

# Caring for your Heart: Living Well with Heart Failure Patient Guidebook



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# **At Northern Light Health, we're all behind you... and your care team is right beside you.**

Northern Light wants every patient to get the full value of our medical care. Successfully treating heart failure requires specialized treatments, careful monitoring and extensive lifestyle changes. We know following your personalized treatment plan can seem overwhelming, especially for patients with other conditions or stress factors. That is why we provide heart failure patients with specially trained care providers. Just one more way Northern Light Health is by your side, every step of the way.



# Table of Contents

**Chapter 1:** What is Heart Failure?



**Page 4**

**Chapter 2:** Your Daily Check Up



**Page 6**

**Chapter 3:** Your Heart Failure Medicines



**Page 17**

**Chapter 4:** Nutrition and Fluids



**Page 27**

**Chapter 5:** Heart Failure and Exercise



**Page 37**

**Chapter 6:** More Information/Resources



**Page 43**





# Chapter 1

## What is Heart Failure?

- Heart failure means that either the heart cannot pump blood well or the heart has become stiff over time and can't fill as easily.
- When your heart doesn't pump well, it can make you feel weak, tired, or dizzy.
- Heart failure causes fluid to leak out of your blood vessels. This fluid can fill up your lungs and make you short of breath; it can also cause your legs to swell.



**Fluid in  
legs causes  
swelling**



**Fluid in lungs  
can make you  
short of breath**

# Things You Can Do to Live Well with Heart Failure



Take your medicines (every day) correctly.



Eat less salt.



Exercise regularly.



Weigh yourself every morning.

If your weight increases by two to three pounds (or more) overnight, or by five pounds in a week, please call your Provider.



Restrict fluids to two liters or two quarts per day. (64 oz.)



## Chapter 2

# Heart Failure Daily Check-up: How to Stay Healthy!



# Daily Check-up

Heart failure can cause a number of symptoms or just make you feel bad. If you can catch these symptoms early, you can take action to feel better and stay out of the hospital.

## Each day, do a check-up.

- How do you feel?
- Do you have shortness of breath?
- Do you have swelling?
- Weigh yourself.

Let's walk through the daily check-up together.



# How do You Feel Today?

You can tell how well your heart is doing by how you feel and what you can do.

## Am I short of breath walking?

Heart failure can make you feel short of breath while walking.



### Doing Well

I can walk easily  
with no shortness  
of breath



### Getting Worse

I have shortness of  
breath after walking  
a short distance



### Call your provider

I am short of breath  
even at rest





# How do You Feel Today?

## Am I short of breath sleeping?

Heart failure can also make you feel short of breath when you are lying down. When it gets really bad, some people find they need to sleep sitting up.



### Doing Well

I can sleep lying flat, no shortness of breath



### Getting Worse

I need 2 pillows or more to avoid shortness of breath



### Call your provider

I have to sleep upright to avoid shortness of breath

# How do You Feel Today?

## Am I feeling faint or dizzy?

Sometimes people with heart failure feel very dizzy or lightheaded.



### Doing Well

I am not dizzy or sometimes a little dizzy when standing up



### Getting Worse

I am dizzy for a long time



### Call your provider

I almost passed out, passed out (fainted), or fell

# Do You Have Swelling?

**Swelling in your legs or abdomen (belly) can be a sign that your body is holding onto too much fluid. This is easy to check.**

To check for swelling each morning:

- Press firmly into the skin on the front part of your lower leg.
- If your finger makes a pit in your skin, you have swelling in that part of your leg.
- Do you have swelling in your belly? Can you button your pants?
- Be aware of how much swelling is usual for you and look for changes.



Doing Well

No swelling

Getting Worse

Swelling in ankle  
or shin

Call your provider

Swelling in  
knee area



# Weigh Yourself Each Day

**Weigh yourself each morning at the same time in your routine; after you pee (urinate), before you eat breakfast, and before you get dressed.**

## **Know your target weight:**

- Ask your provider what your target weight is each time you visit, your target weight is where your heart is working best.
- Work with your provider to make a plan for when your weight goes up too much.

**Mark your weight on the calendar each day, using the chart on page 13 as a guide.**

Mark G for green, Y for yellow, or R for red next to your weight, or use colored pens or markers, for easy reference.

**\*Bring your chart with you to your next appointment.\***

# Daily Monitoring Calendar

**\*Bring this chart with you to your next appointment with your provider.\***

**Which Heart Failure Zone are you in today? Green, Yellow, or Red**

Provider \_\_\_\_\_ Provider Phone # ( \_\_\_\_\_ ) \_\_\_\_\_ - \_\_\_\_\_

**Instructions:** Weigh yourself each morning after you “pee”, before breakfast, and before you get dressed. Mark G for green, Y for yellow, or R for red next to the weight, using the chart below as a guide.

Month: \_\_\_\_\_

Year: \_\_\_\_\_

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Weight	Weight	Weight	Weight	Weight	Weight	Weight
Weight	Weight	Weight	Weight	Weight	Weight	Weight
Weight	Weight	Weight	Weight	Weight	Weight	Weight
Weight	Weight	Weight	Weight	Weight	Weight	Weight
Weight	Weight	Weight	Weight	Weight	Weight	Weight

## Green Zone: Doing Well

- Feeling well
- Breathing is easy
- Weight is the same
- Normal energy level
- No increased swelling or bloating, near your normal

## Yellow Zone: **Caution**

- Weight gain of 2-3 pounds overnight or 5 or more pounds in a week
- Breathing is harder with normal activity or at night.
- Increased swelling or bloating
- Increased fatigue or weakness
- Loss of appetite
- Propped up more at night or difficulty sleeping
- Persistent cough

## Red Zone:

### **Danger Medical Alert**

- Very hard to breathe with any activity or at rest
- Chest heaviness
- Weight gain of 4 pounds or more in one day
- Severe increase in swelling or bloating
- Fainting

## Action Plan: Doing Well

- Keep up the good work!
- Continue your medicines
- Continue your daily weights
- Avoid salt
- Keep your medical appointments
- Feeling well
- Breathing is easy
- Weight is the same
- Normal energy level

## Action Plan: **Caution**

- Call your provider to find out how to prevent symptoms from becoming severe.

Providers Instructions:

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## Action Plan:

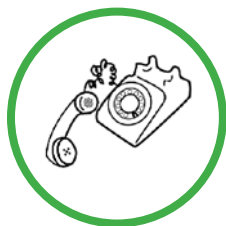
### **Danger Medical Alert**

- **You need to be seen by your provider right away.**
- **Call your provider right away.**

Provider Number:

( \_\_\_\_\_ ) \_\_\_\_\_ - \_\_\_\_\_

**Emergency number: 911**



# When should I call?

## Call your provider if:



- You find it very hard to breathe with any activity or at rest.



- You can't lie down or have to sleep upright or in a chair.



- You have a severe increase in swelling in your legs or bloating in your belly.



- You have a lot of dizziness or light-headedness that is worse than usual.



- Your weight goes up by 2-3 pounds overnight or 5 or more pounds in a week.

**Call your provider:** \_\_\_\_\_

Identify yourself as a Heart Failure Patient.

Ask for an immediate appointment.



## **Go to the Emergency Room or call 911 if you:**

- Feel that you can't breathe or have trouble breathing at rest and it does not get better no matter what you do.
- Start to turn blue.
- Cough up frothy or pink saliva.
- Have chest discomfort that does not go away with nitroglycerin or lasts more than 20 minutes.
- Have a fast or uneven heartbeat that will not go away or makes you feel dizzy or lightheaded.
- Faint.
- Have sudden confusion, trouble speaking, or understanding.
- Have sudden numbness or weakness of the face, arm, or leg especially on one side of the body.
- Have sudden trouble seeing in one or both eyes.
- Have sudden trouble walking.
- Have sudden severe headache with no known cause.

**Note: these are the more common reasons for heart failure patients to call 911 or to come to the emergency room. HOWEVER, they are not the only reasons to do so.**



# You can do it

Here is a place to write down ideas or questions you have about your daily check-up.

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**Remember, your daily check-up helps you know how your heart failure is doing.**



## Chapter 3

# Heart Failure Medicines: Things You Need to Know





# How to take your medicines

Heart failure can be controlled with medicine. Taking your medicine right will help your heart pump better and can make you feel better and live longer.

## Take your pills



- Take your medicines on the right days and times.
- Do not skip doses of your medicines, even when you feel good.
- If you think you are having side effects from your medicines, don't stop taking them, talk to your provider immediately.
- If you are having trouble paying for your medicine, talk to your provider.



# How to take your medicines

## Don't run out of pills

- Make sure you always have enough medicine left in your pill bottles. Don't let your medicine bottles run out.
- Be aware of how many refills you have left.
- Every time you pick up your medicines, check the number of refills you have left. If the label says **No Refills** or **Refills: 0** then call your pharmacy or provider right away to get more refills.
- Get all of your pills from the same pharmacy every time.
- Take only medications that are prescribed.





# How to take your medicines

## Have a system

Have a system that helps you remember how and when to take your medicines.

- Keep a list of your medicines with instructions for how many pills to take, when to take them, and what they are for. Keep the list updated and current.
- Keep your medicine bottles in a place that makes it easy to remember to take them. Keeping your medicines next to your toothbrush, at your bedside, or in the kitchen are good ideas.
- One of the best ways to keep your medication straight and organized is to use a pill box to organize your pills for each day of the week.
- If you are going out of the house for a long time, bring enough medicine with you.







# How to take your medicines

## Bring your pills when you go to your provider

- Bring all of your pill bottles (not your pill box) and medicine list to each visit with your provider.
- Show your provider how and when you take your pills. This will help you and your provider keep you safe, and make sure you don't run out of pills.
- Save at least one bottle of each medicine.





# How to take your medicines

Make sure you know which pills are your heart failure medicines — ask your provider or pharmacist.

## Beta Blockers

- This medicine can help you **Live Longer**.
- This is a very important heart pill that protects your heart from damage.
- The dose may change, make sure you are taking the right amount.
- Don't stop taking this medicine without talking to your provider first.
- You should only be on **one** of these medicines.

## Examples of Beta-Blockers

Generic Name	Brand Name
Metoprolol succinate	Toprol XL®
Carvedilol	Coreg®
Bisoprolol	Zebeta®

**My Beta Blocker:** \_\_\_\_\_



# How to take your medicines

## ACE-Inhibitor, ARNi or ARB

- This medicine can help you **Live Longer**.
- It relaxes the blood vessels and makes it easier for the heart to pump blood.
- This medicine can help prevent or reverse changes in the shape of the heart that can happen because of heart failure.
- The dose may change. Make sure you are taking the right amount.
- You should only be on one of these medicines.

### Examples of ACE-Inhibitors

Generic Name	Brand Name
Lisinopril	Zestril®, Prinivil®
Enalapril	Vasotec®
Captopril	Capoten®
Ramipril	Altace®
Benazepril	Lotensin®

### Examples of ARBs

Generic Name	Brand Name
Losartan	Cozzar®
Valsartan	Diovan®
Irbesartan	Avapro®
Candesartan	Atacand®
Olmesartan	Benicar®

### Examples of ARNi

Generic Name	Brand Name
Sacubitril/ Valsartan	Entresto®

**My ACE-Inhibitor, ARNi, or ARB:** \_\_\_\_\_



# How to take your medicines

## Diuretic or “Water Pill”

- Diuretics reduce heart failure symptoms and can make you feel better.
- Your water pill (or diuretic) controls how much salt and water you have in your body. Taking more of this pill will make you “pee” (urinate) more to get rid of salt and water.
- The dose may change to keep you in balance; make sure you are taking the right amount.
- Taking your diuretic in the morning can help prevent you from getting up at night to use the bathroom. If you take it twice a day, take it in the morning and early afternoon unless your provider instructs you differently.
- Talk with your pharmacist, provider, or nurse if frequent urination becomes a problem for you.
- You should only be on one of these medicines.
- It is important to have regular blood tests to check your potassium level as this medication can cause your potassium level to be low.

## Examples of Diuretics

Generic Name	Brand Name
Furosemide	Lasix®
Bumetanide	Bumex®
Torsemide	Demadex®

**My Water Pill (Diuretic):** \_\_\_\_\_



# How to take your medicines

## Other Heart Failure Medicines

You may or may not be on one of these medicines. They are not appropriate for some patients. Your provider will decide what is best for you.

### Aldosterone Blockers

- These can help the body get rid of extra salt and fluid.
- It is important to have **regular blood tests** to check your potassium level as this medication can cause your potassium level to be high.

#### Examples of Aldosterone Blockers

Generic Name	Brand Name
Spironolactone	Aldactone®
Eplerenone	Inspira®

### Nitrates with hydralazine

- These work together to relax blood vessels to help the heart.
- These are sometimes used in people who cannot take an ACE inhibitor or ARB.

#### Examples of Nitrates with hydralazine

Generic Name	Brand Name
Isosorbide mononitrate	Imdur®
Isosorbide dinitrate	Isordil®
Hydralazine	Apresoline®



## You can do it

Here is a place to write down ideas to help you take your medicines.

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**Remember, taking your medicine correctly will help your heart pump better, and can make you feel better and live longer.**





## Chapter 4

# Heart Failure and Nutrition: What You Need to Know





## How to eat less salt

- Salt is also called “sodium” and is found in many foods.
- Most foods you eat have salt even if you can’t see it or taste it.
- Salt acts like a sponge and makes the body hold fluid.
- Eating too much salt can cause your weight to go up, swelling in your legs, and fluid in your lungs.

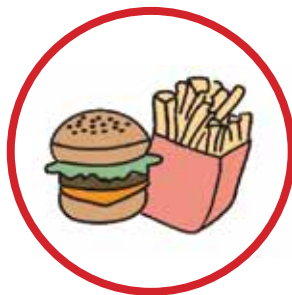
**Eating less salt will help you feel better.  
You can eat less salt if you:**

- Choose foods that are low in salt.
- Don’t add salt when you cook.
- Take the salt shaker off of the table.



# How to eat less salt

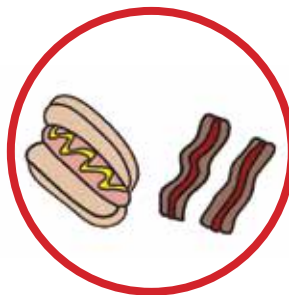
**Avoid or limit these high salt foods:**



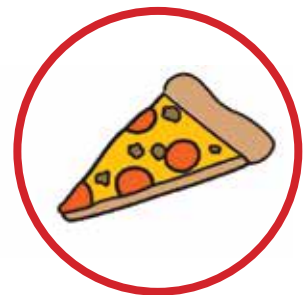
fast food



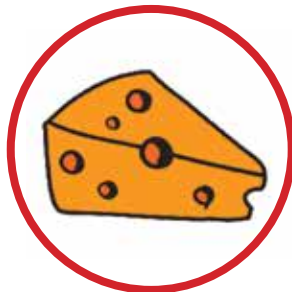
frozen meals



hot dogs, bacon,  
smoked meat



pizza



most cheeses



canned beans  
and vegetables



flavored instant  
hot cereals



canned or  
potted meat



sauces and  
salad dressings



snack foods



smoked or  
canned fish



canned soup

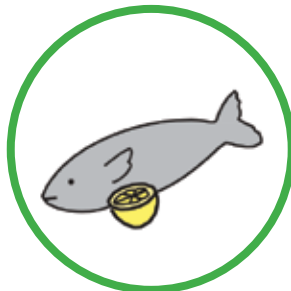


# How to eat less salt

**Choose these low salt foods:**



fruit



fresh fish



fresh meats



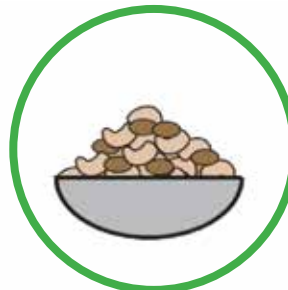
yogurt



frozen vegetables  
without sauce



lemon slice, olive oil, and  
vinegar



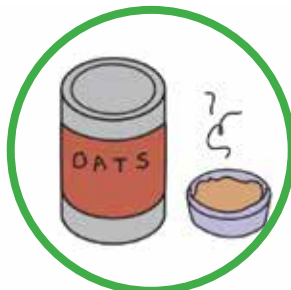
dried beans



fresh vegetables



unsalted margarine



whole oats



graham crackers



eggs



## More tips on how to eat less salt

### When you eat out:

- Ask for food cooked with no salt.
- Avoid butter, cheese, and sauces.
- Avoid fried foods — choose grilled, baked, or steamed foods.
- Choose oil and vinegar salad dressing.
- Limit or choose fast food items with less sodium.
- If you are going to eat salad dressing, sauces, or condiments, ask for them on the side.
- Avoid bacon, sausage, and ham.



## More tips on how to eat less salt

### When you eat at home:

- Don't add salt to food when you cook or eat.
- Season foods with herbs and seasonings that do not have salt.
- Make your own or choose low sodium sauces, salad dressings, breads, and desserts.
- Avoid instant foods that come in a bag or box.
- Rinse canned foods (even canned fish) before cooking and eating them.

**Read food labels and choose foods that have less than 300mg of sodium per serving.**





# How to eat less salt

## Reading a food label:

### Step 1:

Look at the serving size



### Step 2:

Look at the sodium per serving



### Step 3:

Choose foods with less than 300mg sodium per serving

<b>Nutrition Facts</b>	
12 servings per container	
<b>Serving size 1 egg (50g)</b>	
<b>Amount per serving</b>	
<b>Calories</b>	<b>70</b>
<b>% Daily Value*</b>	
<b>Total Fat</b> 5g	<b>6%</b>
Saturated Fat 1.5g	<b>8%</b>
Trans Fat 0g	
<b>Cholesterol</b> 185mg	<b>62%</b>
<b>Sodium</b> 70mg	<b>3%</b>
<b>Total Carbohydrate</b> 0g	<b>0%</b>
Dietary Fiber 0g	
Total Sugars 0g	
Includes 0g Added Sugars	<b>0%</b>
<b>Protein</b> 6g	<b>12%</b>
Vitamin D 1mcg	6%
Calcium 28mg	2%
Iron 1mg	6%
Potassium 69mg	2%
<small>*The % Daily Value tells you how much a nutrient in a serving of food contributes to a daily diet. 2,000 calories a day is used for general nutrition advice.</small>	

- This food has 70mg of sodium in one serving.
- This food is a good choice!



# How to eat less salt

## Reading a food label:

Choose items labeled:

Low Sodium

NO SALT ADDED

Sodium Free

Watch out for items labeled:

LOWER SODIUM



- This food has 440mg of sodium in one serving.
- This food is **not** a good choice!

Nutrition Facts	
Serving Size 4 oz (5g)	
Servings Per Container 4	
Amount Per Serving	
<b>Calories</b> 90	Calories from Fat 30
% Daily Values*	
<b>Total Fat</b> 3g	<b>5%</b>
Saturated Fat 0g	<b>0%</b>
Trans Fat 0g	
<b>Sodium</b> 440mg	<b>18%</b>
<b>Total Carbohydrate</b> 13g	<b>4%</b>
Dietary Fiber 3g	<b>12%</b>
Sugars 3g	
<b>Protein</b> 3g	<b>6%</b>
*Percent Daily Values are based on a 2,000 calorie diet.	



## You can do it

**Choose or write down 1 or 2 things you will do for the next few weeks.**

- ☐ I will use a salt-free seasoning for cooking and at meals.
- ☐ I will rinse canned foods before cooking and eating them.
- ☐ When I eat out, I will ask for my meal with no added salt.
- ☐ I will remove one high salt item from my diet this week.
- ☐ I will make low sodium sauces and salad dressings.
- ☐ I will avoid eating at fast food restaurants.
- ☐ I will choose fruit or fresh vegetables for snacks.
- ☐ I will \_\_\_\_\_.

**Remember, small changes in your eating can make a big difference in salt intake. You will find that your taste adjusts over time and you get used to eating less salt.**

# How to Measure 2 Liter or 2 Quart Fluid Restriction

Start by obtaining a 2L or 2Qt soda/juice bottle



- Fill with water first thing in the morning and keep by the sink. (Do NOT drink this water - it is a measuring tool)
- For every beverage you complete drinking, use the same vessel (cup, mug, glass, etc.) and fill it with water from your 2L or 2Qt measuring bottle.
- Dump that amount down the sink.
- Repeat this with any beverage you have through the course of the day.
- Use the 2L/2Qt bottle as an indicator of how much you already drank and how much you have to go.

**REMEMBER: Anything that is liquid at room temperature contributes to the fluid intake, including yogurt, ice cream, pudding, jello, popsicles, and fruit pops.**



## Chapter 5

# Heart Failure and Exercise:

**You can do it!**



# Exercising well with heart failure

## What's in it for you?

- Being more active is one of the best things you can do for your heart failure.
- Moving more can help you have more energy and feel more upbeat.

## Start now!

If you are not exercising, start with 10 minutes a day. It can be as simple as walking five minutes from your door and turning around and walking back.

## Be safe.

- Start slowly.
- Stop if you feel chest pain, dizziness, or have severe shortness of breath.
- Work with your provider to set realistic goals.



# Exercising well with heart failure

## You can exercise by:

- Using a stationary bicycle.
- Walking in your neighborhood or at the mall.
- Going to an exercise class.
- Sweeping, vacuuming, or dusting.
- Mowing the lawn or working in your garden.
- Walking to the bus.

A lot of people say that walking is the easiest exercise for them. Many people walk with a friend or their pet. Walking is easy, fun, and free.

**Put down the electronics. Get up, and get moving!**



# Exercising will get easier

**Your body needs time to get used to being more active.**

You will notice that it will get easier and you will be able to do more.

## **Steps for doing more:**

- Begin by doing an activity for 10 minutes, three times per week.
- After a couple of weeks, add five minutes, so that you are exercising 15 minutes at a time.
- When you feel comfortable doing more, add another five minutes.
- You want to work up to 30 minutes of exercise three times a week.





# Exercising will get easier

- Exercise with a friend or partner if possible.
- Wear clothes and shoes that fit well.
- Start slowly. Ease your way into exercise.

“I enjoy walking after  
dinner with my husband.”

“I found an exercise class at the senior  
center that works well for me.”



## You can do it

**Pick things YOU like to do. Try one of these suggestions or write down one or two things you enjoy that make your body move.**

- ☐ I will take a short walk every day.
- ☐ I will take a walk for 10 minutes three days a week.
- ☐ I will dance for 10 minutes at home three days a week.
- ☐ I will ride a stationary bike for 10 minutes three days a week.
- ☐ I will stretch for 10 minutes when I wake up three days a week.
- ☐ I will do a water exercise for 10 minutes three days a week.
- ☐ I will \_\_\_\_\_



## Chapter 6

# More Information and Resources



American  
Heart  
Association®

**American Heart Association**



**American College of Cardiology**



HEART FAILURE SOCIETY OF AMERICA

**Heart Failure Society of America**



Northern Light  
Health.

**Northern Light Health**

# What else will help me live well with heart failure?

## Keep your visits with your provider

Be sure to keep all your appointments, and partner with your provider to plan your care.

- By learning more about heart failure, you and your care team can better manage your care.
- When you see your provider, bring a list of your medications and your weight records.
- Keep your visits with your provider, even when you are feeling well.

## Get a flu shot

- Get a flu shot every year and pneumonia shots as directed by your provider.
- When you have heart failure, the flu can be deadly.
- A flu shot will help you to not get the flu.

## Take control of your healthcare choices

- Talk to your family and your provider about medical treatments that you might want or might not want if you become very ill.
- Advance Directives and Living Wills are ways to let your family and your provider know what you want.

## Heart health resources:

**American Heart Association** .....[www.aha.org](http://www.aha.org)  
**American College of Cardiology** .....[www.acc.org](http://www.acc.org)  
**Heart Failure Society of America** .....[www.hfsa.org](http://www.hfsa.org)  
**Northern Light Health** ..... [www.northernlighthealth.org](http://www.northernlighthealth.org)

# What about Tobacco and Alcohol?

**Quitting TODAY is the most important thing you can do for your heart.**

**Avoid using all tobacco or vaping products.**

- Smoking, secondhand smoke and other tobacco products make your heart and lungs work harder.
- If you smoke, talk to your provider or nurse about getting help to quit.

**You can get help to quit from the Maine Tobacco Helpline, 1-800-207-1230.**

**Avoid drinking alcohol.**

- Drinking alcohol can weaken your heart.

# Telehealth



Telehealth equipment - Photo courtesy of Honeywell.

Your Care Team may recommend Telehealth monitoring after discharge.

This service is free of charge.

A Northern Light Home Care technician will come to your home to set up the equipment and show you how to use it. The monitor checks your blood pressure, heart rate, weight and oxygen status. The results are sent to the Home Care office within a matter of minutes. It takes less than 5 minutes to complete the vital signs test. A nurse at the office monitors the results and contacts you and your provider as needed.

# Palliative Care

The Palliative Care Team is a multi-disciplinary team of providers who work in partnership with your own provider to give you an extra layer of support when you have been diagnosed with a serious illness. Palliative Care can be provided along with aggressive treatments.

## **The goal of palliative care is to:**

- Help you better understand your condition and choices for care.
- Help you set Goals of Care that are important to you and your family.
- Manage and control distressing symptoms of your illness.
- Address psychological and spiritual wellness in addition to physical distress.
- Assist with Advance Directives.
- Improve your quality of life.

Talk to your provider about a referral for palliative care at your next appointment.

## **Goals of Care**

Goals of Care refers to joint discussions between you and your providers to understand the treatment options for your illness. This includes the potential benefits as well as the risks and burdens of different treatment options. Goals of Care discussions can be held with your Primary Care Provider and/or your Specialist.

When you aren't sure of the right way to proceed with treatment, ask your provider to discuss YOUR Goals of Care.

# Advance Directive

An Advance Directive tells your provider and others what medical care you want to receive if you ever become too sick to tell them what you want. It also gives you the ability to appoint an Agent, someone to make medical decisions for you if you are not able to communicate for yourself.

If you have not already done so, please talk to your provider and family about completing your Advance Directive.

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## Northern Light Health

Acadia Hospital  
AR Gould Hospital  
Blue Hill Hospital  
CA Dean Hospital  
Eastern Maine Medical Center  
Northern Light Healthy Life EAP  
Home Care & Hospice  
Maine Coast Hospital

Mayo Hospital  
Mercy Hospital  
Sebasticook Valley Hospital  
Northern Light Health Foundation  
Northern Light Medical Transport &  
Emergency Care  
Northern Light Pharmacy  
Northern Light Work Health