

A Roadmap for Living with Heart Failure



The goal of this roadmap is to help you prepare for an annual wellness visit about your heart failure. In this conversation with your doctor, you will talk about how things are going with your health and what to focus on in your heart failure treatment for the next year.

By thinking about how you want to live your life with this disease, you will be prepared to have better conversations with your doctors, family, and loved ones. This will also help you make choices about the type of treatments you want and set goals for your future.

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



In this booklet, you will...

1. **Learn** about your heart failure
2. Think about your **values and goals**
3. Discover your **decision-making style**
4. Think about **your preferences** and consider your **tradeoffs**
5. **Plan for a conversation** with your doctor and loved ones

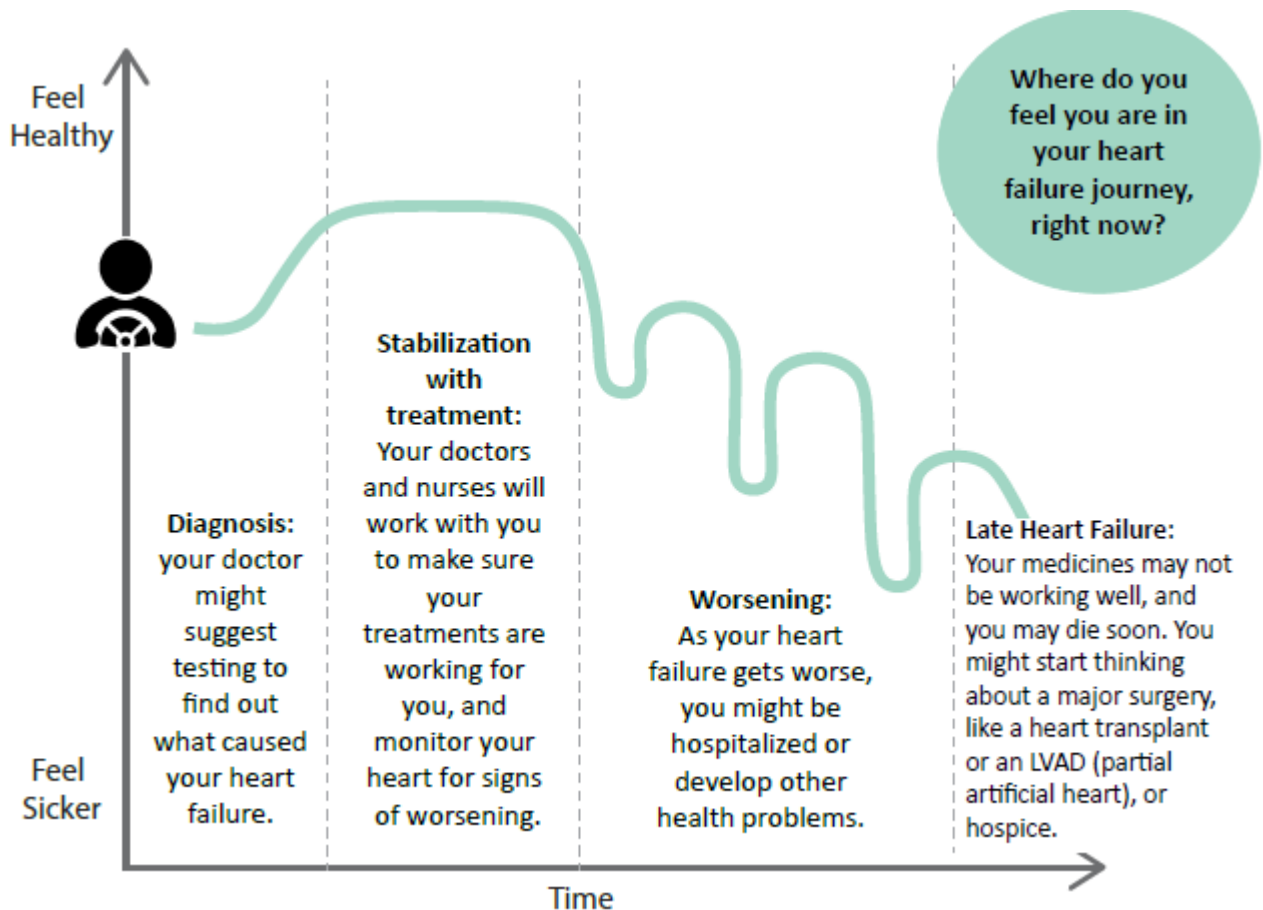




Step 1: LEARN about your heart failure

Heart failure, or a weak heart, is when the heart is unable to pump enough blood for the body. Heart failure can cause shortness of breath, tiredness, and swelling. It affects people from all backgrounds.

Heart failure is a chronic disease that you will likely live with for the rest of your life. 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. However, many people with heart failure will eventually feel worse over time.



There are many treatment options and ways to manage your health with this disease. To learn more about heart failure, scan this QR code or visit the website www.PatientDecisionAid.org/XXXXXX

QR
Code



Step 2: Think about your VALUES and GOALS

What **matters most** to you?
What makes **life worth living**?
What do you want **your care team**
to know about you? ¹

Connecting and 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?



Step 3: Discover 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 that are right for you.

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.**

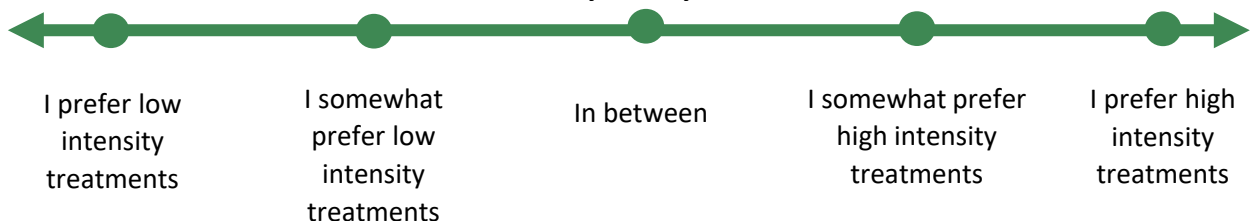
In situations where it's not clear, do you lean towards a high intensity or low intensity approach to treatment?²

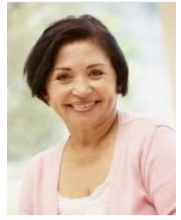
Low Intensity

High Intensity



Which way do you lean?





Step 4: Think about your PREFERENCES

Your preferences are the route you choose. Preferences are your specific treatment choices. Your preferences should help you get closer to your goals and values.

During your annual wellness visit, you will talk with your doctor about your treatment options for the next year. Think about...

- How do you feel about taking **new medications** or changing your doses?
- How do you feel about **lifestyle changes**, like changing your diet, new medication regimens, and exercise?
- How do you feel about **high intensity treatments**, like surgeries or devices?

"It gives me some comfort, even though it's a little scary, to know what treatments are possible and in my toolkit"
--Person with heart failure

Consider your 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 aggressive medical treatments. At some point during your care, you might have to think about which goals matter most to you and your loved ones in order to make decisions.

Tradeoffs to think about:

- Cost
- Quality of life
- Side effects
- Lifestyle changes
- Hospitalization
- Recovery from procedures

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



Step 5: Plan for a CONVERSATION

Use your notes on the previous pages to have a conversation with your doctor.

- Ask your doctor about your heart failure prognosis and current treatment options.
- Share your values, goals, and decision-making style.
- Talk about tradeoffs and your treatment preferences.
- Come up with at least **one action item** that you can do to reach your goals, right now.

“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.”
-Person with heart failure

Next, have a conversation with your family and loved ones.

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.

- Talk about your heart failure prognosis and current treatment options.
- Share your values, goals, and decision-making style.
- Talk about tradeoffs and your treatment preferences.

Your goals and preferences will probably change over time.

This booklet should be used every year, or whenever you have a big decision to make.

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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