

# A Caregiver's Guide: Congestive Heart Failure



This is a guide for family members, friends and other caregivers who are supporting someone who has congestive heart failure (CHF).

*This is a guide for family members, friends and other caregivers who are supporting someone who has congestive heart failure (CHF).*

## **Contents**

<b>What is congestive heart failure?</b> .....	1
<b>Heart failure over time</b> .....	2
<b>Focusing on comfort</b>	
Anxiety .....	2
Confusion .....	2
Emotional health.....	3
Difficulty breathing and cough .....	3
Edema .....	4
Feeling tired and weak .....	4
Abdominal discomfort .....	5
Difficulty sleeping .....	5
Pain .....	5
Skin care .....	6
<b>Implanted devices in the heart</b> .....	6
<b>Heart failure emergencies</b> .....	7

REV 9/17

## What is Congestive Heart Failure?

In congestive heart failure, the heart cannot supply the body with adequate blood, because the heart's pumping power has been weakened due to damaged muscle. This could be caused by heart disease, heart attack, enlarged heart, high blood pressure, valve disease, thyroid disease, kidney disease, diabetes, and certain birth defects in the heart. Often, people with heart failure have to be admitted to the hospital or see a doctor for frequent medication changes.

When someone has heart failure:

- Their blood moves through the heart and body at a slower rate and pressure in the heart increases.
- The heart begins to struggle to pump blood, causing oxygen and nutrient delivery to be impaired.
- Their heart may start stretching to hold more blood to pump through the body, or it may become stiff. This helps keep blood flowing, but also weakens the heart and makes it less efficient.
- They might also have salt and water retention, which can cause fluid buildup in the body or lungs.

**Heart failure can be in the left side of the heart, the right side, or both.** The chart below shows signs or symptoms someone may experience, depending on where their heart failure is.

Signs of Left-sided Heart Failure	Signs of Right-sided Heart Failure
Fluid buildup in lungs	Fluid buildup in the body
Difficulty breathing, fast breathing	Low blood flow through kidneys, causing less urination and fluid buildup
Difficulty breathing while lying down	Swelling in the body, weight gain
Dry, hacking or bloody cough	Needing to urinate more often at night, or less urination
Loud breathing sounds (wheezes)	Nausea (related to bloating in stomach)
Fast or irregular heart rate	Decreased appetite (due to bloating in stomach)
Anxiety, restlessness, confusion	Weakness, low energy
Low energy, tired	Fluid buildup in abdomen
Bluish skin (related to low blood oxygen levels), pale skin	Enlarged/swollen neck veins, enlarged liver and spleen

## What is it like to have heart failure?

During their illness, people with congestive heart failure (CHF) may have had multiple tests or procedures, such as X-rays, EKGs and stress tests. Some will have had surgery, valve repairs or replacements, pacemaker or defibrillator placement, or a heart transplant.

## Heart Failure Over Time

Congestive heart failure can be somewhat stable at first, and may only require routine check-ups with a doctor. In the next stages, people might need more support and hospitalizations. There can be ups and downs, with a general worsening of the disease and symptoms over time. The last stage of decline can last from days to weeks. **Even so, death can be unexpected due to earlier patterns of the person getting worse, then better. People often believe they can “get through” one more time as they have done before.**

It is very hard to predict how someone with heart failure will decline over time. Thirty-five to 45 percent of people with heart failure experience sudden death.

Medical management of heart failure can include:

- treating and monitoring fluid build-up based on weight (gaining weight might be a sign of fluid build-up), and
- using medications and treatments to manage symptoms of the CHF. One commonly used medication is a diuretic, which rids the body of extra fluid.

## Focusing on Comfort

People with heart failure may have a number of uncomfortable issues. Here are some ways to help bring relief to a person who is suffering from heart failure.

### Anxiety

Thirty percent of people with congestive heart failure experience some form of anxiety.

- If you sense a problem and the person is able to respond, ask if they are feeling anxious or restless.
- Ask what is making them feel anxious; treating the cause or symptom can help.
- Ask what has helped when they have felt anxious in the past.
- Offer support and reassurance.

### Suggestions for care:

- Try distraction or guided imagery.
- Guide them through simple breathing techniques, such as pursed-lips breathing: Tell the person to breathe deeply through their nose (“smell the flowers”) and exhale through pursed lips (“blow out the candle”).
- Use medications for anxiety that have been ordered by their doctor.

### Confusion

There are many possible causes of confusion in people with heart failure. They might have low oxygen levels, symptoms may be getting worse, or they could be reacting to new or changed medications.

**Suggestions for care:**

- Use basic reminders to re-orient them: “You are at home and today is Wednesday.”
- Keep their room well-lit, with familiar objects, a visible clock and calendar.
- Try to limit noise.
- The presence of familiar faces and voices can calm them.
- Ask PalliaHealth or their primary care doctor about other ideas or support.

**Remember:**

- If someone with heart failure has unexpected changes and you are concerned about their safety, call their doctor.
- Sometimes we can find the cause of the confusion and work to treat it; however, the symptoms could be caused by worsening disease, which makes it more difficult to treat.

**Emotional Health: Depression, anger, guilt, and thoughts of suicide**

Depression is common in people with heart failure (up to 59 percent). In addition to depression, they can experience despair, anger, regret, guilt and thoughts of suicide.

People with heart failure often come to a point where they have found a way to live with the ups and downs of the disease. They may believe that there is always something more that can be done; the ups and downs can make them think that they will recover again each time symptoms get worse. And as with other illnesses, there can be disheartening financial worries as medical costs build.

**Suggestions for Care:**

- Encourage the person to talk through their feelings. Sharing their experience with others can be helpful.
- Consider talking with their doctor about medications for depression.

**Difficulty Breathing and Cough**

One study suggests that 61 percent of people with heart failure have shortness of breath. When the left side of the heart doesn't pump the way it should, fluid collects in the lungs they can't expand to let enough air in. Breathing gets harder, and the person may feel short of breath, especially when they are moving around or lying down flat.

**Suggestions for care:**

- Be calm and reassuring.
- Consider using oxygen.
- Try breathing techniques, such as pursed-lips breathing: Tell the person to breathe deeply through their nose (“smell the flowers”) and exhale through pursed lips (“blow out the candle”).
- Keep the room cool. Warm air can “feel” heavier.
- Cool air from a fan directed at the face can make people feel like they are breathing easier.
- Help them find ways to conserve their energy. Is getting up to the bathroom exhausting? Consider putting a commode beside of the bed. Talk to their doctor about other ways to conserve energy.

- Reclining can make breathing harder for people with heart failure. Lift the head of the bed or prop them on pillows.
- If sitting, have them lean forward with their elbows on a table.
- Talk with their doctor about medications. Are they working the way they should? Do they need to be changed or increased?
- If the person has a cough, cough medicine can be helpful.
- Morphine can make them feel like they don't have to work as hard to catch their breath.
- Giving their breathing medications *before* they move can help them better tolerate activity.
- If the person is having difficulty breathing that continues to get worse, call their doctor.
- Talk to their doctor about diuretics—medications that can help the body get rid of extra fluid.
- Ask their doctor about other options for fluid removal that could help reduce swelling in the person's abdomen.
- If fluid appears to be “leaking” from the areas of their body that are swollen, use absorbent towels to catch the fluid. Change the towels as necessary to keep their bed dry.
- Be careful to prevent falls: People who have a lot of swelling are more likely to fall, as movement becomes awkward.
- Elevate the legs if swelling is uncomfortable. When legs are elevated (if they are lying down or in a recliner), they might need to urinate more often.

### Edema (Fluid Build-up)

When the right side of the heart isn't working well, fluid can collect in the feet and lower legs. Puffy legs are a sign of right-side heart failure, especially if you can press on the area and a dent or “pit” remains. As right-sided heart failure gets worse, the upper legs, genital area and abdomen can begin to collect fluid. The person might also gain weight from the fluid that accumulates.

#### Suggestions for care:

- Limit the amount of fluid or salty food the person drinks and eats. If they take in extra fluid or salty foods (foods with high sodium), their swelling could get worse and they could become uncomfortable.

### Feeling Tired and Weak

Feeling tired or weak has a big effect on the lives of people with heart failure. This can be caused by things like infection, dehydration and depression. If we cannot completely treat the cause, caregivers can offer support in other ways.

#### Suggestions for care:

- Encourage them to avoid “overdoing it” and help them find ways to conserve energy.
- Help them set limits: Find out what times of the day they have the most energy, and plan activities during that time.
- Discuss their goals. If getting clean and dressed drains their energy and prevents them from doing things that are important to them, consider finding help in those areas.

- Work with PalliaHealth to find ways that volunteers or nursing assistants could help the person conserve energy.

## Abdominal Discomfort

Some people with CHF feel sick to their stomach because they have abdominal swelling, an enlarged liver or slow-moving bowels. Others find that they have less appetite, or that food doesn't taste the way it did before. They may want to eat less. It is important to look for ways to manage and treat these issues if we can.

### Suggestions for care:

- Offer small, frequent meals.
- Encourage the person to eat slowly.
- Suggest that they sit up at least an hour after eating.
- Talk with their doctor about medications that can help with slow bowels, since that can lead to constipation and nausea. If the person is using morphine or other narcotic, be sure they use a stool softener and/ or laxative to prevent constipation.

## Difficulty Sleeping

According to one study, 45 percent of people with heart failure have difficulty sleeping. Trouble with breathing, stress, worry, getting up to use the bathroom and fear of dying during sleep can all cause sleep problems.

### Suggestions:

- Elevating the head of the bed can help.
- Try using a fan or oxygen to make breathing easier.

- Consider placing a commode or hand-held urinal next to the bed so they don't have to walk to the bathroom in the night.
- Talk to their doctor about the timing of medications that have an effect on sleep. Medicines that make them sleepy could be taken later in the day. If diuretics are taken before bed, the person might be getting up to use the bathroom more often at night.

## Pain

Studies show that up to 78 percent of people with heart failure have pain at some time or another. Some have pain in their chest. Others might feel stretching pain from their enlarged liver. There could also be pain that they have had all their lives, such as back pain or arthritis, which could get worse when combined with other heart failure symptoms. Whatever the cause, it is important to find ways to manage and treat any pain the person is feeling.

### Suggestions for care:

- Work with the person to keep them comfortable on their own terms. Is it OK with them if they feel a little sleepy after taking pain medication?
- As you are caring for the person, watch for signs of pain. Does their forehead wrinkle when they move? Are they holding their chest or abdomen? These signs can help their care team figure out what is bothering them.
- If the pain is due to swelling, diuretics can help get rid of extra fluid.
- Narcotics like morphine or oxycodone can help with both pain and shortness of breath.

REV 9/17

## Skin

Swelling, along with moving less and eating less, can put people with CHF at risk for skin injury. Areas that are most likely to break down due to pressure or friction are the legs, heels, elbows and bottom. Wounds and injuries can lead to pain or infections; this can happen quickly.

### Suggestions for care:

- Wash the skin with warm water and mild soap.
- Avoid friction or rubbing.
- Clean the skin after each soiling.
- Use alcohol-free lotions to moisturize dry skin.
- Do not massage reddened areas.
- Apply moisture barrier creams or ointments to fragile skin that comes in contact with moisture.
- Raise heels off of the bed by placing pillows under calves and knees for support.
- Change position at least every two hours while in bed and every one hour if sitting up in a chair.
- Keep the angle of the head of the bed at less than 30 degrees except when they are eating or drinking.
- Remove restrictive clothing, such as TED stockings, to allow the skin to breathe.
- Use pillows between the ankles and knees, behind the back, under elbows, and under calves to float heels. Pillows protect these bony parts of the body from extended periods of pressure.

Use towels or gauze to keep the skin clean and dry if you notice any leaking fluid. Contact their doctor for advice.

## Implanted Devices in the Heart

### Implantable cardioverter defibrillator (ICD):

This small device is placed in the chest or abdomen and is used to help treat irregular heartbeats or rhythms. An ICD uses electrical pulses or shocks to help control life-threatening arrhythmias, especially those that can cause sudden cardiac arrests.

**Ventricular assist device (VAD):** This mechanical pump is used to support heart function and blood flow in people who have weakened hearts. The VAD takes blood from a lower chamber of the heart and helps pump it to the body.

**Pacemaker:** A pacemaker is a small device placed in the chest or abdomen to help control abnormal heart rhythms. It uses electrical pulses to “tell” the heart to beat at a normal rate. Worldwide, about 3 million people have pacemakers.

### Can it be turned off?

All of these devices can be turned off. Such decisions should be discussed with the person’s doctor, family and care team, so they can understand any issues related to end-of-life. For example, if someone has a pacemaker and becomes ill with a condition that isn’t related to how the heart works, it’s possible the pacemaker could make the dying process longer.

### Should it be turned off?

**ICD:** Many people have their ICD turned off when their goal changes from living longer (aggressive treatment) to getting the most comfort possible at end of life (allowing for a natural death).



**VAD:** The decision to deactivate a VAD is similar to the decision to withdraw a ventilator. See the “How is it turned off?” section below for more information.

**Pacemakers:** Usually, pacemakers do not need to be turned off in end-of-life situations unless the person or family requests it, which usually happens if they feel the device is making the dying process longer.

If a person’s heart is dependent on the pacemaker, then death may occur within days of deactivation. In most situations, deactivation is not recommended since it could lead to a very low heart rate (which can cause tiredness, dizziness and difficulty breathing). It would be rare to turn off a pacemaker and have someone experience a quick death, as few people rely on their pacemaker 100 percent, especially during the dying process.

### How is it turned off?

**ICD:** Turning off an ICD is not difficult. Usually the vendor will re-program a computer to reset the device. This will not cause death. It will not make the person feel worse. If the person was to have a life-threatening heart rhythm after it is turned off, it will not deliver a shock.

**VAD:** A VAD is turned off in a similar way to an ICD; however, VADs also have an external power source and controlling unit, which makes turning it off similar to removing a ventilator. There should be a plan in place to manage any breathing difficulties, agitation or discomfort that could occur after the device is turned off. The person and their family should be prepared for death to occur in a range from a few minutes to a few days.

**Pacemaker:** Some pacemakers can be deactivated with a large magnet. However, newer pacemakers cannot be turned off without a cardiologist.

## Heart Failure Emergencies

With heart failure, there is a possibility of life-threatening emergencies, like the symptoms described below. PalliaHealth will work with you to help prepare you for things that might happen. If you ever have a concern about a symptom of CHF that is getting worse, **call your doctor.**

### Flash Pulmonary Edema

Flash pulmonary edema, or a sudden, excessive buildup of fluid in the lungs, can lead to the person feeling like they can’t breathe. They may cough up pink, bubbly spit and become sweaty or “clammy.” They might also feel confused or have pain in their chest. This can be distressing for both the person and caregivers.

Work with your doctor and PalliaHealth to talk about ways to prepare for the possibility of this heart failure emergency.

### Difficulty breathing

- Using oxygen can help the person breathe more easily.
- Try position changes and breath coaching (see Difficulty Breathing on page 3 for reminders).
- Narcotic medications can work to quickly ease the work of breathing.