Advanced Cardiac Care Program

A specialized program for people living with advanced cardiac disease

PATIENT AND CAREGIVER HANDBOOK

Provided by:

American Heart Association.

Avow®

NPHI National Partnership for Healthcare and Hospice Innovation

Table of Contents

Welcome 1

Acknowledgements 3

Program Overview 4

Understanding Your Heart and Heart Failure 5

Symptom Management and Self-Care Tips 8

Medications 12

Diet 18

Advance Care Planning 23

Appendices 24

- Appendix A: Monitoring Systems Chart 24
- Appendix B: My Action Plan—What to do When I Feel... 25
- Appendix C: Monitoring your Blood Pressure and Weight Logs 26
- Appendix D: Recipes for Salt-Free Herb Blends 31

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American Heart Association.

NPHI National Partnership for Healthcare and Hospice Innovation

National Partnership for Healthcare and Hospice Innovation is collaborating with the American Heart Association to improve quality and access to hospice and palliative/advanced illness care.

To Our Patients and Their Caregivers:

Thank you for choosing Avow for advanced cardiac care in your home. You can rest easy, knowing you will soon feel better and more in control of your life. Your caregivers will also feel more confident about how to help you and how to relieve their own stress and worry.

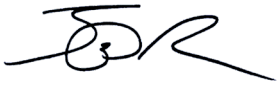
As our patient, you will receive care from Avow clinical specialists who are experts in treating people at home. We have been caring for Collier County since 1983, and we are proud of our quality ratings and Joint Commission accreditation. We are ready to listen to your goals for care, and to provide the services that help you live with the greatest comfort at home.

Avow has taken an additional step to make sure you get the best care possible. We will support you using the latest in treatments and guidance developed by two organizations, The National Partnership for Healthcare and Hospice Innovation (NPHI) and the American Heart Association (AHA).

While you might be familiar with the AHA, you probably don't know much about NPHI. This national organization develops innovative approaches to at-home care for those living with a serious illness. NPHI members, including Avow, are nonprofit, community-focused hospices and palliative care providers. Our goal, together and as individual companies, is to provide a safety net of care for the most vulnerable patients in our communities. We are impressed with the care plans developed jointly by AHA and NPHI, and believe you will soon feel the positive benefits they promise.

You can reach Avow 24/7/365 by calling (239) 261-4404 or (888) 484-AVOW (2869). Thank you again for trusting us with your care.

Sincerely,



Jaysen F. Roa
President & CEO
Avow Companies

Dear Cardiac Patients and Caregivers,

In cooperation with the American Heart Association (AHA), The National Partnership for Healthcare and Hospice Innovation (NPHI) has developed a special Advanced Cardiac Care Program to support the home care of patients with cardiac disease. Our mission is to ensure you and your family are well supported and informed so symptoms can be managed under our care with you safely at home.

This guide represents the best standards of care for end-stage heart failure, as defined by the AHA with the collective input of more than 70 advanced illness and hospice care organizations.

Many patients living with end-stage heart disease frequently visit the doctor's office, emergency room and hospital due to breathing difficulties, fatigue and other worsening symptoms. These exacerbations could be prevented or managed with hospice and palliative care.

We are pleased to share this Advanced Cardiac Care Guide, which includes valuable information to address your questions and concerns and ensure high-quality cardiac care from the safety and comfort of your home.

Please reach out to us 24/7 with any questions at 1-844-GET NPHI (438-6744) or visit us at www.hospiceinnovations.org.

On behalf of The National Partnership for Healthcare and Hospice Innovation and the American Heart Association, we wish you the best, knowing you have access to the best in cardiac care.

Sincerely,

Nancy Brown
CEO
American Heart Association

American Heart Association.

Tom Koutsoumpas
CEO
National Partnership for Healthcare & Hospice Innovation

NPHI National Partnership for Healthcare and Hospice Innovation

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Program Overview

Home Is Where the Heart Is

We understand that your wish is to remain at home and avoid repeated trips to the emergency room.

Our goal is to take care of your symptoms and concerns so that you can remain at home.

Working with NPHI, we have developed a special Advanced Cardiac Care Program to meet your individualized needs. Our mission is to be sure you and your family are well supported and educated to manage your symptoms and keep you safely at home. With our program, you can expect:

- To receive regular visits by a nurse with specialized training in the evaluation of cardiac disease, to evaluate and manage your cardiac disease, and to control the symptoms at home. The nurse will follow the direct orders of your physician or medical provider.
- To receive patient education specifically designed for you and your family. If you have any questions about the contents of this booklet, please ask your nurse.
- To be part of a team overseen by our doctor who is board certified in Palliative Medicine and who works directly with your primary care physician or medical provider.
- To have medications ordered by your physician or medical provider to help control symptoms. Your nurse will review your medications with you and order those medications that are essential for your symptom management.
- To receive additional supportive care in the form of visits provided by a social worker, a nurse assistant, a chaplain, a counselor, and/or a volunteer at your request.

The management of your heart disease takes a team effort and YOU are the KEY member on the team. The rest of your team members depend on you to call your nurse if you have any concerns.

Understanding Your Heart and Heart Failure

How Your Heart Works

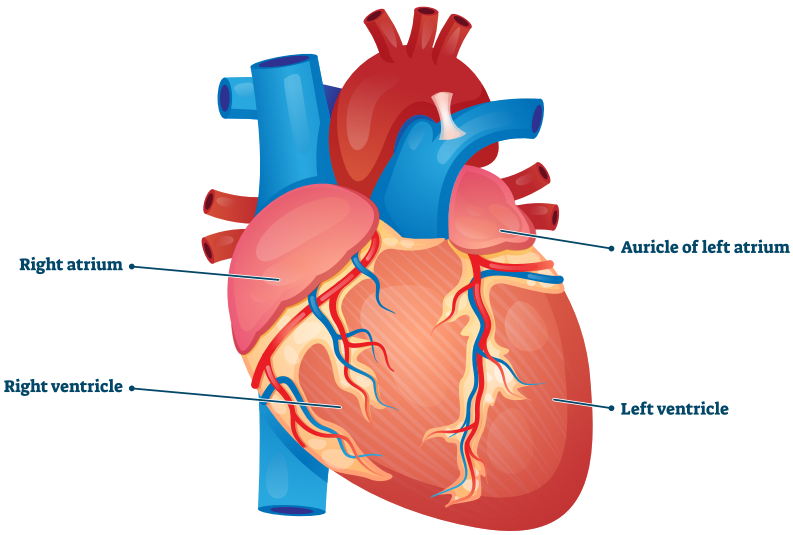
Your heart is a muscle that pumps blood throughout your body. The right side of the heart pumps blood to the lungs, where the blood receives oxygen. The oxygen-rich blood travels to the left side of the heart, where it is pumped to your brain, organs, arms and legs, and the rest of your body. After your body uses up the oxygen in the blood, it sends the blood back to the right side of the heart. This circulation of blood is provided continually by the heart.

What is Heart Failure?

Heart failure is a condition in which the heart is not pumping blood throughout the body as well as it should. The heart keeps pumping, but not as efficiently as a healthy heart.

Heart failure may involve the left side, the right side or both sides of the heart. Each side has two chambers—an atrium (upper chamber) and a ventricle (lower chamber). Heart failure occurs when the heart is unable to pump enough blood to meet the body's needs.

Heart failure usually does not occur suddenly, unless it is a consequence of a severe heart attack. Most of the time it develops and progresses gradually. While heart failure may shorten lives, good medical management, implemented by a team including doctors, nurse practitioners, nurses, the patient, and others, can help a person live longer, with a better quality of life.



Common Symptoms of Heart Failure

- Shortness of breath
- Cough (persistent)
- Weight gain
- Edema (swelling in the legs, ankles and occasionally the abdomen, due to a build-up of fluid)
- Fatigue
- Loss of appetite and nausea
- Chest pain

Many of the above symptoms can be managed or controlled with medications and self-care techniques in the comfort of your own home.

Self-care Techniques to Reduce Symptoms (see "My Action Plan" in appendix)

- Shortness of breath: A feeling of shortness of breath may be experienced with activity or when lying down. Shortness of breath can be reduced by elevating your head and shoulders with several pillows or sitting upright, lowering the legs, turning on a fan, and using oxygen.
- Chest pain: Chest pain associated with the increased workload of your heart, as well as the pain associated with low oxygen levels to your heart muscle itself, can be addressed. Descriptions of some of the common medications used to reduce chest pain are included in the "medication" section of this booklet.
- Edema (swelling): Edema is a medical term for fluid retention. Swelling or edema can be managed using diuretics or "water pills". Nutritional support and reduction of salty foods and fluids contribute greatly to the reduction of edema (swelling) in your body.
- Anxiety and restlessness: Anxiety and restlessness may occur on an emotional basis from the stress of living with a debilitating disease. They also may precede or accompany shortness of breath from heart failure. It may help to take a calming breath, concentrate on relaxing or meditate for 5–15 minutes, or take an easy walk for a few minutes. (See also Stress and Relaxation page 9.)

Other Self-care Tips

- Wear loose clothing: Tight clothing (garters, panty hose, socks, knee highs) can restrict blood flow.
- Avoid people with colds: Avoiding being exposed to the cold and flu is important because these conditions put extra demand on the heart and lungs.
- Healthy environment: Take steps to reduce dust and humidity in your living area. This will help with breathing.
- Exercise and activity: Try to remain as active as possible. Walking for several minutes each day could help you feel stronger. If several minutes of walking is too demanding, walking only a few minutes, more than once a day, may be better tolerated.
- Sleep: Getting good rest is important and if you are struggling to do so, try the following:
  - Get regular physical activity
  - Eliminate or limit alcohol intake to less than one drink per day
  - Avoid caffeine
  - Develop pre-bedtime routine—warm bath, dimming lights, or herbal tea
- Manage sleep apnea: Managing sleep apnea can help lower blood pressure and reduce stress on the heart. Sleep apnea can be managed with a CPAP or Continuous Positive Airway Pressure. The CPAP device works to keep air pressure in the breathing passages, so they do not close.

Symptom Management and Self-Care Tips

Eleven Tips to Keep Your Symptoms Managed

Here are some things you can do to manage your symptoms and keep yourself out of the emergency room:

1. Limit your fluids per your doctor's instructions. Ask your nurse or medical provider how much fluid you should drink each day. Patient total fluid intake daily_____
2. To maintain consistency, weigh yourself daily, same time (first thing in the morning if possible), same scale, unclothed after toileting. An increase in weight may signal fluid build-up.
3. Keep a notebook to write down your weight and any symptoms so you can report them to your team nurse. A weight gain of 2 pounds overnight or 3 pounds in one week (7 days) should be reported to your care team. (See weight table in the appendix)
4. If you have lower leg swelling, elevate them. Your medical provider may recommend compression stockings or wraps. Regular physical activity can help reduce swelling.
5. For difficulty breathing, elevate your head and shoulders with pillows or sit upright, turn on a fan, and/or use oxygen.
6. Take your medication as prescribed by your medical provider. Do not make changes to your medication without speaking with your medical provider or team nurse. Your team nurse can help with your medication management and will review it with you at each visit.
7. Eat a heart-healthy diet that is low in sodium. Focus on fresh foods and avoid processed or canned foods, as they are usually high in salt or sodium content.
8. Avoid activities that make you more than a little tired or short of breath. Rest completely between activities.
9. Avoid or limit caffeine intake, if recommended by your medical provider or healthcare team.
10. Reduce stress by talking with your hospice social worker and/or chaplain. They can help guide you on ways to relax and reduce anxiety. Remember that anxiety can be a subtle sign of shortness of breath and may require medication adjustment.

11. Call and ask for a nurse if you:

- Begin to have an increase in shortness of breath or develop chest pain
- Notice increasing fatigue, particularly with activities previously tolerated
- Notice that you have gained weight. Patient weight range: _____
- Notice that you have an increased swelling in your feet or ankles or legs or abdomen
- Wake at night with shortness of breath and/or anxiety, which is not relieved by sitting up for several minutes
- Notice a reduction in appetite or a tendency to nausea
- Experience any unpleasant side effects after you take your medication
- If you have unusual feelings or problems
- If you have not had a regular bowel movement in three days

Working Together to Manage Your Symptoms

The support of your family and loved ones is very important. They are a part of your life and are affected by your condition too. Including your family in your decisions and lifestyle changes will help to foster support and understanding. Share the information you read. Invite family members to talk with your care team. Let them know what they can do to help you. The team social worker can help you and your family with important decisions regarding your care.

How Your Family Members Can Help

- Set realistic goals and plans
- Participate in your healthcare decisions
- Keep track of your medications and appointments
- Adapt favorite family recipes to your diet
- Assist with activities of daily living and physical activities
- Ask questions. It is important for you and your family to understand your condition

Stress and Relaxation

When you're stressed, your heartbeat speeds up, blood pressure rises, muscles may tighten, and your stomach may become tense. Over time, you may show some of these symptoms of being stressed:

- Trouble sleeping
- Muscle tension
- Headaches
- Poor concentration
- Forgetfulness
- Anxiety
- Frequent negative thoughts
- Depression
- Feelings of helplessness
- Anger
- Irritability
- Showing aggression
- Poor eating
- Abuse of alcohol or drugs
- More accidents

When you're facing a stressor, pause for a moment, then take a deep breath to clear your mind so you can respond to stress better.

HOW TO DO IT

Take a deep breath and hold it gently for about five seconds. Breathe out slowly. Try to relax your arms and legs as you breathe out. If necessary, repeat. Your care team will teach you other relaxation techniques.

Medications

Taking medication every day is necessary to manage heart failure. There may be several medications prescribed for heart failure and most people will take more than one medication. It is essential to take your medications as they are prescribed by your medical provider to help control your symptoms. Never stop taking your medications or change your dose unless instructed by your nurse, physician or medical provider.

Common medications include:

ACE Inhibitors (Angiotensin Converting Enzyme Inhibitors) Some examples include benazepril (Lotensin), captopril (Capoten), enalapril (Vasotec), lisinopril (Zestril or Prinivil) and fosinopril (Monopril) Your Prescribed Medication Name: _____	This medication works to increase the flow of blood, lower blood pressure and reduce the amount of work the heart must do. You may experience a dry cough, dizziness, constipation or a dry mouth. Your physician/medical provider can easily change your prescription or offer other medications to manage blood pressure. Let your nurse know if any of these symptoms occur. To minimize light-headedness always rise slowly from a lying position and dangle feet before standing; avoid sudden changes in position. Take your medication one hour before meals and only as directed.
ARBs (Angiotensin Receptor Blockers) Some examples include: losartan (Cozaar), candesartan (Atacand), and valsartan (Diovan) Your Prescribed Medication Name: _____	This medication works very similarly to the ACE Inhibitors but avoids some of the side effects. As with the ACE Inhibitors, you may experience light-headedness if you rise quickly from sitting or lying. To reduce this, rise slowly from a lying position and dangle feet before standing; avoid sudden changes in position.

Continues.

Angiotensin-Receptor Neprilysin Inhibitors (ARNIs) Example: valsartan/sacubitril (Entresto) Your Prescribed Medication Name: _____	This is a combination of two medications. Valsartan is an ARB and as listed above. The second drug, sacubitril, works to strengthen a hormonal system regulated by the heart, which releases Brain Natriuretic Peptide (BNP). BNP helps to reduce/lower blood pressure, aides in elimination of increased salt and helps reduce fluid.
Antiplatelet Some examples include aspirin, (Bayer), (Ecotrin), or (Aspirin Childrens) Your Prescribed Medication Name: _____	This medication works to prevent platelets from clumping together to form a clot. During a heart attack, it is effective in decreasing damage to the heart. Taken regularly, it can decrease risk for further heart attacks or strokes. In some people, aspirin can produce bruising or bleeding, and it may be irritating to the stomach. It may also affect other blood thinning agents. If you are taking aspirin and experience bleeding, bruising, abdominal pain or nausea, notify your nurse.
Beta Blockers Some examples include carvedilol (Coreg) and metoprolol (Toprol) or (Lopressor) Your Prescribed Medication Name: _____	This medication works to lower blood pressure and slows the heart rate. Do not stop this medication without speaking with your care team. Avoid sudden changes in position to minimize light-headedness.

Continues.

Benzodiazepines Some examples include lorazepam (Ativan), alprazolam (Xanax) Your Prescribed Medication Name: _____	lorazepam (Ativan) This is an anti-anxiety medication. You may have been given Lorazepam previously in your treatment plan for use as an anti-nausea medication or to help you rest better at night. Lorazepam may be included as one of your symptom management medications to help ease the anxiety that can accompany heart failure symptoms. alprazolam (Xanax) This medication is an anti-anxiety medication. This may be included as one of your symptom management medications to help ease the anxiety that can accompany heart failure symptoms. It is important for you to report your feelings and symptoms to your care team. Both lorazepam and alprazolam can cause dizziness and sometimes forgetfulness or drowsiness.

Continues.

Cardiac Glycosides Some examples include digoxin (Digitalis), (Digitek), or (Lanoxin) Your Prescribed Medication Name: _____	This medication helps the heart pump more strongly by improving the contraction of the heart muscle and helps stabilize rapid or irregular heart rhythms. Take after meals. The dose of digoxin needs to be precise, so it is important to watch for the following signs that the dose is too high. • Loss of appetite (anorexia) • Nausea or vomiting • Diarrhea • Abdominal/lower stomach pain • Confusion • Visual disturbances • Extreme weakness or dizziness If you have any of these symptoms, notify your nurse immediately.

Continues.

Diuretics Some examples include furosemide (Lasix), bumetanide (Bumex) or (Burinex), torsemide (Demadex), and metolazone (Zaroxolyn) Your Prescribed Medication Name: _____ 	This medication is commonly called a "water pill". It helps rid the body of excess water, making it easier to breathe. Sometimes a diuretic causes people to lose potassium. Your medical provider or healthcare team may recommend that that you eat foods that are high in potassium such as bananas, tomatoes and strawberries. It is recommended to take your diuretic in the mornings on an empty stomach for better absorption. It is better to take your last dose no later than 3pm to reduce and prevent having to disrupt sleep at night to urinate, unless directed differently by your physician or medical provider. Signs of too much potassium loss include: • Muscle pain or cramps (especially legs) • Muscle weakness • Dry mouth • Increased thirst • Mental status changes • Heartbeats that skip • Nausea or vomiting • Weak pulse • Excessive fatigue
Mineralocorticoid Receptor Antagonists (MRAs) Example: spironolactone (CaroSpir) or (Aldactone) Your Prescribed Medication Name: _____	This medication is given to help rid the body of excess water, making it easier to breathe. It is usually taken at the same time as other diuretics.

Continues.

## Nitrates Some examples include nitroglycerin (Rectiv), (Nitro-Time), (Nitrosta), (GoNitro), or (Nitrolingual) Your Prescribed Medication Name: _____ 	This medication causes blood vessels to dilate, allowing more blood flow to the heart, which decreases chest pain. It also dilates blood vessels throughout the body, slowing circulatory return to a fluid-overloaded heart with heart failure. The tablet should be placed under your tongue (sublingual) and allowed to dissolve. It should not be swallowed. The tablet may produce a mild stinging sensation while under your tongue. This is normal and indicates the medication is being absorbed. You may take a small sip of water before placing the tablet under your tongue to help it dissolve. This medication may also be provided in a paste or spray formulation. As a spray, the spray container should be held as close as possible to your mouth. Press the button firmly with forefinger to release the spray 1 or 2 times onto or under the tongue. Do not inhale or breathe in the spray. As a paste, use the paper applicator to measure and apply the ordered dose. Apply to the skin—do not rub or massage into the skin. Spread it in a thin, even layer, and cover an area of skin that is the same size each time it is applied.
## Opioids Example: morphine sulfate (Roxanol) ** If you have an abnormal renal (kidney) function, your provider may prescribe another opioid to help with pain symptoms. Example: hydromorphone (Dilaudid) ** Your Prescribed Medication Name: _____	This medication is given for the treatment of chest pain that is not relieved by nitroglycerin. This may be included as one of your symptom management medications to help control pain. It may also be given to treat your shortness of breath. Some side effects of Morphine may include nausea, indigestion, anxiety, drowsiness, or itching. Tell your nurse if you experience any of these symptoms.

Diet

Making a few dietary changes can make you feel more comfortable and improve your quality of life. Salt (Sodium), water, and protein metabolism all play a significant role in regulating the amount of fluid load and stress on your heart. This excess fluid may cause your feet, ankles, legs and abdomen to swell. Keep in mind there are other names for salt(sodium) such as: Sodium Chloride, Monosodium Glutamate (MSG), Cured, Corned, and Pickled. Processed foods and canned foods are often high in sodium.

Listed below are dietary suggestions that may help you optimize your food and fluids to minimize fluid retention.

- Eliminate or limit alcohol intake to less than one drink per day. Alcohol is a toxin (poison) and is not good for a weakened heart muscle.
- Avoid excessive fluid intake (See more detailed information in the following section on Fluid)
- Increase your frequency of lean protein choices; try to incorporate unsalted nuts, legumes, beans and tofu. Try to consume fish at least twice per week (salmon, mackerel, herring and tuna).
- Boost fiber intake. Increased fiber can help with constipation problems. Increase whole grains, some fruits, and vegetables. Look for 100 % whole wheat flour, pastas made with at least a whole wheat blend and choose brown rice.
- As a side effect of medications, you may need to replace potassium in your body. Foods high in potassium include bananas, melons, sweet potatoes, white potatoes, prunes, oranges (or juice), some fish, low-fat yogurt, low-fat milk, low-sodium tomato juice and tomato sauce, lentils, and kidney beans. Make sure your medical provider or healthcare team wants you to keep your potassium high enough. Some people need to avoid potassium.
- When you use canned foods with added salt, rinse canned foods in a colander under running water to remove some of the salt.
- Avoid adding salt when cooking or shaking salt on your food.
- Season with herbs, spices, and herbed vinegar and fruit juices. (See recipes in the Appendix)
- Before using a salt substitute, ask your medical provider.
- Limit eating out and eating processed or canned foods.
- Some over-the-counter drugs contain lots of sodium. If you are taking any over-the-counter drugs, review this with your team nurse to see if the drug is OK for you.

** These are suggestions for a cardiac diet, diabetic patients will need to alter recommendations to meet the restrictions. Please discuss diet with your medical provider and care team. **

Where is the Sodium?

The American Heart Association recommends no more than 1,500 milligrams (mg) a day. However, follow your medical provider's instructions.

How to Read Food Labels

The serving size is the basis for all values on the label. In this case, 1 serving is 1 cup (half a can of soup). If you eat the whole can (2 servings, or 2 cups), you have to double all the numbers on the label.

Sodium is given in milligrams (mg). How does this number compare to your daily goal?

Nutrition Facts

Serving size 1 cup
Servings per container 2

Amount per serving

Calories 90 Calories from fat 20

	% Daily Value
Total Fat 2g	**3%**
Saturated Fat 0g	**0%**
Trans Fat 0g	
Cholesterol 10mg	**3%**
Sodium 690mg	**37%**
Total Carbohydrate 13g	**4%**
Dietary Fiber 1g	**4%**
Sugars 1g	
Protein 6g	

Ingredients: Chicken broth, carrots, cooked white chicken meat (white chicken meat, water salt, sodium phosphate, isolated soy protein, modified cornstarch, cornstarch), potatoes, celery, rice, monosodium glutamate. Contains soy.

Percent daily value gives the percentage of the standard recommended amount per day. If this is over 25%, the food probably contains too much sodium for you.

Check the ingredients list of salt. Also watch for high-sodium ingredients such as sodium phosphate, brine, monosodium glutamate (MGS), baking soda, and any other ingredient that has "sodium" in its name.

What Do These Labels Really Mean?

- Sodium free or salt free means less than 5mg per serving
- Very low sodium means 35mg or less per serving
- Low sodium means 140mg or less per serving
- Unsalted or no salt added means no salt is added to the product during processing (the product may still contain sodium, please read the labels)
- Reduced sodium or less sodium means at least 25% less sodium than the standard version. (Please read the label it may still be too much sodium for you)
- Light in sodium means 50% less sodium than the standard version. (Again, please read the label the sodium content may still be too much for you)

The foods listed below are usually low in sodium:

Always read the labels of your items to verify sodium content (sodium content varies from product to product and brand).

- Most fresh fruits and vegetables (1 serving, 0–20mg of sodium)
- Breads: white, whole grain (1 serving, 120–140mg of sodium)
- Cereals: cooked; granola, puffed rice, puffed wheat, shredded wheat, oatmeal
- Crackers: graham, low salt, melba toast
- Pasta: macaroni, noodles, spaghetti, rice (20mg to 140mg of sodium)
- Unsalted butter, margarine, oil
- Yellow mustard, spices, herbs, sugar, syrup
- Cheese: cream cheese, Monterey, mozzarella, ricotta
- Cream: half & half, sour, whipping
- Vanilla ice cream, sherbet, yogurt
- Milk (please read labels)
- Non-dairy creamer
- Frozen fruits and vegetables without sauces
- Canned vegetables: low sodium or rinsed
- Meats, fish, and poultry, unprocessed (75mg to 120mg of sodium per serving)
- Eggs (1 egg, boiled, 60mg)
- Unsalted peanut butter, 2 tablespoons (10mg)
- Tuna: low sodium or canned that you rinse
- Snacks: Nuts, 1oz, mixed, unsalted; unsalted popcorn, 1 cup (0 to 65mg of sodium)

The foods listed below are usually high in sodium and should be avoided:

- Canned soups and dry soup mixes (½ to 1 cup, 890mg to 915mg of sodium)
- Canned meats and fish
- Ham, 3.5oz; bacon, 2 slices; and sausage (290mg to 1500mg of sodium)
- Processed meats, such as deli items and hot dogs (290mg to 1500mg of sodium)
- Salted butter and margarine
- Salted peanut butter, 2 tablespoons (150mg sodium)
- Salted snack foods, such as nuts, pretzels, and chips
- Foods soaked in brine like pickles, olives, feta cheese, and sauerkraut
- Prepackaged frozen dinners over 400mg per serving
- Condiments, especially soy sauce (1 tablespoon 1230mg of sodium)
- Others include salad dressings, sauces, dips, ketchup, and Dijon Mustard

- Any seasonings that taste salty, including bouillon cubes, meat tenderizer, seasoned salts, tamari, and Worcestershire sauce
- Canned vegetables and frozen vegetables that have seasoning packs included for flavoring
- Seasoning mixes (tacos, chili, rice, gravies, etc.)
- Fast food (hamburger 475mg to 1000mg of sodium)
- Salt (1 teaspoon, 2400mg of sodium)
- Ramen noodle soup (1 package, 830mg to 1300mg of sodium)

Some foods and beverages WILL increase your symptoms; however, your care and recommendations are directed by your overall goals of care.

** These are suggestions for a cardiac diet, diabetic patients will need to alter recommendations to meet the restrictions. Please discuss diet with your medical provider and care team. **

Fluid

Sometimes a fluid restriction is necessary to help reduce the amount of stress that is put on your heart by excess fluid. Your medical provider will let you know if this is necessary. A fluid restriction is necessary because sodium draws fluid from your body into your bloodstream, increasing your overall blood volume. This in turn will cause your heart to work harder to rid your body of the excess fluid. A typical fluid restriction would be 1200–1500ml (5 to 6 ¼ cups) of total fluid per day.

Since you may need to limit your intake of fluids, it is important that you choose the fluids that your body needs the most. Unless you are craving water, choose fluids other than water that will give you needed calories, energy, and nutrients, but usually not liquids that have mostly simple sugars.

Keep commercially prepared liquid supplements, like Boost or Ensure, on hand for the days you do not feel like eating solid food. Supplements are very nutritious and are a liquid meal packed with nutrients, vitamins, and minerals.

Cholesterol

Cholesterol is a waxy substance found in your blood. High levels of cholesterol can build up in your arteries and cause damage. Therefore, it is wise to limit your cholesterol to less than 300mg a day. Cholesterol is found in all animal products such as meat, egg yolks and organ meats.

Some foods and beverages WILL increase your symptoms; however, your goals of care direct the recommendations and care provided by your medical provider or healthcare team.

Advance Care Planning

Sharing what matters most to loved ones helps families, clinicians, and communities alike understand your values. That knowledge—and the exercise of talking to one another about deeply personal desires and eliminating the need for family to guess what your wishes might be—can bring comfort and peace of mind in times of stress. There are important topics that must be explored regarding your health care wishes, hopes and fears with each other. It is a big step and not easy, however, it is necessary and will give those you love the guiding principles required to confidently make decisions for you if needed, assuring that your health care journey takes the course that you establish and lead. Advance Care Planning allows you to have your voice heard when you are not able to physically speak for yourself.

Your healthcare team will talk to you more about this and help guide the discussion with you and those you choose to participate in this discussion- this person is often called your health care surrogate or proxy.

Appendix A: Monitoring Symptoms

Green Zone Symptoms indicate the patient is doing well My Goal Weight: _____ My symptoms are under control: • No shortness of breath • No swelling • No weight gain • No chest pain • No decrease in my ability to maintain my activity	Actions to follow: • Take daily medicines • Weigh myself daily • Follow a low-salt diet
Yellow Zone Symptoms indicate the patient is having a bad day or a flare up My "Caution "Weight: _____ My symptoms are elevated (any of the following): • Weight gain of 3 or more pounds in 2 days • Weight loss of 5 or more pounds in 2 days • Increased cough • Increased swelling • Increased shortness of breath with activity • Increased number of pillows needed • Any other unusual symptoms	Actions to follow: • I may need an adjustment of my medications • Take daily medications • Weigh myself daily • Call your nurse for an evaluation Phone number: _____
Red Zone Symptoms indicate urgent care medical needs requiring immediate evaluation by your care team My "Alert "Weight: _____ My symptoms are extremely elevated (any of the following): • Unrelieved shortness of breath • Shortness of breath at rest • Unrelieved chest pain • Wheezing or chest tightness at rest • Need to sit/sleep in recliner or chair • Weight gain of more than 5 pounds in 2 days • Confusion	Actions to follow: Call your Nurse immediately for an evaluation Phone number: _____

Appendix B: My Action Plan— What to do When I Feel…

Please refer to this guide created for you by your care team to help you when you experience any of the following symptoms:

SYMPTOM	TREATMENT	DESIRED GOAL
ANXIETY		
CHEST PAIN		
EDEMA		
SHORTNESS OF BREATH		
OTHER SYMPTOMS		

Appendix C: Monitoring your Blood Pressure and Weight

It is important to keep a record of your blood pressure and weights as determined by your care team. The following charts can be used for record keeping.

Blood Pressure

	BLOOD PRESSURE	HEART RATE (PULSE)
Date/Time		
Reading 1		
Reading 2		
Reading 3		
Comments		
Date/Time		
Reading 1		
Reading 2		
Reading 3		
Comments		
Date/Time		
Reading 1		
Reading 2		
Reading 3		
Comments		
Date/Time		
Reading 1		
Reading 2		
Reading 3		
Comments		

	BLOOD PRESSURE	HEART RATE (PULSE)
Date/Time		
Reading 1		
Reading 2		
Reading 3		
Comments		
Date/Time		
Reading 1		
Reading 2		
Reading 3		
Comments		
Date/Time		
Reading 1		
Reading 2		
Reading 3		
Comments		
Date/Time		
Reading 1		
Reading 2		
Reading 3		
Comments		
Date/Time		
Reading 1		
Reading 2		
Reading 3		
Comments		

Weight

Weigh yourself daily, same time (first thing in the morning if possible), same scale, unclothed after toileting. Keep track of your weight and any symptoms so you can report them to your team nurse. A gradual weight gain of 2 pounds overnight or 3 pounds in one week (7 days) should be reported to your care team.

	WEIGHT	COMMENTS
Date/Time		
Weight		
Date/Time		
Weight		
Date/Time		
Weight		
Date/Time		
Weight		
Date/Time		
Weight		
Date/Time		
Weight		
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	WEIGHT	COMMENTS
Date/Time		
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Weight		

Week of _____

Date	Weight Lbs.	Swelling Abdominal Measurements	Shortness of breath. Circle level of distress 0 (none) – 10 (the worst)	Coughing or Wheezing?	Pain? Where?	Have there been any changes from yesterday? (Eating, sleeping, restlessness, activity, anxiety, etc.)
		ABD_____ cm	0 1 2 3 4 5 6 7 8 9 10	Yes/No		
		ABD_____ cm	0 1 2 3 4 5 6 7 8 9 10	Yes/No		
		ABD_____ cm	0 1 2 3 4 5 6 7 8 9 10	Yes/No		
		ABD_____ cm	0 1 2 3 4 5 6 7 8 9 10	Yes/No		
		ABD_____ cm	0 1 2 3 4 5 6 7 8 9 10	Yes/No		
		ABD_____ cm	0 1 2 3 4 5 6 7 8 9 10	Yes/No		
		ABD_____ cm	0 1 2 3 4 5 6 7 8 9 10	Yes/No		

Have you gained 2 pounds overnight or 5 pounds in 5 days? If so, call your Hospice program. Did you take all medications as directed, if not, what medication was held and why?

Date	/	/	/	/	/	/	/
Took all meds	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
Did not take							
Reason							

New or Worsening Symptoms? Call your Nurse anytime —24/7

Appendix D: Recipes for Salt-Free Herb Blends

CHINESE 5-SPICE—FOR CHICKEN, FISH OR PORK

- ¼ cup ground ginger
- 2 tablespoons of each: ground cinnamon, ground cloves
- 1 tablespoon of each: ground allspice, anise seeds

MIXED HERB BLEND—FOR SALADS, PASTA SALADS, STEAMED VEGETABLES, VEGETABLE SOUP OR FISH

- ¼ cup dried parsley flakes
- 2 tablespoons dried tarragon
- 1 tablespoon of each: dried oregano, dill weed, celery flakes

ITALIAN BLEND—FOR TOMATO-BASED SOUPS, PASTA DISHES, CHICKEN, PIZZA, FOCACCIA AND HERBED BREAD

- 2 tablespoons of each: dried basil, dried marjoram, thyme, crushed dried rosemary, crushed red pepper
- 1 tablespoon of each: garlic powder, dried oregano

EASY DIP BLEND—FOR MIXING WITH COTTAGE CHEESE, YOGURT, OR LOW-FAT SOUR CREAM

- ½ cup dried dill weed
- 1 tablespoon of each: dried chives, garlic powder, dried lemon peel and dried chervil

Notes

Notes

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