

Managing Heart Failure @home



INFORMATION
FOR PATIENTS

The Managing Heart Failure @home patient information booklet has been co-produced between NHS England and Pumping Marvellous Foundation.

You have received this booklet because you have discussed Managing Heart Failure @home with your team and agree this is the right choice for you. You might want to refer back to this booklet throughout your care and treatment.

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GLOSSARY

Words or phrases marked with an asterisk * in this booklet are referenced here.

Cardiomyopathy

A general term for diseases of the heart muscle, where the walls of the heart chambers have become stretched, thickened or stiff. This affects the heart's ability to pump blood around the body.

Cardiac rehabilitation

A term used to describe a programme of exercise and information sessions to help you reduce your risk of heart problems. It gives you and your family the information, support and advice you need to return to everyday life and is a vital part of your long-term recovery.

Discharge

This is when you are released from a healthcare team and may be moved to a different healthcare team. For example, when you are released from a hospital ward to the care of your general practitioner (GP) or a community team.

Ejection fraction

Refers to the amount of blood squeezed out of the main

chamber of your heart with every heartbeat. It's usually measured as a percentage; 50% or higher is considered normal. You can have a normal ejection fraction measurement and still have heart failure. This is called heart failure with preserved ejection fraction (HFpEF).

Heart and circulatory disease

Also known as cardiovascular disease and is a general term for conditions affecting the heart or blood vessels.

Heart attack

A serious medical emergency in which the supply of blood to the heart is suddenly blocked, usually by a blood clot.

High blood pressure

When your blood pressure is consistently too high your heart must work harder to pump blood around your body.

Multidisciplinary team/Team

A group of health and care professionals with different skills who work together with you to make decisions about your care, treatment and services relevant

to you. Read more information about your multidisciplinary team on page 11.

Palliative care

Palliative care improves people's quality of life who are facing challenges associated with life threatening illness. It also gives you and those important to you practical, emotional and spiritual support if and when you need it.

Personalised care and support plan

A plan which describes your health and wellbeing needs and how they will be met. After completing an assessment, you and/or your family work together with your health and social care professionals to develop your plan (this will be electronic where possible) and agree health and wellbeing outcomes you want to achieve.

Remote monitoring

Is when you monitor your health measurements, such as heart rate, blood pressure, and/or heart failure symptoms away from a healthcare setting, such as a hospital. You may use non-digital, digital or new technologies/ devices without the need to

see someone in person. You may need to submit your results to your team yourself, or your information may be automatically submitted with your consent. Your team will talk with you about the devices you may use to help monitor your symptoms, including how to use them.

Self-care

The things you can do to manage your own health and wellbeing.

Shared decision making

Ensures that individuals are supported to make decisions that are right for them. It is a collaborative process through which a clinician supports a patient to reach a decision about their treatment.

Supported self-management

The ways that health and care services provide support to help you manage your ongoing physical and mental health. Supported self-management does not mean doing it alone. Your team will support and encourage you to manage your health.

What is heart failure?

Heart failure does not mean that your heart is about to stop. Heart failure means that the heart is unable to pump blood around the body as well as it should. It usually happens because the heart muscle has become enlarged, stiff or has another problem.



Heart failure is different for every person and there are many causes of heart failure, such as a heart attack*, cardiomyopathy* and high blood pressure*. Your type of heart failure will be grouped depending on your ejection fraction* among other factors. Heart failure can happen quickly, or it can build slowly over months or years. It can happen at any age but is most common in older people. People from some ethnic backgrounds have also been found to be at higher risk from heart failure and other conditions linked to the heart and circulation of blood.

While heart and circulatory disease is more common in men, women are also at risk if they do not recognise signs and symptoms of heart failure and heart attacks.¹

Living with heart failure is becoming more common and symptoms can be controlled by medications, treatments and care, helping you to live better and longer.

What are the symptoms of heart failure?

Heart failure symptoms are different for each person. Make sure you talk through how you are feeling and your symptoms with your team*. This will help you learn what to do if your symptoms get worse.

¹ <https://www.bhf.org.uk/information-support/heart-matters-magazine/medical/women-and-heart-disease>

If you have been diagnosed with heart failure, you could be experiencing these heart failure symptoms:

- **Being breathless** after activity or at rest. This can feel like you have difficulty breathing or are breathing more quickly. It may be worse when you are lying down, and you may wake up at night needing to catch your breath.
- **Feeling very tired** particularly after doing normal activities. This is because your body needs oxygen and other things carried in your blood to create energy.
- **Swollen ankles and legs** are caused by a build-up of body fluid (this may also be related to age, as many elderly people have swollen ankles).
- **Feeling lightheaded and even fainting** can feel like you are floating and you may become dizzy which can lead to fainting. Fainting is when you pass out for a short time, usually caused by a drop in blood pressure.

Other symptoms can include:

- New or worsening cough
- Wheezing (a whistling sound when breathing)
- A bloated tummy (where your tummy feels like it is full and uncomfortable)
- Loss of appetite
- Weight gain or weight loss
- Confusion
- A fast heart rate
- A fast-beating or fluttering heartbeat
- Some people with heart failure may also experience feelings of anxiety (a feeling of unease, such as worry or fear, that can be mild or severe) and depression (feeling sad for weeks or months, rather than just a few days).



Help is at hand to help you manage your symptoms

Heart failure is different for each person, and you are the only one who knows how you feel. For example, your ideal heart rate, or the right medication for you, will be different to somebody else's.

If your symptoms change or are getting worse than normal, look at the **Pumping Marvellous Traffic Light Symptom Checker** which is included in your introductory pack.

The Symptom Checker can help you to manage a change in your symptoms and advise what to do if you need help.

You may also want to speak with your team* if your symptoms change or worsen.



When you need to get urgent help

If you are unable to contact your team* and you think you need urgent medical help, visit NHS 111 online www.111.nhs.uk or call 111. NHS 111 will assess and direct you to the right place for you, such as an urgent treatment centre. It's free and is available 24 hours a day, 7 days a week. If you feel seriously ill and feel your life may be at risk, call 999 for an ambulance or go to your local accident and emergency department.

Keep this booklet nearby and tell your friends and family where you keep it, in case you have to go to hospital.

There is a page at the back of this booklet where you can write down who you should contact, both during and outside of normal working hours.

There is also a page at the back of this booklet for you or your team to write down details of your medication. You will also have a personalised care and support plan* which your team will regularly update with details of your medication and dosage. This will help healthcare staff to understand your heart failure if your symptoms get worse and you need to go to hospital.

If you have chosen to receive care at home rather than be admitted to hospital if your health gets worse, such as if you are frail or receiving palliative care*, this should be in your personalised care and support plan*.

How can I better manage my heart failure at home?

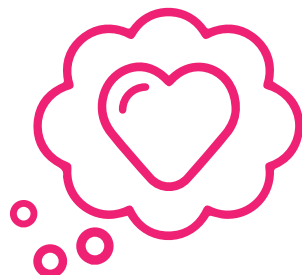
Lots of people tell us that they want to manage their heart failure better at home. Your team has a way of helping people to do this. It's called 'Managing Heart Failure @home' and it may help you to keep well and improve your quality of life. This may result in fewer hospital visits, but you will still go into hospital when needed, such as if your condition worsens and you are unable to manage at home.

You can choose whether Managing Heart Failure @home is right for you, and you and your multidisciplinary team* can talk about this together. If it isn't, you can talk to your team about other care options. This is called shared decision making*.



How could Managing Heart Failure @home help me?

Managing Heart Failure @home is one way to make sure you have the right treatment, support and care you need. This will be achieved by bringing together your team to support you to do the following:



Have a personalised care and support plan*

This helps to give you more control of your own health and care choices. It is based on what matters to you in your life and your physical, emotional and social needs. The personalised care and support plan will be produced by you and your team. The plan will ensure your needs are listened to and acted on by your team.

Learn more about how to manage your heart failure

The education and support you need to keep well at home might include supported self-management* such as cardiac rehabilitation* or health coaching. In 2019, 77% of people met recommended activity levels after completing cardiac rehabilitation*, lowering their risk of being readmitted to hospital.² Learning how to manage your condition can also help to improve your confidence and wellbeing.

Monitor your health measurements

Monitoring things such as heart rate, blood pressure or weight over time through remote monitoring* helps you to know when things are getting better or worse and when to ask for more support from your team*. This may help you to get treatment quicker and stop your symptoms from getting worse.

Who will support me?

Your team* will support you throughout your care. We have included a list of people below who may be part of the team and when you might speak to them:



Cardiologist – a doctor who specialises in heart disease, with a focus on treating people who have heart failure. They will lead the team who will support you.

Heart failure specialist nurse – a nurse who specialises in heart failure. Many heart failure specialist nurses can prescribe medicine or change how much of it you should take. Heart failure specialist nurses may work in a hospital or in the community. They will support you with your care, treatment and managing your condition at home.

General practitioner (GP) – a doctor in the community who treats patients with different illnesses. If you are discharged* into primary care, you may need an appointment with your GP to discuss your care plan. You should be reviewed at least once per year by a member of your primary care team. Your GP will contact heart failure specialists if they are concerned about your condition.

Other healthcare staff – such as **care coordinators** may support you at your first appointment and throughout your heart failure treatment and care. They may also support you with remote monitoring* and learning about how to manage your condition through your personalised care and support plan*. **Health and wellbeing coaches** may support you to make changes in your life that will improve your health and wellbeing.

Social prescribing link workers may connect you to community groups and other services for practical and emotional support.

Community nurses, such as district nurses and matrons, may support you with remote monitoring*, taking your medicines and helping you throughout your treatment and care. **Pharmacists** in the community may also give you support about lifestyle changes. For example, stopping smoking, healthy living, checking your health measurements and symptoms, and advice about your medicines, such as what medicines to take and when you should take them.

² The National Audit of Cardiac Rehabilitation, Quality and Outcomes Report, 2019, pp. 39-52.

What do I need to do during my appointments?



Your first appointment

During your first appointment, you and your team* will create a personalised care and support plan*. Once you and your team have talked about Managing Heart Failure @home, you will have time to think about your choices and what is right for you.

After your first appointment

If you decide Managing Heart Failure @home is right for you, you will work with your team to update your personalised care and support plan to include information on Managing Heart Failure @home. Your team will also make your planned telephone or online appointments for you. You will both decide the time and date of these appointments and how they will take place.

Between appointments

Your team* will help you to learn about your condition and your symptoms and how to monitor them remotely. Your team will tell you what remote monitoring* equipment or tools you need, how to use them, and how you should submit readings. There are pages at the back of this booklet to write this down and your team will keep your personalised care and support plan* up-to-date.

You can talk to your team about what to do if your symptoms start to get worse, and what symptoms to watch out for.

After your planned appointments

You and your team* should have found the medications and doses that are right for you and how best to take them. Your symptoms might also be getting better or no longer changing. If this is the case, then you may be discharged* to your GP and have an updated personalised care and support plan*. If you

are discharged, your local team will keep your details on file. You will continue to manage your condition and monitor your symptoms.

Your team will have already spoken with you about how to start cardiac rehabilitation* in your local area. If you haven't already done so, you may now feel ready and able to take part in cardiac rehabilitation.

If, after your planned appointments, your symptoms are either not improving, getting worse than normal, or are continuing to change, your team* will monitor you for longer.

Top tips from other people living with heart failure



These 'top tips' have been shared by people living with heart failure who have helped to develop this booklet. They are patient educators who volunteer for the Pumping Marvellous Foundation, the UK's patient-led heart failure charity.

1. Don't be afraid to speak up

Try to be open and honest when you talk about your heart failure with your team, family, friends, and/or employer.

Your team is there to help you.

- Tell them what is important to you
- Say how you feel
- Tell them about your worries and symptoms
- Ask who will help you out of hours if you need it.

2. Peer-to-peer support is important

Peer-to-peer support is when people use their own experiences to help and support each other.

There are lots of peer support groups across the country. Pumping Marvellous offers a peer support group that provides advice and friendship to help support people with heart failure. You can find a QR code and a webpage that will direct you to the Pumping Marvellous website at the back of this booklet.

3. Self-care* is key

Take the time to look after your physical and mental health. You can't do everything. Make sure you are kind to yourself, listen to your body, eat a healthy diet, let yourself rest, and take the time to recharge your batteries.

4. Play an active role

We know how important it is to manage your heart failure symptoms.

Playing an active role in managing your heart failure means:

- sticking to your care plan
- keeping active
- taking your medication
- weighing yourself every day
- eating well
- remote monitoring*.

These are all tools to help you live a healthier and happier life.

5. You can live well with heart failure

One key message to take away from reading this booklet is that **you can live well with heart failure**.

If you are worried about your condition, talk to your team.

If it would be helpful to have this booklet in another format, such as large print, please contact your team or organisation supporting you who will be able to help you with this.

Please note: this booklet should not replace advice you are given from your team*.

Further support

This section includes details of national patient and medical organisations and related services. Ask your team about local support in your area.

www.nhs.uk/conditions/heart-failure

NHS information on heart failure symptoms, diagnosis and treatment.

www.pumpingmarvellous.org

The UK's patient-led heart failure charity.
Managing Heart Failure @home - Information on Managing Heart Failure @home.

www.bhf.org.uk

UK charity specialising in heart and circulatory diseases.

www.cardiomyopathy.org

Specialist national charity for people affected by cardiomyopathy.

www.selfmanagementuk.org

UK-based charity supporting people with long-term conditions to self-manage.

www.nice.org.uk/guidance/cg187

www.nice.org.uk/guidance/ng106

National Institute for Health and Care Excellence gives national advice to improve health and social care.

www.mind.org.uk

Provides advice and support to empower anyone experiencing a mental health problem.

www.ageuk.org.uk

The UK's leading charity for older people.

www.carersuk.org

The UK's only national membership charity for carers.

Managing my heart failure

This section is for you to write down the contacts from your team*, details of your medication and remote monitoring*, and other important details to help you manage your heart failure. This information will also be captured in your personalised care and support plan*.

My local team

My name:

My carer's name and telephone number(s) (if applicable):

.....
.....

My team's contact details during normal working hours:

.....
.....
.....

My team's contact details for **outside** normal working hours:

.....
.....
.....

My emergency contact details:

My next of kin's name:

My next of kin's telephone number(s):

.....
.....

My weight:

This section is to help you to record and monitor your weight.

Date:

My weight:

.....
.....
.....
.....

My target weight:

.....

My medication and remote monitoring:

This section is to help you to monitor and manage your medication and remote monitoring.

Name of
medicine:

Date began
medication:

How often
to take:

.....
.....
.....
.....

Name of
equipment:

How often
to use it:

When to report
on readings:

How to submit
my readings:

.....
.....
.....
.....

Name and contact information of team member(s) supporting my medication and remote monitoring:

Tips on how to use the equipment:

My notes:

Use this section to write down how you are feeling, updates about your heart failure or other important notes.

Questions I have for my appointments:



www.pumpingmarvellous.org

www.england.nhs.uk/nhs-at-home/managing-heart-failure-at-home/

How to scan a QR code with the Camera app

1. Open the Camera app from the Home Screen, Control Centre or Lock Screen.
2. Select the rear-facing camera. Hold your device so that the QR code appears in the viewfinder in the Camera app. Your device will recognise the QR code and display a notification.
3. Tap the notification to open the link associated with the QR code.



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