

Planning ahead with advanced heart failure

What is heart failure?

Heart failure is a long-term condition where the heart doesn't pump blood as well as it was able to. This can lead to symptoms like breathlessness, tiredness, and swollen ankles. It's often caused by things like high blood pressure, heart attacks, damaged heart valves, or irregular heart rhythms.

What symptoms might I notice?

You might feel breathless, even when resting or asleep, and more tired than usual. You also may notice swelling in your ankles, legs, or tummy.

How is heart failure treated?

Although heart failure can't usually be cured, there are many treatments that can help slow down the progression. Health care professionals may consider:

- **Medications**
- **Devices like pacemakers**
- **Sometimes surgery**

Your care team will work with you to find the best options for your situation.

What is advanced heart failure?

As heart failure progresses, treatments may not work as well, or might cause other issues. This stage is called advanced or chronic heart failure. It's different from a sudden flare-up (called acute heart failure), which can often be treated quickly.

Many people living with heart failure also have other health conditions, like kidney problems, diabetes, or lung disease, which can make their symptoms feel even more challenging and may limit the types of treatments that are safe or effective for them. At this stage, the focus may shift from trying to fix the heart to helping you feel as comfortable and well as possible. This includes managing symptoms and supporting your emotional wellbeing.

Signs that heart failure may be getting worse:

- Feeling breathless even when resting
- Constant tiredness that doesn't improve with rest
- Pain or discomfort from swelling in your legs or tummy, or from sitting for long periods
- Feeling sick, losing your appetite, or losing weight
- Changes in bowel habit, like constipation
- Memory problems or poor sleep
- Needing to go to hospital more often
- Worsening in kidney function

How might I feel emotionally?

It is completely normal to feel a mix of emotions – sadness, frustration, anxiety, or fear. You might feel like you're losing control or worry about being a burden. Many people aren't aware that advanced heart failure is a serious condition, and it can be difficult for you, and those around you, to come to terms with it. This can sometimes lead to feelings of loneliness or isolation. Often people with heart failure look well on the outside, even when they feel unwell inside. You're not alone, and support is available for both you and your loved ones.

Who will support me?

You will be cared for by a team that may include: your GP, Heart failure specialist nurses, Cardiologists, Palliative care specialist nurses and doctors.

What is palliative care?

Palliative care is about improving your quality of life. It helps manage the symptoms of the illness, and offers emotional and practical support for you and your family. It is not just for people with cancer or those at the very end of life. It complements treatments offered by usual heart failure treatments.

What is the Advanced Heart Failure Symptom Management Clinic?

This is a joint clinic where heart failure and palliative care experts work together to help manage your symptoms. It's also a safe space to talk about your wishes for the future and ask any questions you may have.

What is advance care planning?

Advance care planning means thinking ahead and sharing what matters most to you. Talking about the future isn't always easy, but it can bring a sense of comfort and reassurance. It helps your loved ones and healthcare team understand what matters most to you, especially in an emergency situation where your health may have changed suddenly.

Planning ahead is not about giving up. It's a way of staying in control, making your wishes known, and continuing to live your life in the way that is right for you.

Why plan ahead?

Heart failure can be unpredictable. Some people's symptoms remain stable for a long time, while others may notice changes more quickly. Planning ahead gives you time to think about what is important to you and make informed choices, and you are more likely to have time to think about treatment options and your personal priorities.

For many people, sharing their hopes and worries about the future with loved ones can be a comforting and helpful step. But for others, these conversations can feel more difficult. Some may worry about being a burden or upsetting those they care about. Others might fear that talking about the future could be seen as 'giving up.' Families, too, often try to stay strong and positive, even when they're feeling anxious or unsure inside. These feelings are completely natural, and it's okay to take these conversations at your own pace, when the time feels right.

Who can I talk to?

You can talk to: a trusted family member or friend, your GP or heart failure nurse or a member of the palliative care team.

There's no pressure to talk about everything at once. You can take your time and only share what you feel comfortable with.

Things you might want to think about:

- **Where you would like to be cared for in the future, for example, home, hospice, nursing home**
- **Treatment options like resuscitation, organ donation or defibrillator deactivation**
- **Legal matters such as organising a Lasting Power of Attorney**
- **Making a will or organising finances**
- **Planning a funeral**
- **Leaving messages or keepsakes for loved ones**

Supporting someone with heart failure

Caring for someone with advanced heart failure can be emotionally and physically demanding. Carers may feel worried, upset or lonely. They may have questions about how to care for their loved one as their condition changes. The healthcare professionals involved are also there to offer carers practical and emotional support, recognising the emotional and physical demands of caregiving.

Where can I look for more information?

European Society of Cardiology Information for Patients with Heart Failure

cdn-endpoint-hfm.azureedge.net/heartfailurematters/2024/04/1167029_ESC_heart_failure_patient_guidelines_Update_EN.pdf

Pumping Marvellous, a UK patient-led Heart Failure charity

pumpingmarvellous.org/

The British Heart Foundation

bhf.org.uk/information-support/heart-matters-magazine/wellbeing/end-of-life-care/talking-about-death-and-dying

With thanks to

patient.info/heart-health/heart-failure-leaflet

mariecurie.org.uk/professionals/palliative-care-knowledge-zone/condition-specific-short-guides/heart-failure

heart.org/en/health-topics/heart-failure/living-with-heart-failure-and-managing-advanced-hf/planning-ahead-advanced-heart-failure

bhf.org.uk/information-support/support/emotional-support-and-wellbeing/facing-the-end-of-life

nhs.uk/conditions/heart-failure/