

Understanding NICE guidance

Information for people who use NHS services

Chronic heart failure

NICE 'clinical guidelines' advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive.

This booklet is about the care and treatment of people with chronic heart failure in the NHS in England and Wales. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence). It is written for people with chronic heart failure but it may also be useful for their families or carers or for anyone with an interest in the condition.

The booklet is to help you understand the care and treatment options that should be available in the NHS. It does not describe chronic heart failure or the tests or treatments for it in detail. A member of your heart failure team should discuss these with you. There are examples of questions you could ask throughout this booklet to help you with this. You can get more information from the organisations listed on page 15. Medical words and terms printed in **bold** type are explained in more detail on page 14.

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The advice in the NICE guideline covers the care of:

- adults (18 years and older) with chronic heart failure in primary and secondary care.

It does not specifically look at the care of:

- adults with heart failure due to respiratory disease
- pregnant women with chronic heart failure.

This is an update of advice on the care of adults with chronic heart failure that NICE produced in 2003. The advice on diagnosis, drug treatments, monitoring and rehabilitation has been updated.

Your care

In the NHS, patients and healthcare professionals have rights and responsibilities as set out in the NHS Constitution (www.dh.gov.uk/en/Healthcare/NHSConstitution/index.htm).

All NICE guidance is written to reflect these. You have the right to be involved in discussions and make informed decisions about your treatment and care with your healthcare team. Your choices are important and healthcare professionals should support these wherever possible. You should be treated with dignity and respect.

To help you make decisions, healthcare professionals should explain chronic heart failure and the possible treatments for it. They should cover possible benefits and risks related to your personal circumstances. You should be given relevant information that is suitable for you and reflects any religious, ethnic or cultural needs you have. It should also take into account whether you have any physical or learning disability, sight or hearing problem or language difficulties. You should have access to an interpreter or advocate (someone who helps you put your views across) if needed.

Your family and carers should be given their own information and support. If you agree, they should also have the chance to be involved in decisions about your care.

You should be able to discuss or review your care as your treatment progresses, or your circumstances change. This may include changing your mind about your treatment or care. If you have made an 'advance decision' (known as a 'living will' in the past), in which you have already given instructions about any treatments that you do not wish to have, your healthcare professionals have a legal obligation to take this into account.

All treatment and care should be given with your informed consent. If, during the course of your illness, you are not able to make decisions about your care, your healthcare professionals have a duty to talk to your family or carers unless you have specifically asked them not to. Healthcare professionals should follow the Department of Health's advice on consent (www.dh.gov.uk/consent) and the code of practice for the Mental Capacity Act. Information about the Act and consent issues is available from www.publicguardian.gov.uk In Wales healthcare professionals should follow advice on consent from the Welsh Assembly Government (www.wales.nhs.uk/consent).

Chronic heart failure

What is heart failure?

Heart failure means your heart does not pump enough blood to meet all the needs of your body. Usually this is because the heart muscle has been damaged. The term 'chronic heart failure' is used to describe heart failure as a long-term condition.

What causes heart failure?

Heart failure can be caused by:

- heart attack (**myocardial infarction**), which is usually due to narrowing or blockage of blood vessels to the heart (coronary artery disease)
- high blood pressure (hypertension)
- disease of the heart muscle, which may be genetic
- birth defects (congenital heart disease)
- irregular heart beat
- damaged heart valves
- damage to the heart muscle from a viral infection or from long-term heavy drinking
- some cancer treatments.

Symptoms of heart failure

Shortness of breath – either with exercise or at rest – is the most common symptom. Weight gain and ankle swelling may occur. Fatigue and increased need to pass urine at night are common. A person who has heart failure may be woken suddenly from a sound sleep, gasping for breath. Other signs of heart failure can include a cough that won't go away, nausea, lack of appetite and confusion.

Types of heart failure

There are two main types of heart failure. **Heart failure due to left ventricular systolic dysfunction** is a type of heart failure in which the heart chamber that pumps blood around the body (called the left ventricle) isn't working as well as it should. **Heart failure with preserved ejection fraction** is a type of heart failure in which the heart has difficulty filling with blood.

It is important that the heart failure team finds out which type of heart failure you have because this will affect the treatments you are offered.

If you think that your care does not match what is described in this booklet, please talk to a member of your heart failure team in the first instance.

Questions you might like to ask your heart failure team

- Please tell me more about heart failure
- Are there any support organisations in my local area?
- Can you provide any information for my family/carers?

Diagnosis of heart failure

If you have shortness of breath or ankle swelling your doctor may consider a diagnosis of heart failure. Your doctor will ask you about all your symptoms and your medical history, and will examine you.

If you've had a heart attack in the past

A heart attack often damages heart muscle and can mean that you are more likely to have heart failure. So, if you've had a heart attack in the past and you have symptoms of heart failure, your doctor should arrange an urgent appointment for you:

- to see a specialist from the heart failure team **and** have an **echocardiogram** within 2 weeks.

An echocardiogram is a simple test that uses ultrasound waves to view the heart. It can help your healthcare team to find out whether you have heart failure and, if so, how they should treat it. After the echocardiogram, a member of the team will talk to you about the results and about other tests that might give more information about your condition.

If the echocardiogram is normal but heart failure is still suspected, you may be offered a blood test to measure substances in the blood called **serum natriuretic peptides** (also known as BNP or NTproBNP). If you have raised levels of serum natriuretic peptides the heart failure team will consider whether you have heart failure with preserved ejection fraction, which is not easily detected by an echocardiogram. The team may arrange for you to have other tests to investigate the extent of your condition and its cause.

Normal levels of serum natriuretic peptides (if you are not on any medication) mean that heart failure is unlikely. If this is the case you'll be offered other tests to rule out conditions with symptoms similar to heart failure (see page 6).

If you've not had a heart attack in the past

If you've not had a heart attack in the past but your doctor suspects you may have heart failure, you should be offered a blood test to measure substances in the blood called **serum natriuretic peptides**. If the test shows you have raised levels your doctor should arrange for you:

- to see a specialist from the heart failure team **and** have an echocardiogram.

How quickly you are seen by the specialist will depend on your level of serum natriuretic peptides. NICE recommends that if you have raised levels you should be seen within 6 weeks.

The echocardiogram will help the team to find out if you have heart failure and, if so, how they should treat it. A member of the team will talk to you about the results and other tests that might give more information about your condition.

If you have normal levels of serum natriuretic peptides (and you are not on any medication) a diagnosis of heart failure is unlikely. Your doctor may offer you other tests to rule out conditions with symptoms similar to heart failure.

Tests to rule out conditions with symptoms similar to heart failure

When making a diagnosis, your doctor will consider other conditions with symptoms similar to heart failure. You can expect to have blood, urine and breathing tests and an X-ray of your chest. You are also likely to have an **electrocardiogram** (usually called an ECG), which gives an electrical recording of your heart's action.

If you've had a heart attack in the past it's important that you are seen by a specialist in heart failure and have an echocardiogram within 2 weeks of your first visit to your doctor. Your doctor should not wait for the results of other tests before arranging these appointments.

Reviewing the diagnosis

If you've had a diagnosis of heart failure in the past, your diagnosis may be reviewed and confirmed.

Questions about finding out what is wrong (diagnosis)

- Can you give me more details about the tests/investigations I should have?
- What do these tests involve?
- Where will these be carried out? Will I need to have them in hospital?
- How long will I have to wait until I have these tests?
- How long will it take to get the results of these tests?

Treatments for heart failure

If you've been diagnosed with heart failure there are many treatments that can help. Your heart failure team will work with you to determine which treatments are most suited to you. You can expect that you will be kept fully informed about your heart failure and the treatments available at each stage.

Lifestyle

There are several things you can do to help your heart to pump more efficiently and to keep a check on your condition.

- If you smoke, try to stop (your doctor and practice nurse will offer you support and can refer you to specialist smoking cessation services if you need extra help).
- If your heart failure was caused by drinking alcohol, you should talk to your doctor or nurse about stopping drinking. If alcohol was not a cause of your heart failure, your doctor or nurse will discuss with you how much alcohol you can safely drink.
- Your doctor will suggest that you have an annual flu jab. Your doctor should also offer you vaccination against pneumococcal pneumonia, if you haven't already been vaccinated.
- Talk to your doctor or nurse if you are worried about impotence or whether it's safe for you to have sex.
- Most people with heart failure can safely travel by air. However, during flight, legs and ankles tend to swell and breathing may become more difficult for people with severe heart failure. You should check with your doctor or specialist heart failure nurse before planning any air travel.
- If you drive large goods vehicles or passenger carrying vehicles ask your doctor or nurse to check the current guidance from the Driver and Vehicle Licensing Agency on chronic heart failure (available at www.dft.gov.uk/dvla).

If you have talked to your heart failure team, and you think that a treatment is suitable for you but it is not available, you can contact your local patient advice and liaison service ('PALS') or NHS Direct Wales.

Some treatments may not be suitable for you, depending on your exact circumstances. If you have questions about specific treatments and options covered in this booklet, please talk to a member of your heart failure team.

Drug treatment

Heart failure is a serious condition that needs treatment. All people with heart failure will gain some benefit from drug treatment. The drug treatments you are offered will depend on the cause of your heart failure and your situation. Your doctor or specialist heart failure nurse should discuss the various treatments with you and make sure that you and your family or carers have as much information as you want, including information about possible side effects. You are likely to need a combination of drugs and your heart failure team will work with you so that you can decide together which drugs are most likely to be suitable. Finding the right combination may take a little time and you may need changes to your drugs or their doses. The team will look at the effect of these changes on your symptoms.

The box on page 9 lists most of the drugs you might be offered. You may already be taking one or more of these drugs if you have high blood pressure, diabetes or have had a heart attack in the past.

If you have heart failure due to left ventricular systolic dysfunction, you will usually be offered a combination of three different types of drug:

- a diuretic (often known as water pills)
- an angiotensin-converting enzyme inhibitor (usually called an ACE inhibitor) **and**
- a beta-blocker.

If your symptoms continue or you have problems, you may also be offered other drugs.

If you have heart failure with preserved ejection fraction you will usually be offered a diuretic. You may also be taking some of the drugs listed on page 9 if you have diabetes, high blood pressure or have had a heart attack in the past.

Drugs used to treat heart failure

Offered to patients with heart failure due to left ventricular systolic dysfunction

- ACE inhibitors
- Improve life expectancy and wellbeing.
 - You'll be offered a low dose at first. The dose will be increased until the right dose for you is reached.
 - Each time the dose is increased you'll have a blood test to check for any kidney problems.

- Beta-blockers
- Improve life expectancy.
 - If you are already taking one for angina or high blood pressure, your doctor will switch you to a beta-blocker specific for heart failure when your condition is stable.
 - You'll be offered a low dose at first. The dose will be gradually increased over weeks or months.

May be offered to patients with heart failure due to left ventricular systolic dysfunction

- Aldosterone antagonists
- Improve life expectancy.
 - May be offered if you still have troublesome symptoms of heart failure despite taking an ACE inhibitor and a beta-blocker.
 - Will be offered if you've had a heart attack in the past 14 days.
 - You'll have regular blood tests to check kidney function.

- Angiotensin II receptor antagonists
- May be offered if you can't take ACE inhibitors because of intolerable side effects.
 - May be offered if you still have troublesome symptoms of heart failure despite taking an ACE inhibitor and a beta-blocker.
 - Each time the dose is increased you'll have a blood test to check for any kidney problems.

- Hydralazine with nitrate
- May be offered if you can't take ACE inhibitors and angiotensin II receptor antagonists.
 - You may be offered this combination if you still have troublesome symptoms of heart failure despite taking an ACE inhibitor and a beta-blocker, particularly if you are of African or Caribbean origin.

Offered to patients with heart failure and fluid retention

- Diuretics
- The most common type of drug used in heart failure.
 - Work by reducing the amount of fluid in the body.
 - Help you breathe more easily and be more active.

Other drugs

- Digoxin
- May be offered if heart failure is difficult to treat.
 - Can be affected by other drugs so you must tell your doctor about any other drugs, herbal remedies or other treatments you are taking.

- Anticoagulants
- Thin the blood and stop blood clots from forming.
 - A common type (warfarin) can be affected by other drugs, so tell your doctor about any other drugs, herbal remedies or other treatments you are taking.

You might find it helpful to make a list of all the drugs you are taking and take the list along to your appointments.

Taking your drug treatment

It is very important to take your drugs for heart failure. Your heart failure team will encourage you to suggest any changes (for example, the times you take particular drugs) that you might find helpful. You may need to take several drugs, and the different times and ways they need to be taken can be confusing. If you are unsure about how and when to take your drugs, speak to your doctor, specialist heart failure nurse, practice nurse or pharmacist. They will help you to organise your drugs in a way that makes them easier to take. You can find out more about this from 'You and your prescribed medicines: enabling and supporting patients to make informed decisions' (information about NICE clinical guideline 76), which is available from www.nice.org.uk/guidance/CG76/PublicInfo

Questions about the treatment

- Why have you decided to offer me this particular type of treatment?
- What are the pros and cons of this treatment?
- What will the treatment involve?
- How will the treatment help me? What effect will it have on my symptoms and everyday life? What sort of improvements might I expect?
- Will it help me to live longer?
- How long will it take to have an effect?
- Are there any risks and side effects associated with this treatment?
- How many drugs will I need to take?
- How long will I be on the drugs? Will I have to take them for the rest of my life?
- Will I need any changes in drugs in the future, and if so who will manage these?
- What should I do if I miss a dose?
- What are my options for taking treatments other than the recommended treatment?
- Is there a leaflet about the treatment that I can have?

Other treatments

Cardiac resynchronisation therapy

Cardiac resynchronisation therapy may be considered to bring the pumping action of the heart chambers back in time with each other. This type of therapy is usually delivered by a **pacemaker**, a battery-operated device that stimulates the heart to beat. It is placed just under the skin in the chest. Some people need a special type of pacemaker with a **defibrillator**. When this detects a serious change in the heart's rhythm it delivers a short electric shock to the heart to return the heart beat to normal.

Surgery

As well as drug treatment, it may be possible to improve your heart failure through surgery. However, this is not done routinely and your doctor will need to refer you to a specialist to see if this is an option for you.

In very severe heart failure, a heart transplant may be considered. This is a big step and your doctor will discuss this with you. It is not an option for everybody because of the risks of surgery and a shortage of hearts for transplantation.

Rehabilitation

When your condition is stable, you should be offered a rehabilitation programme, which provides activities such as exercise training for people with heart failure. The programme should also offer you information and other support.

Monitoring heart failure

Your condition and treatment (including any possible side effects) will be regularly assessed. How frequently you are seen will depend on how stable your heart failure is. It may be every 6 months or as often as every 2 weeks. If your drugs have recently been changed your doctor may wish to see you every few days until the effect of the change is clear. You may be offered a blood test to measure serum natriuretic peptides.

You can also monitor your symptoms and weight and tell your doctor about any changes. Your doctor or nurse will explain exactly how to do this.

If you have to go into hospital

You may need to go into hospital if your symptoms become worse. While you're in hospital your heart failure will be managed by the specialist heart failure team, your drugs may be changed to improve your symptoms and you'll be more closely monitored.

Your GP will be given information on any changes to your drug treatment by the hospital doctors, including changes in dose and timing of doses. It is very important that you take your drugs, so you should tell your doctor if for any reason you find it difficult to do so. It's also very important that you are given clear instructions about how to get advice when you come out of hospital. You will be seen frequently during the early days after you leave hospital.

Support at home

If you need help at home because of your heart failure, your GP or the hospital staff can arrange for a nurse or other carer to visit you. They can also arrange for you to borrow equipment, such as a commode if you find it difficult to walk to the toilet.

Prognosis

Naturally, one question that you will want answered is whether the heart failure will get better or worse. Unfortunately, it is not easy for doctors to know exactly what might happen (the prognosis). They should be open and honest with you. Your doctor should try to give you guidance on living with the uncertainty even if they cannot be definite about the future.

End-of-life care

If your condition becomes terminal, the heart failure team should discuss the need for end-of-life care (also known as palliative care) with you and your family and carers. If necessary they should offer you a referral to a member of the team with specialist skills in this area. End-of-life care aims to improve the quality of life for patients with a terminal illness. It seeks to accurately identify, assess and treat specific physical needs such as pain control. It also addresses individual psychological, social and spiritual needs.

Depression and anxiety

If you feel depressed and anxious about your heart failure, this is not unusual. Any chronic illness is likely to make a person feel depressed. Do talk to your doctor or nurse about your feelings. There may be much that can be done to improve things. You may find it helpful to read the booklet NICE has produced about depression and long-term physical health problems. You can find this at www.nice.org.uk/guidance/CG91/PublicInfo. If you are thinking about using 'complementary medicines' such as a herbal preparation to help you, be sure to tell your doctor because these may interfere with the drugs for your heart failure.

It is common and understandable to feel anxious, confused and depressed after a diagnosis of heart failure. Do talk to your doctor or nurse about your feelings.

Explanation of medical words and terms

Chronic heart failure is a long-term condition in which the heart does not pump enough blood to meet all the needs of the body. Symptoms include shortness of breath and ankle swelling.

A **defibrillator** delivers an electric shock to the heart when it detects a serious change in rhythm. This returns the heart beat to normal. Some special types of **pacemaker** (see below) contain a defibrillator.

An **echocardiogram** is a test that uses sound waves to look at the pumping action and structure of the heart, including the heart valves. A probe is moved over the chest and picks up echoes of sound, which are shown as a picture on a screen.

An **electrocardiogram** is a test that measures the rhythm and electrical activity of the heart. Small patches called electrodes are attached to the arms, legs and chest. These pick up electrical signals from the heart, which can show how the heart is beating.

Heart failure due to left ventricular systolic dysfunction is a type of heart failure in which the chamber of the heart that pumps blood around the body isn't working as well as it should.

Heart failure with preserved ejection fraction is when the heart has difficulty filling with blood.

Myocardial infarction is the technical term for a heart attack. A heart attack happens when the blood supply to the heart is interrupted by a blockage. A heart attack can cause damage to the heart and make heart failure more likely.

A **pacemaker** is a battery-operated device that is placed just under the skin of the chest and stimulates the heart to beat.

Serum natriuretic peptides (also known as BNP or NTproBNP) are substances in the blood that are raised in people with heart failure. A blood test for serum natriuretic peptides can help your doctor make a diagnosis.

More information

The organisations below can provide more information and support for people with chronic heart failure. NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- British Heart Foundation, 0300 330 3311
www.bhf.org.uk
- The Cardiomyopathy Association, 01494 791224
www.cardiomyopathy.org

NHS Choices (www.nhs.uk) may be a good place to find out more. Your local patient advice and liaison service (usually known as 'PALS') may be able to give you more information and support. You should also contact PALS if you are unhappy with the treatment you are offered, but you should talk about your care with a member of your healthcare team first. If your local PALS is not able to help you, they should refer you to your local independent complaints advocacy service. If you live in Wales you should speak to NHS Direct Wales for information on who to contact.

About NICE

NICE produces guidance (advice) for the NHS about preventing, diagnosing and treating medical conditions. The guidance is written by independent experts including healthcare professionals and people representing patients and carers. They consider the evidence on the condition and treatments, the views of patients and carers and the experiences of doctors, nurses and other healthcare professionals. Staff working in the NHS are expected to follow this guidance.

To find out more about NICE, its work and how it reaches decisions, see www.nice.org.uk/aboutguidance

This booklet and other versions of the guideline aimed at healthcare professionals are available at www.nice.org.uk/guidance/CG108

*You can order printed copies of this booklet from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N2269). The NICE website has a screen reader service called *Browsealoud*, which allows you to listen to our guidance. Click on the *Browsealoud* logo on the NICE website to use this service.*

We encourage NHS and voluntary organisations to use text from this booklet in their own information about chronic heart failure.