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YOUR GUIDE TO LIVING WITH HEART FAILURE

**Aloha Kākou (Greetings between you & I),**

More than 5 million people in the United States and 23 million people worldwide live with Heart Failure. Though the term Heart Failure sounds scary, it does not mean your heart has failed or has stopped beating. Heart Failure is a treatable condition.

This book will help you and your ‘ohana (family) understand Heart Failure, its symptoms and how to manage the condition. This book will also describe common symptoms of Heart Failure, common medications prescribed, and lifestyle changes that will need to be made.

Your Heart Failure team here at The Queen’s Medical Center, as well as your primary care physician, cardiologist and health care team, are all here to help you succeed in the management of your Heart Failure. Please involve your family and friends in your care and know that your health care team is here to guide you and help you make the changes that are needed to get you and keep you feeling better. By taking charge of your health and with the support of your family, friends and health care team, you can improve your condition.

Replacing old habits with new ones can be hard. Your willingness and positive outlook will help you to lead a full, happy and active life.

Please contact your health care team with any questions or concerns that you may have as you read this book.
YOUR KULEANA (RESPONSIBILITY)
Managing your Heart Failure is a group effort. Your friends, family and health care team are here to support you, but it is your kuleana to:

1) Involve and inform your family and friends on your education and treatment

2) Follow the recommendations of your health care team regarding:
   • diet and fluid intake
   • exercise and daily activity
   • medication

3) Manage your medications by:
   • knowing the names and doses of all your medications
   • refilling your medications in a timely fashion
   • taking your medications as prescribed
   • reporting any side effects

4) Report any of these symptoms to your health care team:
   • Sudden weight gain of 2-3+ pounds in one day or 5+ pounds in one week
   • Increased shortness of breath, especially when lying flat
   • Increased swelling in the legs, ankles and/or belly
   • Decreased urination during the day
   • Dizziness that doesn’t go away
   • Rapid, pounding heart rate (palpitations)

5) Create an Advanced Directive, Durable Power of Attorney & POLST
   • Ask your health care team for more information regarding these legal documents
   • An advanced directive provides specific instructions to help your family and caregivers make decisions in a medical emergency
   • A durable power of attorney allows someone to act on your behalf if you are not able to make decisions about your care
   • A POLST (Physician Orders for Life-Sustaining Treatment) is a medical decision-making form completed with your health care provider and kept at home to communicate your wishes in case of an emergency
HOW DOES MY HEART WORK?
Understanding how your heart works will help you understand Heart Failure and the reasons why your health care team designs certain treatments for you. The more you know, the more you can be involved.

The heart has four chambers: two small upper chambers called atria receive blood from the body; two large lower chambers called ventricles pump blood to the body. A thin muscle called the septum separates the right and left sides of the heart.

The left side of the heart receives blood with oxygen from the lungs and pumps it out to the rest of the body. The blood then returns to the right side of the heart, which pumps it to the lungs to pick up more oxygen.

When you exercise, or do any physical work, your heart adjusts and will beat faster to deliver more oxygen and nutrients the body needs.
WHAT IS HEART FAILURE?

Heart Failure occurs when the heart cannot pump enough blood to the body because the muscle is weak or too stiff. While it is not curable, it is treatable.

With less blood pumping out from the heart due to either stiffened or weakened heart muscles, the chambers of the heart overfill, causing pressure and fluid to build up in your lungs and other parts of the body.

WHAT CAUSES HEART FAILURE?

Each patient’s condition is unique and requires a reliable team that can tailor a plan of care to match the patient’s specific needs. Your health care provider will explain what caused your condition.

Common causes of heart failure include:

1) Coronary Artery Disease: a condition where blocked arteries cause a heart attack, which may weaken the heart muscle and cause it to not pump as well as it did before.

2) High Blood Pressure (Hypertension): this condition causes the heart to work harder to pump blood to the rest of the body.

3) Heart Valve Problems: leaky or narrow heart valves cause blood to flow improperly through the heart, making the heart work harder and potentially weaker.

4) Family History: heart disease can run in the family.

5) Other causes: Infections, lung disease, anemia, thyroid disease, diabetes, alcohol or illegal drug use can damage the heart.

WHAT ARE THE SYMPTOMS OF HEART FAILURE?

There are different symptoms of Heart Failure depending on the cause. Symptoms may come suddenly or happen over time, and can be mild to severe.

The main symptoms of Heart Failure are:

1) Shortness of breath, or having trouble breathing while lying flat at rest or with activity.

2) Edema, or swelling, of the legs, ankles, feet, belly or lower back.

3) Feeling extremely tired or fatigued.

4) Lacking the energy to do what you normally do.

Other symptoms include: chest pain or discomfort; racing heartbeat; dizziness; upset stomach; decreased appetite; rapid weight gain; wheezing or rapid breathing; waking up breathless; trouble breathing when walking; needing to sleep with multiple pillows; or requiring sleep in a chair or recliner.
WHY DO I NEED TO TAKE HEART FAILURE MEDICATIONS?

Heart Failure is a chronic disease that requires you to take medications. Medications prescribed by your health care provider are used to:

• Reduce symptoms
• Improve heart function
• Slow progression of the disease

WHAT ARE THE MEDICATIONS USED TO MANAGE HEART FAILURE?

Some of the medications that you are taking may be the following:

• Diuretics (water pills)
• Beta Blockers
• Angiotensin Converting Enzyme (ACE) inhibitors
• Angiotensin Receptor Blockers (ARBs)
• Aldosterone Receptor Blockers
• Neprilysin Inhibitor/Angiotensin Receptor Blocker
• Hydralazine and Nitrates
• Digoxin
• Potassium and Magnesium supplements

HOW DO I TAKE MY MEDICATIONS EFFECTIVELY?

Medications are most effective when taken as instructed at the same time every day. Never skip taking your medications, change doses or take extra pills unless instructed by your doctor or health care team.

Tips:

• Use a daily or weekly pillbox to help organize your medications
• Always carry a list of your medications with you
• Bring ALL medication bottles to every clinic appointment
• Refill your medications early so that you do not run out
• Ask your pharmacy to send a refill fax to your doctor’s office
• Notify your health care team if you are unable to obtain your medications due to cost; there may be ways to reduce cost
HEART FAILURE MEDICATIONS

Angiotensin Converting Enzyme Inhibitors (ACE Inhibitors)
ACE Inhibitors relax blood vessels and can lower your blood pressure, making it easier for the heart to pump blood forward. ACE Inhibitors also block the effects of bad hormones that can cause scarring of the heart tissue and affect the heart shape and function.

Examples Of ACE Inhibitors:
• Benazepril (Lotensin™)
• Captopril (Capoten™)
• Enalapril (Vasotec™)
• Lisinopril (Zestril™, Prinivil™)
• Ramipril (Altace™)

Common Side Effects May Include:
• Dizziness, particularly with position changes. Stand up slowly over a few minutes from sitting or lying down.
• Dry cough
• Headache
• Bad taste in mouth
• Upper respiratory symptoms such as running nose or congestion

Rare Side Effects:
Swelling of the lips or throat. You should go to the emergency department or call your health care provider immediately if you experience these effects.

Angiotensin Receptor Blockers (ARBs)
ARBs work similar to ACE inhibitors and are often used in place of ACE inhibitors due to medication intolerance or side effects.

Some Examples Of ARBs:
• Candesartan (Atacand™)
• Irbesartan (Avapro™)
• Losartan (Cozaar™)
• Olmesartan (Benicar™)
• Telmisartan (Micardis™)
• Valsartan (Diovan™)

Common Side Effects:
• Dizziness, particularly with position changes; try to stand up slowly, over several minutes, when doing so from a sitting or lying down position
• High potassium level, which can cause weakness, numbness, tingling or palpitations
• Loose stools

Things To Know For Both ACE Inhibitors and ARBs:
• You may be asked to have blood tests done regularly while you are on these medications to monitor your potassium level and kidney function
• If dizziness occurs, take your time when changing position (e.g. moving from a sitting to standing position)
**Beta Blockers**
Beta blockers slow the heart down, help prevent bad rhythms, reduce the energy demands of the heart, and block bad hormones which can worsen the heart function and shape.

**Some Examples Of Beta Blockers:**
- Carvedilol (Coreg™)
- Metoprolol succinate (Toprol XL™)
- Bisoprolol (Zebeta™)

**Common Side Effects May Include:**
- Tiredness, fatigue or weakness
- Dizziness, particularly with position changes, such as standing up from a sitting or lying down position
- Loose stools
- Slow heart rate
- Change in sexual ability

**Things To Know:**
- When first taking beta blockers, people sometimes experience extra tiredness or fatigue while the body becomes accustomed to the medicine. This feeling usually goes away within a few weeks.

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**Aldosterone Receptor Blockers**
Aldosterone blockers help the body get rid of extra salt and water, block bad hormones that cause the heart to weaken and form scar tissue, and prevent dangerous heart rhythms.

**Some Examples Of Aldosterone Receptor Blockers:**
- Spironolactone (Aldactone™)
- Eplerenone (Inspra™)

**Common Side Effects May Include:**
- High potassium level, which can make you feel weak, lightheaded or dizzy; numbness and tingling can also occur
- Upset stomach or vomiting
- Change in sexual ability

**Things To Know:**
- You may be asked to have blood tests done regularly while you are on these medications to monitor your potassium level and kidney function.
Angiotensin Receptor Blocker/Neprilysin Inhibitor (ARNI)
ARNI is a combination pill or tablet which has an ARB to block bad hormones that causes the heart to scar or worsen heart function, and a neprilysin inhibitor, which prevents the breakdown of the good hormones that help the heart.

Example Of Angiotensin Receptor Blocker/Neprilysin Inhibitor:
• Sacubitril-valsartan (Entresto™)

Common Side Effects May Include:
• Low blood pressure, which can make you feel weak, lightheaded or dizzy
• High potassium level, which can make you feel weak, lightheaded or dizzy
• Cough
• Impaired kidney function

Rare Side Effects:
Swelling of the lips or throat. You should go to the emergency department or call your health care provider immediately if you experience these effects.

Things To Know:
• You may be asked to have blood tests done regularly while you are on these medications to monitor your potassium level and kidney function
• This medication usually is started once you are stable, either in-clinic by your health care provider or prior to discharge

Hydralazine And Nitrates
Hydralazine and nitrates (isosorbide) work together to relax blood vessels, making it easier for the heart to pump blood throughout the body. Nitrates also prevent and relieve chest pain.

Example Of Hydralazine And Nitrates:
• Hydralazine
• Isosorbide Dinitrate
• Isosorbide Dinitrate/hydralazine (Bidil™)

Common Side Effects May Include:
• Temporary headache
• Dizziness
• Muscle weakness
• Upset stomach or vomiting

Things To Know:
• Avoid using erectile dysfunction medication such as sildenafil (Viagra™) or tadalafil (Cialis™) if you are on nitrates as it can cause severe low blood pressure that can be life threatening
**Digoxin**

Digoxin (Lanoxin™) helps the heart pump better, which can help to reduce some symptoms of Heart Failure and prevent the need for hospitalization.

**Common Side Effects May Include:**
- Dizziness
- Gastrointestinal symptoms such as belly pain, upset stomach, vomiting, diarrhea or poor appetite
- Visual disturbances (yellow and blue color)

**Rare Side Effects:**
Abnormal rhythm of the heart – either faster or slower than normal.

**Things To Know:**
- You may be asked to have blood tests done regularly while you are on these medications to monitor the drug level, your potassium level and kidney function

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**Diuretics**

When you have Heart Failure, your body holds on to extra fluid causing troubled breathing, swelling in the legs or belly and a poor appetite. Diuretics can reduce heart failure symptoms by helping the body get rid of extra sodium and fluid.

**Examples Of Diuretics:**
- Bumetanide (Bumex™)
- Furosemide (Lasix™)
- Hydrochlorothiazide (Microzide™)
- Metolazone (Zaroxolyn™)
- Torsemide (Demedex™)

**Common Side Effects May Include:**
- Dizziness
- Belly pain
- Headache
- Low potassium levels, which can make you feel tired or weak, have numbness or tingling, muscle cramps, hard stools (constipation), vomiting or fast heartbeat
- Dry mouth
- Hearing loss, which can be long-lasting

**Things To Know:**
- Diuretics may make you urinate more often which means the medication is working
- Taking the medication late in the evening can negatively impact your sleep; avoid taking it too late at night
- Even though you are urinating more, you still need to reduce your salt and fluid intake
- You may need to monitor your blood work while you are on diuretics as it can cause low potassium and magnesium levels
**Electrolyte Supplements/Replacements**

Potassium supplements (potassium chloride) and magnesium supplements (magnesium oxide) are common for patients on water pills to replace the potassium and magnesium lost from increased urination.

**Common Side Effects May Include:**
- Belly pain, upset stomach and vomiting
- Loose stools

**Things To Know:**
- Potassium is an important electrolyte in the body that needs to be replaced if levels are low
- Potassium supplements come in the form of pills, liquid or powder
- You may need to have blood work checked regularly to monitor potassium levels in your body

**MEDICATIONS TO AVOID**

**Non-Steroidal Anti-Inflammatory Drugs (NSAIDS)**

NSAIDs should be avoided if you have Heart Failure. Use of these medications can make your Heart Failure worsen and lead to kidney problems.

**Examples of NSAIDS:**
- Ibuprofen (Advil™, Motrin™)
- Naproxen (Naprosyn™, Aleve™)
- Celebrex™

**Pseudoephedrine (Sudafed)**

Pseudoephedrine (Sudafed) should be avoided if you have Heart Failure. It can cause your heart to work harder than normal, or cause abnormal heart rate and rhythm. It is found in over-the-counter cold and allergy medications.

**Examples Of Similar Medications:**
- Phenylephrine
- Ephedrine
- Phenylpropanolamine

**Herbal Remedies**

Herbal remedies should be avoided if you have Heart Failure. Many herbs and vitamins can prevent your Heart Failure medications from working properly. Before using any herbal treatment, consult with your health care team.
**LIFESTYLE CHANGES**
**What can YOU do to make your heart work better?**

Due to the changes your body goes through when living with Heart Failure, you will need to focus on improving habits in your everyday routine. These areas include knowing your body, changes in your diet and exercise routines, and avoiding drugs, tobacco and alcohol.

**MANAGE YOUR WEIGHT**
Diets for weight management or losing weight are different than for heart failure and fluid management. The focus when trying to lose weight is on calorie intake, balancing meals, and making healthy food choices. Being overweight is a risk factor for heart disease, and contributes to diabetes and high blood pressure.

**General Suggestions:**
- Ask your health care provider regarding an overall calorie goal; this will be different for each person
- Know your Body Mass Index (BMI); this is a measurement of weight as compared to height, and there are general goals for both men and women

**Tips:**
Weight loss is best achieved by a combination of healthy eating and exercise
- Exercising daily helps to burn off calories
- Eat smaller portions; avoid snacking
- Decrease consumption of foods that are high in fats and sugars
- Increase your intake of fruits, vegetables, grains and lean meats
- When eating out, share meals to decrease portion sizes

**Record Your Weight Daily**
Recording your weight every day will help you notice a quick weight gain sooner than only looking for swelling. When your weight goes up by two to three pounds from one day to the next, or three to five pounds in one week, it is usually due to gaining water weight. This can be caused by increased fluid or salt intake, medication changes, or changes in your heart or kidney function.

**General Suggestions:**
- Weigh yourself every day

**Tips:**
- Weigh yourself first thing in the morning after using the bathroom; try to use the same scale at around the same time, with the same amount of clothes on
- Write your weight down on a log sheet; bring this with you to your appointment
- Notify your provider’s office of any sudden weight changes
**CHANGE YOUR DIET**

Fluid and salt go together in the body. If you increase your salt intake, your body will hold on to more fluid; if you increase your intake of fluid, the existing salt in your body will hold onto it.

With extra fluid built up in the body, blood volume increases and your heart may not be able to pump the extra fluid, causing fluid to build up in the lungs and body and resulting in shortness of breath, fatigue, weight gain and swelling.

Medications like water pills (diuretics) can only do so much, but limiting your sodium and fluid intake may help!

**Limit Sodium (salt) Intake**

**General Suggestions:**
- 2,000 milligrams (2 grams) of sodium per day
  - 1 teaspoon of table salt = 2,000 milligrams
  - 1 teaspoon shoyu (soy sauce) = 780 milligrams sodium
- Use about 500-700 milligrams of sodium in each meal

**Tips:**
- Don’t add salt or shoyu to meals
- Eat more fresh foods and less processed or canned meats or canned foods
- Use less prepared seasonings, sauces, or dressings – make your own from scratch
- Read food labels and notice what is in each ingredient you use
- Eat less fast food or plate lunches, and avoid eating out
- If you do eat out, ask for foods to be prepared without salt
- Season foods with herbs and spices other than salt including vinegar, citrus juice, and no-salt seasonings (Ms. Dash™, Lawry’s salt free™, Morton’s nature™)

**Limit Fluid Intake**

**General Suggestions:**
- 1,500 milliliters (mL) or 1.5 Liters (L) per day
  - This is six 8-ounce glasses per day
  - 1 Liter = 32 ounces
  - 1.5 Liters = 48 ounces

**Tips:**
- “Fluid” includes any substance that is liquid at room temperature (examples: water, coffee, juice, soda, soup broth, ice, popsicles, ice cream, jello and pudding)
- If you’re thirsty, instead of drinking more fluid, suck on a sugar-free hard candy, frozen grapes or ice chips
- Use a 1 Liter bottle to keep track of your fluid intake. Fill it up each morning with water; this leaves you 500mL (half a liter) to use in food, or other drinks
STAY ACTIVE
Aside from keeping your muscles strong, maintaining a regular exercise routine can also help you notice a change in your Heart Failure symptoms sooner, such as increased shortness of breath when walking. Keeping a healthy weight has many health benefits as well, such as lowering your blood pressure and heart rate.

Being inactive may cause the body to lose muscle mass, feel weak and tired, and cause your heart to work harder.

Exercise and Daily Activity
There are three basic types of exercise: aerobic, strengthening and flexibility. While all three are important, patients with heart failure should focus on aerobic exercise which may include walking, bicycling or swimming.

General Suggestions:
30 minutes of exercise, 5-7 days per week

Tips:
• Start slow: begin with walking in your house or in the yard
• Increase slowly over several days or weeks to reach your goal level of exercise
• Choose an activity that you enjoy
• Schedule exercise in your daily routine
• Consult your health care provider about activity options; they may have limitations to discuss with you
• Speak with your doctor about how your prescribed medications can affect your response to exercise
• Ask about a cardiac rehabilitation program if you need a structured setting, or education on what your body can tolerate

Knowing your limits can be difficult, but as a rule, you should be able to speak easily while you exercise.

If you notice increased shortness of breath during exercise or have increased fatigue after exercise, call your health care team. Stop exercise immediately if you develop chest pain, feel pressure in your chest, neck, jaw, or arm, feel weak, or feel dizzy. Call 9-1-1 or go to the emergency room if these symptoms do not go away.
Cardiac Rehabilitation
Cardiac rehabilitation is a medically supervised program which offers tailored programs that include monitored exercise, education of cardiac risk factors and psychosocial support for patients with various types of heart disease. Studies have demonstrated that cardiac rehabilitation decreases re-hospitalization rates and improves patients' long-term survival.

Health care professionals monitor for signs and symptoms of heart failure and determine if you are exercising at an appropriate intensity with the use of various cardiac monitoring.

Sexual Activity
Remaining sexually active may be very important to your quality of life. However, it is not uncommon for sexual function to be affected by your medications, your heart function, or depression.

General Suggestions:
If you can tolerate walking up two flights of stairs, or walking one block at a brisk pace, you should be able to resume sex with your partner. As with any activity, listen to your body, and only do what you can tolerate. If you have any symptoms of chest pain, shortness of breath, fatigue or palpitations, stop and rest.

Tips:
• Choose a time of day when you are rested
• Wait an hour after meals, showering or exercise
• Always check with your health care team before using any sexual-enhancing medications
AVOID HABIT-FORMING AGENTS
Alcohol, illicit drugs (cocaine and methamphetamine specifically) and smoking tobacco can cause damage to your heart. If you have not used these substances, don’t start. If you currently use any of these substances, discuss a plan to quit with your health care provider.

General Suggestions:
Alcohol: The use of alcohol can damage the muscle cells in your heart. Even if alcohol is not the cause of your Heart Failure, drinking alcohol can worsen the heart’s function. It is best to avoid ALL alcohol intake. For some people, stopping the use of alcohol can improve their heart function.

Illicit Drugs: Recreational drugs have several health risks. Specific to heart failure, cocaine and methamphetamines can cause the heart to weaken. It is best to avoid all recreational drug use. For some people, heart function can improve if they stop using drugs.

Smoking Tobacco: Cigarette smoking can lead to many illnesses, and can worsen Heart Failure symptoms. If you are currently smoking, quitting is the best plan.

Tips:
• Make the decision to quit – you are the only one who can make it happen
• Pick a quit day and make a plan
• Ask for professional help such as counseling or rehabilitation programs
• Stay away from triggers or groups who provide access to these substances
OTHER HEART FAILURE TREATMENTS

IMPLANTABLE CARDIOVERTER DEFIBRILLATOR (ICD)
An ICD is an electronic device that monitors for life-threatening heart rhythms and treats them to prevent possible death.

Why would someone need an ICD?
Patients with weak hearts are at a higher risk for having dangerous heart rhythms that can cause death. Patients that need this device may have a history of:
• Heart stopping (cardiac arrest)
• Rapid, life-threatening heart rhythms not controlled by drugs or surgery
• Weak hearts despite good medications

How is the ICD put in?
The ICD has wires that are placed into a vein that goes into the heart and is then connected to a generator that is placed in the chest wall. If this device is recommended for you, more information will be provided by your doctor or health care team.

BIVENTRICULAR PACEMAKER WITH ICD
A biventricular pacemaker with ICD uses electricity to help the heart pump better. It also stops life-threatening heart rhythms. It can potentially make the heart function better and improve symptoms.

Why would someone need a biventricular pacemaker?
Some patients have an electrical abnormality that makes the heart pump out of sync and inefficiently. A biventricular pacemaker can help the all parts of the heart to pump together and potentially improve symptoms, activity and heart function.

How is the biventricular pacemaker put in?
The biventricular pacemaker usually has three wires and, like the ICD, are placed into the vein that goes into the heart and connected to the generator that is placed in the chest wall. If this device is recommended for you, more information will be provided by your doctor or health care team.
ADVANCED HEART FAILURE THERAPIES

If your Heart Failure worsens despite all the medications, lifestyle changes and treatments, your doctor may send you to an Advanced Heart Failure Clinic. This specialized team may recommend advanced Heart Failure therapies such as a heart transplant or mechanical circulatory support (ventricular assist device or total artificial heart).

- Heart transplantation is a surgery where your failing heart is replaced with a healthier donor heart reserved for patients in end-stage Heart Failure.

- A ventricular assist device (VAD) is a mechanical device that is surgically implanted into the heart that directly helps pump blood from the heart. Blood flows from the heart to the rest of the body using an electrically powered motor. The battery pack and controller are worn outside of the body. VADs are for patients with end-stage Heart Failure to allow additional time to live and improve health while waiting for transplantation, or as “destination therapy” to allow improvement in symptoms and assist the failing heart.