## **QUALITY OF LI** FATIGUE BREATHLESS WEIGHT PATIENT HEART **SWELLING** HOSPITAI

# TAKE CONTROL

## Questions to ask your doctor and nurse

Developed by the Heart Failure Association of the European Society of Cardiology





Once you have been diagnosed with heart failure, **your doctor and nurse will explain what heart failure is** and talk with you about the different options to help manage your condition. Heart failure is a serious condition. However, **by following your doctor's advice and making simple lifestyle changes, you can feel better and do more.** Your doctor will also discuss which treatments are most suitable for you. You need to remember that it's important for you to understand the different types of treatment. This way you will know what they are, how they will work to help your heart failure and what side effects they might have.

## Living with heart failure

As part of your treatment plan, you may have to make changes to your lifestyle. You can read about these in the section on adapting your lifestyle. However, you should also discuss this with your health care team as they may have specific recommendations for the changes you may need to make.

#### What lifestyle changes should I make now that I have been diagnosed with heart failure?

Your doctor will be able to recommend changes that you can make to your lifestyle. He/she will also be able to refer you to a dietitian who will work with you to **make changes to your diet**, and a physiotherapist may work with you to suggest **suitable physical activity or participation in a training or activity program.** 

#### How often will I need to return to the clinic for check-ups?

This will **depend on the treatment plan your doctor recommends for you**. He/she may also refer you to a specialist nurse, dietitian, physical therapist, support group etc, for regular appointments.

#### How much fluid should I be drinking each day?

It's important to be sensible about the amount of fluid you drink to **minimize water and salt retention that often occurs with heart failure**. Your dietitian or nurse may recommend how much fluid and salt you should consume and your doctor may want to discuss your diuretic treatment and explain how you can adjust your treatment if your symptoms get worse. **Remember, fluid you consume comes in different forms including many foods we eat like soup and stews.** 

#### What sort of exercise should I do and how much should I be doing?

**Remaining as active as possible** is an important part of your lifestyle management; **however, you should make sure you are not doing too much too quickly and take your time**. You should try to avoid becoming very short of breath during any activity. Your doctor will be able to advise you on which activities are good to start with and which to avoid. He/she may also be able to put you in contact with a local cardiac rehabilitation center with regards to low-intensity training programs you could participate in.

#### Is there a blood pressure monitor that you would recommend?

There are several blood pressure monitors available, but not all of them have been tested for accuracy. **Your doctor or pharmacist will be able to give you advice** on which monitors have been proven to be accurate and help to check you are using the monitor correctly.

#### What should my blood pressure and heart rate be?

If you are monitoring your blood pressure and heart rate regularly, it's important to know what your normal measurements should be. Heart failure medicines will usually serve to lower blood pressure and reduce heart rate. You will then be able to keep a record of your values and tell your doctor if you notice any major changes.

#### Can I still fly?

Air travel isn't usually a problem for people with heart failure. However, your symptoms should be stable before you travel. If you have a device, you should mention it at security controls because it may be detected by the security alarms. Security controls should not interfere in any way with the functioning of your device.

#### When should I have my next flu/pneumonia vaccination?

Your doctor will be able to advise you on whether you require a flu and/or pneumonia vaccination, and how frequently.

#### What should I do if I think my heart failure is getting worse and I have increasing symptoms?

This is an **important question to discuss with your doctor.** Please see the Warning Signs section of the leaflet "Monitor your heart failure" or directly on Heartfailurematters.org. If, for example, you feel that your **breathing is getting gradually worse** or you notice **progressive weight gain**, then you should contact your doctor or nurse and ask for an appointment as soon as possible. **If symptoms worsen quickly and are accompanied by shortness of breath at rest, rapid heart rate, or chest pain** then you need urgent attention and should contact the emergency services immediately.

## Don't forget to do your part

Monitor your blood pressure & heart rate frequently.

#### HOW DO I MEASURE MY BLOOD PRESSURE AT HOME?

Use a modern blood pressure monitor and a cuff of the appropriate size (see the instruction manual with your monitor, or ask your doctor or nurse).

- Sit down and rest for 3 to 5 minutes before measurement.
- To achieve an accurate measurement, it is better to avoid smoking, eating, or drinking anything except for water at least 30 minutes prior to measurement.
- When you measure your blood pressure, sit in a comfortable chair with your feet flat on the floor, back and arms supported, and your arm at heart level. Don't talk.
- It is better to measure your blood pressure in the nondominant arm (eg, the left arm if you are right-handed).
- Ideally, take 2 measurements 1-2 minutes apart, and record only the second reading, once in the morning and once in the evening.

#### HOW DO I MEASURE MY HEART RATE AT HOME?

Most blood pressure monitors will also measure your heart rate (pulse), or you can measure your heart rate yourself by "taking your pulse."

- Sit quietly for at least 5 minutes.
- Take off your watch and hold your left or right palm facing up, with your elbow slightly bent. With your other hand, gently place your index and middle fingers on the other wrist.
- Press your fingers into the groove between the middle tendons and the outside bone. You should feel a throbbing this is your pulse.
- Count your pulse for 30 seconds and multiply by 2 to get your heart rate.

## **Relationships and emotions**

Many people with heart failure have a lot of questions relating to how they feel after being diagnosed and the impact their condition can have on their life. This section provides information and tips on living with heart failure and coping with your emotions and your relationships, but sometimes you may find it useful to discuss these feelings with a health care professional.

#### Since being diagnosed with heart failure, I have been feeling depressed. What help is available?

Depression and anxiety are **very common** in people who have been recently diagnosed with heart failure. **However**, **if these feelings persist, talking to your doctor may help.** He/she may be able to help you come to terms with your diagnosis and adapt your lifestyle as required and recommend some counseling for you, if necessary. Your medicines may need to be adjusted or changed.

#### Am I still able to have sexual relations?

Just as you should avoid certain very strenuous activities now that you have been diagnosed with heart failure, **you may need to make changes to your sexual activity.** Often **this doesn't mean that you have to stop sexual activity** altogether, but your doctor/nurse will be able to advise you on what level of sexual activity is suitable for you. You may also find that you are not as interested in sex and this may be due to feelings of anxiety or depression caused by your heart failure. Be sure to discuss this with your doctor or nurse. Men may have problems achieving an erection and this may also be due to heart failure medications. Don't be embarrassed to discuss this with your doctor. There is effective medical treatment for this condition.

## **Getting support**

There are many different sources of support available for people with heart failure and their caregivers. Health care professionals often know about various groups and programs available in your community and so you may wish to discuss these with your doctor or nurse.

#### Are there any local support groups that I can contact and attend?

Your doctor will be able to put you in contact with your **local support group**, who will have regular meetings run by specialist nurses and/or other patients. During these meetings, **you will learn more about the day-to-day management of your heart failure** and be able to **share your experiences** with other heart failure patients.

#### Do I have access to a heart failure management program at my hospital?

Many hospitals have a multidisciplinary outpatient heart failure management program organized by nurses and cardiologists in cooperation with other related services such as primary care physicians, physiotherapists, pharmacists, dietitians, geriatricians, and social workers. These programs usually manage people with relatively serious symptoms. **Your doctor or nurse will be able to tell you if such a program is available and appropriate for you.** 

## **Medicines**

For specific information, please refer to the safety instruction leaflet of your medicine.

#### How many tablets should I take and when?

Your doctor, pharmacist, or nurse will help you to create your own personal medicine chart to **keep a track of when** and how often to take your medicines.

#### Can my medicine(s) cause any side effects?

Asking this question will make sure you know what to expect from taking the medicine and allow you to prepare yourself for any unwanted side effects, eg, if dizziness is a side effect of your medication you can prepare by not standing up too quickly and getting out of bed slowly.

#### Who should I contact if I think I am having a bad reaction to my medicine(s)?

**Your doctor will advise** you who to contact if you feel unwell after taking your heart failure medicine. You can then make sure you always have the details on hand and share it with family and friends.

#### What if I miss a tablet?

Your doctor will advise you what to do if you miss one or more doses of your medicine. For most heart failure medicines to work optimally you need to take the correct dose at the correct time. By taking a tablet late, or 2 tablets at the same time, you may be altering or increasing the amount of medicine in your body to a level which might lead to side effects.

#### How often do I need to get a new prescription?

Your doctor will prescribe your medicine for a specific amount of time and will tell you if you need to make another appointment to get a repeat prescription or if you can collect this from your clinic or pharmacy. With most heart failure medicines, **it's important that you take them every day**, therefore it's important to plan ahead to **make sure you don't run out** and always remember holidays or planned travel.

### **Devices**

#### How do I know if I need a device?

Your doctor will evaluate your symptoms and heart function. If your heart beats too slowly, you may need a pacemaker. If you have moderate or serious symptoms of heart failure and evidence of poor, uneven contraction, you may require a cardiac resynchronization therapy (CRT). If you have had episodes with serious rhythm disturbance, you may be considered for an implantable cardioverter-difibrillator (ICD).

#### What are the risks associated with having a device implanted?

Your doctor will be able to tell you the risks involved in having a device implanted. For most patients, the benefits of having a device far outweigh any risks.

#### Will I need a general or local anesthetic in order to have the device inserted?

General anesthetic involves you being put to sleep; but, with local anesthetic, you will be awake but the part of your body being operated on will be made numb. Your doctor will be able to tell you whether you need a local or a general anesthetic so that you can be prepared. You may be asked not to eat or drink anything for up to 6 hours before most procedures, including operations under general anesthetic.

#### Will I need to stay overnight in hospital when I have my device inserted?

**Your doctor will tell you if you need to stay overnight in hospital.** This often depends on whether you will be having a general anesthetic as recovery time will be longer for procedures under general anesthetic than for a local anesthetic. You may need to come in to hospital the night before if your device is being inserted early in the morning.

#### How often will I need to come back to have my device checked?

Your doctor will be able to tell you how often your device needs to be checked. **It's very important to attend these appointments,** so you should make sure you plan ahead and don't book a holiday when your device is due to be checked. Your device will need replacing at some point and your doctor will be able to give you an idea of when you should expect this.

#### Will I be able to travel by plane, drive a car, and perform other normal activities?

Following the insertion of your device, **you should still be able to fly and drive a car** and your doctor will be able to advise you on what you should avoid doing. There may be some restrictions on driving after your device has been inserted and this should be discussed. Your doctor or physiotherapist will recommend a program of gradual physical activity, to make sure that you don't put too much strain on your body too quickly.

#### Will I have to take any extra medicines after the device has been inserted?

You may need to take additional medicines, or you may need to change the medicines you were taking before you received the device. Your doctor will tell you what medicines you need to take, how often, and for how long. You will then be able to add these into your daily routine and add them to a medicine chart to remind you to take them correctly.

## **Surgery and procedures**

#### What are the risks associated with this surgery?

Before you have any surgery, your doctor will discuss the procedure and any associated risks. For most patients, the benefits of surgery far outweigh the risks.

#### Will I have to stay in hospital?

Your doctor will be able to tell you if you need to make arrangements to stay in hospital overnight. You can then plan accordingly.

#### How long will the surgery/procedure take?

You doctor will be able to give you an idea of how long the procedure will take and how long you will be in hospital so you can plan accordingly.

#### Will I feel anything?

Your doctor will inform you whether you will need to have a general or local anesthetic during the procedure. If it's a general anesthetic, you will be put to sleep and you will not be aware of the surgery/procedure taking place. If you are having a local anesthetic, you will be awake during the procedure, but you shouldn't be able to feel the operation as the area being operated on will be numb.

#### Will I have to take any extra medicines following the procedure?

**You may need to take medicines after your surgery** that are different from those you were taking before the procedure. You could take along the questions about the medicines list so that after your procedure you can check how much to take, how often, and if there are any associated side effects.

#### How long before I start to feel better?

Your doctor should be able to give you an idea of how long it will take to recover from your operation. While it may not take too long to recover from the surgery, it may take a while for you to notice the benefits of the surgery on your heart failure symptoms.

#### Will I have to make any lifestyle changes?

After your surgery, you may not be able to go back to your normal diet and physical activity straight away. Your doctor will be able to advise you on what you can do and what you should try to avoid doing.

## Vocabulary to know

#### Your doctor might mention these common terms. Here's what they mean.

**Dyspnea:** The medical name for shortness of breath. In people with heart failure, dyspnea is most often caused when the lungs become congested with excess fluid. Dyspnea is usually the most prominent symptom experienced by a person with heart failure.

**Peripheral edema:** Swelling of the feet, ankles, and legs. Worsening peripheral edema suggests that heart failure may also be worsening and that treatment adjustments may be needed.

**Pulmonary edema:** A condition characterized by severe dyspnea, coughing, and, often, frothing at the mouth, and is a medical emergency. It is caused by excess fluid in the air sacs of the lungs. In people with heart failure, pulmonary edema usually indicates that pressures within the heart are excessively high.

**Congestive heart failure:** The term used when pulmonary congestion is the most prominent symptom of heart failure.

**Dilated cardiomyopathy:** A condition in which the heart muscle becomes weakened, and in response the heart dilates. Dilated cardiomyopathy is the most common cause of heart failure.

**Low-output heart failure:** The inability of the heart to pump sufficient blood out to the tissues, which produces severe weakness and fatigue.

**Diastolic dysfunction:** Refers to relatively "stiff" heart muscle, which makes it difficult for the heart to fill with blood in between heartbeats. Severe diastolic dysfunction can lead to diastolic heart failure, where the poor cardiac filling leads to elevated cardiac pressures, and subsequently to pulmonary congestion.

**Ventricular hypertrophy:** Refers to an abnormal thickening of the heart muscle in the left and/or right ventricle. Hypertrophy is one cause of diastolic dysfunction.

**Ejection fraction (EF):** The left ventricular ejection fraction is the proportion of blood within the left ventricle that is ejected with each heartbeat. A normal ejection fraction is greater than 0.4. A depressed ejection fraction indicates that the heart muscle has weakened and the heart has begun to dilate in response.



Questions for my doctor	









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