you need.

- **Mental and emotional help:** Counseling, therapy, or support groups can be very helpful for patients and their loved ones.
- **Medical help:** You might need extra support from a caregiver or home health aide to make sure you are following your doctor's recommendations.
- **Financial help:** Medical care can be expensive. Many hospitals have ways to help patients afford the care they need, such as help paying for new medications or getting to and from clinic appointments.



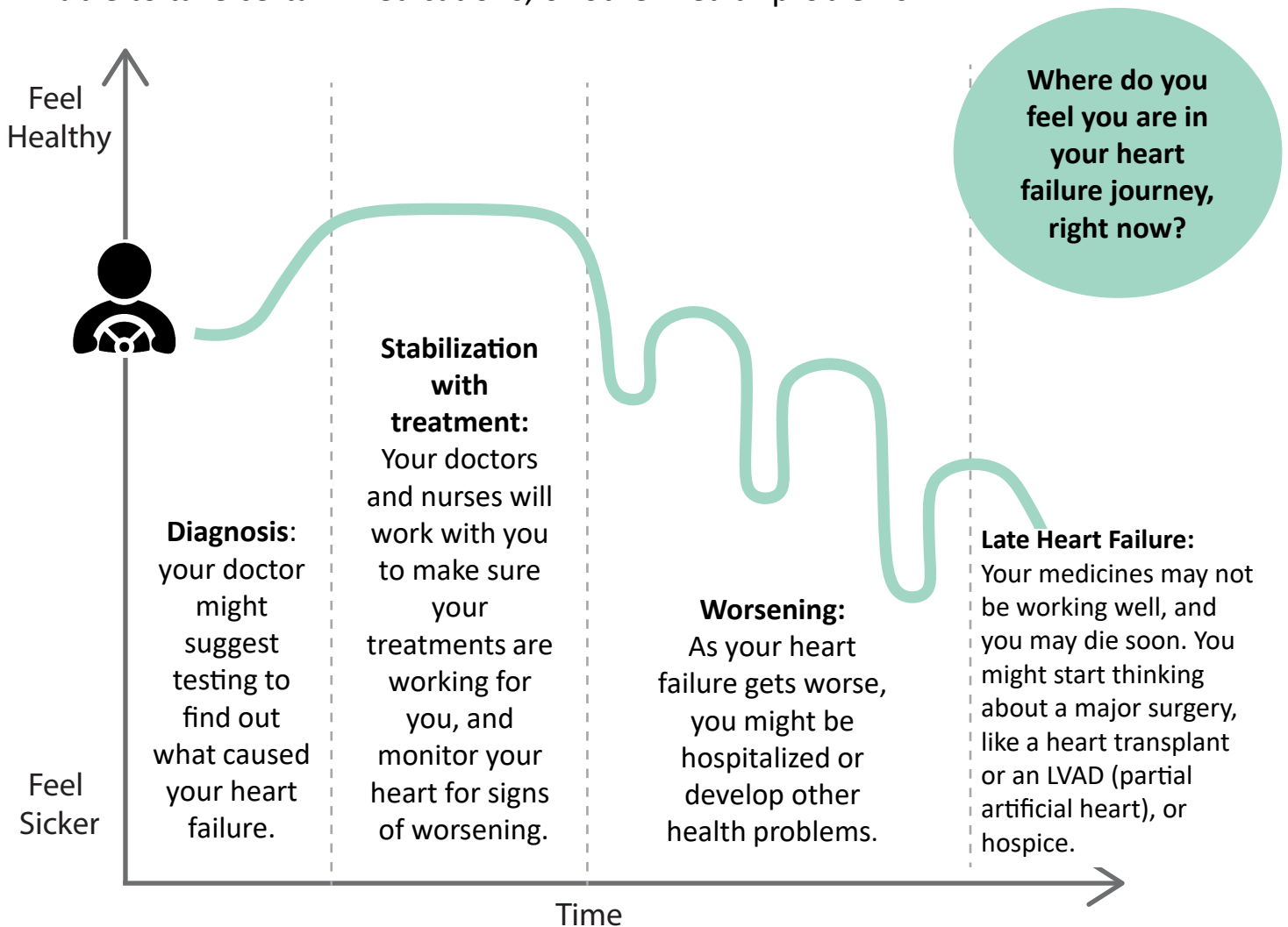


# Step 1: Learn about Heart Failure

Heart failure, or a weak heart, is when the heart is unable to pump enough blood for the body. Heart failure most often causes shortness of breath, tiredness, and swelling and effects people from all backgrounds.

**Heart failure is a chronic disease that you most likely will live with for the rest of your life.** For many, heart failure gets worse over time. Imagine the line on the graph below as how you feel with heart failure. With treatment, most people will start to feel better after being diagnosed with heart failure.

Most people with heart failure will eventually feel worse over time. The bumps in the line might be hospitalizations, kidney problems, feeling tired, not being able to take certain medications, or other health problems.



Everyone's experience with heart failure is different. By thinking about your values and goals, you can plan **for how you want to live** with this disease.

# What can I do for my heart failure?

## All of us face common decisions in heart failure

Your care team will probably talk to you about doing some of these things. How much work you want to do for your heart failure should be based on your values and goals.



### Things you can do to get educated:

- Know what caused your heart failure
- Know your left ventricular **ejection fraction (EF)**
- Know your medications
- Pick a trusted relative, partner, or friend as a medical decision maker (see page 11 for more information)



### Things you can do to manage your heart failure:

- Manage other diseases that impact your heart failure
  - Diabetes or high blood pressure
- **Lifestyle changes you can make:**
  - Never miss medication doses or prescription refills
  - Visit your doctor(s) as recommended
  - Record your weight every morning
  - Watch your sodium and fluid intake
  - Get regular exercise

“It gives me some comfort, even though it’s a little scary, to know what treatments are possible and in my toolkit”

--Patient with heart failure

## What is an Ejection Fraction (EF)? Why does EF Matter?

Your left ventricular EF is a measure of how well your heart pumps. A normal ejection fraction is between 60-70%. **You have heart failure with reduced ejection fraction (HFrEF), meaning your ejection fraction is less than 40%.**


EF can be measured with an **echocardiogram**, an ultrasound of your heart. Your care team may use your EF to help make decisions about your care

# Your Heart Failure Medicines Checklist:

Work with your doctor for **ONE Positive Change!**

Below is a chart that shows the different heart failure medications. Please:

- 1) Check off which medicines you take in the “common names of medicine” column.
- 2) Fill in the dose of medicine that you take each day in the “my current dose” column.

Medicine Family	Common Names of Medicine (Brand name)	My Current Dose	 Target Dose	Your Cost
Water Pill (diuretic)	<input type="checkbox"/> Furosemide (Lasix)		As much as you need to feel better	
	<input type="checkbox"/> Bumetanide (Bumex)			
	<input type="checkbox"/> Torsemide (Demadex)			
Adrenaline Blocking (beta blocker)	<input type="checkbox"/> Carvedilol (Coreg)		25-50 mg 2x per day	
	<input type="checkbox"/> Metoprolol Succinate (Toprol XL)		200 mg daily	
	<input type="checkbox"/> Bisoprolol (Zebeta)		10 mg daily	
Blood Vessel Relaxing (ACE/ARB)	<input type="checkbox"/> Sacubutril/Valsartan (Entresto) [recommended medicine]		97/103 mg 2x per day	
	<input type="checkbox"/> Lisinopril (Prinivil or Zestril)		20-40 mg daily	
	<input type="checkbox"/> Enalapril (Vasotec)		10-20 mg 2x per day	
	<input type="checkbox"/> Captopril (Capoten)		50 mg 2x per day	
	<input type="checkbox"/> Ramipril (Altace)		10 mg daily	
	<input type="checkbox"/> Losartan (Cozaar)		100-150 mg daily	
	<input type="checkbox"/> Candesartan (Atacand)		32 mg daily	
Potassium Raising	<input type="checkbox"/> Spironolactone (Aldactone)		50 mg daily	
	<input type="checkbox"/> Eplerenone (Inspra)		50 mg daily	
Sodium Glucose Eliminating	<input type="checkbox"/> Canagliflozin (Invokana)		100 mg daily	
	<input type="checkbox"/> Dapagliflozin (Farxiga)		10 mg daily	
	<input type="checkbox"/> Empagliflozin (Jardiance)		10 mg daily	
	<input type="checkbox"/> Ertugliflozin (Steglatro)		5 mg or 15 mg daily	
OTHERS to consider	<input type="checkbox"/> Hydralazine/Isosorbide		100 mg/40 mg 3x per day	
	<input type="checkbox"/> Ivabradine (Corlanor)		7.5 mg 2x per day	
	<input type="checkbox"/> Digoxin (Lanoxin or Digoxin)		Depends on kidney function (0.0625-0.25 mg daily or every other day)	

Remember: **YOU** are the person who knows you best. **YOU** have the most to gain by being on the best treatments possible. **YOU** have a right to ask questions about your own care!

# What other treatments might be available?

## Some of us might be faced with bigger decisions

Based on where you are in your journey with heart failure, your care team might talk to you about other treatment options.



### Surgeries:

- **Implantable Cardioverter Defibrillator (ICD)**, a device implanted under the skin that gives an electrical shock to the heart if there is a dangerous heart rhythm.
- **Cardiac Resynchronization Therapy (CRT) or pacemaker**, a device implanted under the skin that helps the heart pump normally, and might make you feel better.
- **Heart transplant**, which involves open-heart surgery that removes a failing heart and replaces it with a healthier donor heart.
- **Left Ventricular Assist Device (LVAD)**, a partial artificial heart that helps your heart pump blood, if you have very severe heart failure. This requires open-heart surgery.



### Other treatments:

- **Palliative Care** – Medical care for people with serious illnesses. The goal is symptom management, to provide comfort, and improve quality of life.
- **Hospice Care** – A type of care for people near the end of life. The goal is to give care that focuses on providing comfort to seriously ill people near the end of their life.

To learn more about these treatments, visit [www.patientdecisionaid.org](http://www.patientdecisionaid.org)



## What are your **values & goals**?

What matters most to you?  
What do you want your care team  
to know about you?<sup>1</sup>

Your **goals** are  
the people or  
experiences  
that make life  
worth living.

**Connecting & Enjoying Life:** family, friends, spirituality, activities, personal growth  
*What brings you the most enjoyment or pleasure?*

**Functioning:** taking care of yourself, being independent, not having to depend on others,  
or being there for others  
*When taking care of yourself or your loved ones, what is most important to you now?*

**Managing Health:** quality of life, mind and body health, managing pain and fatigue  
*What do you hope your health care can do for you?*

### **Other Things that are Important to Me:**

*What is important for your doctor to know about you, to provide you with the best care?*





# What is your decision-making style?

**You are the driver in your health care – you get to choose where you want to go.** Thinking about your approach to medical care will help you make decisions.

Sometimes, medical treatment provides clear benefits. In other cases, treatment is not helpful. However, **when the decision isn't clear, people differ about whether or not they want medical treatment.**

In situations where it's not clear, do you lean towards a high intensity or low intensity approach to treatment? <sup>2</sup>

## Low Intensity

Less is more.

I am sick, I'll wait to see if it gets better before going to the doctor.

If a treatment might have a bad side effect, I would rather not do it.

## High Intensity

I want to do everything I can.

Take care of it right away.

It's okay if there might be bad side effects, I would rather do more.



## Which way do you lean?



I prefer low intensity treatments

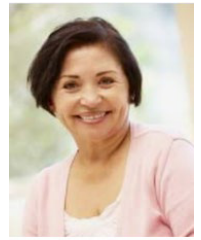
I somewhat prefer low intensity treatments

In between

I somewhat prefer high intensity treatments

I prefer high intensity treatments





## Think about **tradeoffs**

Reaching some goals may require making **tradeoffs**, which is choosing one thing over another.

**Sometimes, your goals might conflict with each other.** For example, you may want to live as long as possible, but you also don't want to spend time in the hospital or get invasive medical treatments. At some point during your care, you might have to think about which goal matters the most to you and your family in order to make decisions.

No matter what path you choose, it will have advantages and disadvantages. Everyone is different, and there is no right answer.

### Ask yourself...

- How do you feel about taking new **medications**?
- How do you feel about **lifestyle changes**, like changing your diet, medications, and exercise?
- How do you feel about getting a more **aggressive treatments**, like surgeries or devices?

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## Step 2: During your visit

Use this page to take notes on the conversation you have with your doctor.

### 1. What do you want your care team to know about you?

- Share your values & goals
- Share your decision-making style
- Talk about tradeoffs

### 2. Ask your doctor about your heart failure, such as:

- Your ejection fraction (EF)
- Your heart failure prognosis
- Your current treatment options and medications

### 3. My treatment preferences are...

**Your preferences are the route, or directions, you choose.**

Preferences are your specific treatment choices. Your preferences should help you get closer to your goals.

### 4. My next steps are...

- Come up with at least one action item that you can do to reach your goals, right now.



## Step 3: After your visit

What should I do next?

Your goals and preferences will probably change over time. This pamphlet is meant to be used every year, or whenever you have a big decision to make.

“For me, goals are helpful to visualize the path I want to be on. Thinking about my goals helps me make choices about my heart failure.”  
-Patient with heart failure

- 1. Talk with your family, friends, and extended support network.** It is important that they know what matters most to you, so that they can help you make decisions, or make decisions for you if you are unable to make a decision.
  - ✓ **Consider choosing a medical decision maker (a medical power of attorney),** and talk with them so that they know what you want
  - ✓ **Keep copies** of this information with other important documents.
- 2. Create an Advance Care Directive (ACD) or Living Will.** An ACD is a legal form for documenting your wishes for medical care, if you cannot speak for yourself.
  - ✓ **For a free, downloadable Advance Care Directive,** visit the website: [prepareforyourcare.org](http://prepareforyourcare.org)
  - ✓ **Share** this information with your loved ones.
  - ✓ **Bring a copy to your doctor** to store in your electronic health record.

# Additional notes:

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## <https://PatientDecisionAid.org>

1. Adapted from Naik AD, Dindo LN, Van Liew JR, Hundt NE, Vo L, Hernandez-Bigos K, Esterson J, Geda M, Rosen J, Blaum CS, Tinetti ME. Development of a Clinically Feasible Process for Identifying Individual Health Priorities. J Am Geriatr Soc. 2018 Oct;66(10):1872-1879.
2. Scherer LD, Zikmund-Fisher BJ. Eliciting Medical Maximizing-Minimizing Preferences with a Single Question: Development and Validation of the MM1. Med Decis Making. 2020 May;40(4):545-550.



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