

Management of heart failure

**Understanding NICE guidance –
information for people with heart failure,
their carers, and the public**

July 2003



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About this information

This information describes the guidance that the National Institute for Clinical Excellence (called NICE for short) has issued to the NHS on chronic heart failure. It is based on *Chronic Heart Failure: Management of Chronic Heart Failure in Adults in Primary and Secondary Care*, which is a clinical guideline produced by NICE for doctors, nurses and others working in the NHS in England and Wales. Although this information has been written chiefly for people with chronic heart failure, it may also be useful for their family members, those who care for people with chronic heart failure and anyone with an interest in chronic heart failure or in healthcare in general.

Clinical guidelines

Clinical guidelines are recommendations for good practice. The recommendations in NICE guidelines are prepared by groups of health professionals, lay representatives with experience or knowledge of the condition being discussed, and scientists. The groups look at the evidence available on the best way of treating or managing a condition and make recommendations based on this evidence.

There is more about NICE and the way that the NICE guidelines are developed on the NICE website (www.nice.org.uk). You can download the booklet *The Guideline Development Process – Information for the Public and the NHS* from the website, or you can order a copy by telephoning 0870 1555 455 and quoting reference number N0038.

What the recommendations cover

This booklet covers the recommendations in the NICE guideline *Chronic Heart Failure: Management of Chronic Heart Failure in Adults in Primary and Secondary Care*. This NICE guideline makes recommendations about:

- the care provided by GPs and hospital healthcare professionals who have direct contact with patients with heart failure
- all the key areas of managing heart failure including diagnosis, drug and non-drug treatments and the management of depression and anxiety.

The recommendations do not cover:

- emergency treatment of heart failure
- screening for heart failure
- management of heart failure caused by lung disease
- care after heart transplantation.

This booklet tells you about the NICE guideline on chronic heart failure. It doesn't attempt to explain heart failure or describe the treatments in detail.

How guidelines are used in the NHS

In general, health professionals working in the NHS are expected to follow NICE's clinical guidelines. But there will be times when the recommendations won't be suitable for someone because of his or her specific medical condition, general health, wishes or a combination of these. If you think that the treatment or care you (or someone you care for) receive does not match the treatment or care described in the pages that follow, you should discuss your concerns with your consultant, GP or other members of your healthcare team.

If you want to read other versions of this guideline

The NICE guideline *Chronic Heart Failure: Management of Chronic Heart Failure in Adults in Primary and Secondary Care* and a longer version that contains all the details of the guideline recommendations and how they were developed are both available from the NICE website (www.nice.org.uk).

About 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?

The most common cause is damage to the heart due to narrowing or blockage of blood vessels to the heart (also called coronary artery disease). Some of the other causes include:

- high blood pressure (hypertension)
- irregular heart beat
- damaged heart valves
- birth defects (congenital heart disease)
- disease of the heart muscle due to genetic causes (cardiomyopathy)
- damage to the heart muscle from a viral infection or from long-term heavy alcohol consumption.

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 urinate 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.

Guideline recommendations

The following advice is written for people with heart failure and their carers and tells you what help, treatment and care you can expect. The first section outlines some issues that are important throughout all stages of the illness. Other sections look at diagnosis and treatment, monitoring your condition, being in hospital because of heart failure, and helping you to cope with heart failure.

Care you can expect at all stages

Good communication between healthcare professionals and you (and your family/carers) is essential. Your healthcare team should be listening to your feelings, fears, views and beliefs. They should give you the information you ask for or need about heart failure, the treatments and the possible side effects. They should tell you about

any tests to be performed, why they are needed and how they will be done. They should work in a constructive partnership with you and your family or carers at all times, including when decisions need to be made about your care. They should offer help and support to cope with any effects that chronic heart failure might have on your daily life.

Diagnosis of heart failure

If you have symptoms such as shortness of breath or ankle swelling, your doctor may consider the possibility that you have heart failure. Your doctor will need to consider your medical history and carry out a medical examination. If, in the past, you have had a diagnosis of heart failure, your doctor should review this diagnosis. The doctor will consider other illnesses that can cause similar symptoms. You can expect to have blood, urine and breathing tests and an X-ray of your chest.

Your doctor will also arrange for you to have an electrocardiogram (usually called an ECG), which gives an electrical recording of your heart's action.

If after doing these tests, your doctor still suspects that you might have heart failure, then an echocardiogram will be arranged. This is a test that uses sound waves to view your heart and see how well it is pumping. It will help the doctor decide whether or not you do have heart failure, and if so, why you have it and how best to treat it.

If you do have heart failure, then as well as seeing how well your heart works, your doctor will want to assess how the heart failure affects your ability to live a normal life (for example, how easily you become breathless).

Treatments for heart failure

There are many treatments that can help your heart to work better and make you feel better too. Your doctor will work with you to determine which treatments are most suited to your particular circumstances. You can expect that your doctor will keep you fully informed about your heart failure and the treatments available at each stage.

Lifestyle

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

- Take regular exercise such as brisk walking or weight training (your doctor, nurse or physiotherapist will be able to give you advice on how much and what sort of exercise you should take). Exercise helps to keep your heart working strongly. Even if you are not well enough to manage brisk walking or weight training, remaining as physically active as possible will still benefit your heart greatly.

- Your doctor may be able to arrange for you to attend a rehabilitation programme, which provides activities such as exercise and breathing training and can offer you information and other support.
- If you smoke, try to stop (your doctor and practice nurse will be able to offer support to help you give up smoking 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 stop drinking now. If alcohol was not a factor, your doctor or nurse will discuss how much alcohol you can safely drink.
- Your doctor will suggest that you have an annual influenza vaccination. Your doctor should also offer you vaccination against a particular form of pneumonia (pneumococcal pneumonia), if you haven't already been vaccinated.
- Your doctor may advise you to avoid adding salt to food, or to limit the amount of fluid that you drink.

Air travel and driving: most people with heart failure are able to travel by air. However, during flight, legs and ankles tend to get swollen and breathing may become more difficult for those with severe heart failure. Therefore, you should check with your doctor before planning any air travel. People who drive heavy goods vehicles or public service vehicles should ask their doctor to

check the latest information from the Driver and Vehicle Licensing Agency for current guidance on chronic heart failure (this guidance is available on the Internet at www.dvla.gov.uk).

Drug treatment

All people with heart failure will benefit from drug treatment. Your doctor should discuss the various treatments with you and tailor the choice of drugs to your own situation. It may be that the first medicines to be tried do not suit you or do not work as well as expected and so some changes in the drugs or their doses may be needed until the right combination is found. When you are offered medicines, you should be given as much information as you want about them before the treatment is started.

Unfortunately, as with any drug therapy, there is a risk that some of the drugs prescribed to you may cause unwanted side effects. Some of the most common side effects that occur with drugs used for heart failure are described below. Not everyone experiences these side effects, but if you experience these or, indeed, any unusual symptoms, you should contact your doctor. He or she will be able to assess whether the symptom is due to the drug and whether or not it will wear off with time. Your doctor may suggest trying a lower dose or changing to a different drug of the same type. Most people with heart failure will

benefit from a combination of treatment with three different types of drug: a diuretic, an angiotensin converting enzyme inhibitor (usually called an ACE inhibitor) and a beta-blocker.

Diuretics

The most common medicines used in heart failure are diuretics (known as water pills). Diuretics reduce the amount of fluid in the body. Diuretics help you to breathe more easily and to be more active. They also lower blood pressure, so if you have high blood pressure you may already be taking one of these drugs. A common side effect is that blood pressure falls to too low a level, and if this happens you may feel giddy or dizzy when you get up from sitting or lying down. Diuretics will make you urinate more often.

ACE inhibitors

Your doctor is also likely to recommend a type of medicine called an ACE inhibitor (this stands for 'angiotensin converting enzyme inhibitor'). These medicines help the heart to pump more blood. They are also often used to lower blood pressure, so if you have high blood pressure, you may already be taking this type of drug. A common side effect is that blood pressure falls to too low a level, and if this happens you may feel giddy or dizzy when you get up from sitting or lying down. ACE inhibitors may also cause a dry cough or make you feel as if you have a cold.

If for some reason you cannot take an ACE inhibitor, perhaps because of unwanted side effects, your doctor may wish to try a medicine called an 'angiotensin II receptor antagonist'. Again, the main side effect of these medicines is blood pressure falling to too low a level.

Beta-blockers

After you have started on a diuretic and an ACE inhibitor, your doctor may start you on a beta-blocker. Clinical studies have shown that beta-blockers improve life expectancy for people with a common type of heart failure. You may already be taking one of these drugs (for example, for high blood pressure). When starting beta-blockers, it is usual for your doctor to prescribe a low dose at first and then gradually increase the dose over weeks or months. The most common side effects with beta-blockers are a slowing of the heart rate, tiredness, cold hands and feet, insomnia, dizziness or giddiness and impotence in men. Of course, not everyone experiences these side effects. If these occur, your doctor may reduce the dose of your beta-blocker or adjust your other medications to help. Some people will have to have the beta-blocker stopped.

Other drugs

Other drugs may also be used for heart failure. The most common are listed below.

Digoxin is well known as being the heart drug extracted from the foxglove plant. It has been used for over 200 years to treat heart problems. Digoxin helps your heart to beat more strongly and regularly. The most common side effect with digoxin is nausea. Digoxin can be affected by other drugs, so it is important that you tell your doctor about any drugs, herbal remedies or other treatments that you are taking.

Spirolactone: some people with heart failure may be advised to take a drug called spironolactone. It is only used at a low dose but for some people it may cause nausea or make the breasts tender. Not everyone will experience these side effects but if these occur, your doctor may reduce the dose of the spironolactone or stop it.

Anticoagulants: sometimes what causes the heart failure may also increase your chance of having a stroke. In such circumstances, your doctor may also prescribe an 'anticoagulant' called warfarin. This type of drug thins the blood and prevents blood clots from forming. If you are on warfarin you will need regular blood tests to make sure that you are on the right dose (so that it does not thin the blood too much or too little). If you are prescribed warfarin you will be given an information sheet that explains exactly how to take it. The main side effect is that it can thin the blood too much and cause bleeding. Because warfarin can be affected by other drugs, be sure to tell your doctor about any drugs, herbal remedies or other treatments that you are taking.

Taking your medicines

It is very important that you take your medicines exactly as instructed by your doctor. You may need to take several medicines, and the different times and ways they need to be taken can be confusing. If you are at all unsure about how and when to take your medicines, speak to your doctor, practice nurse or pharmacist. They will be able to help you to organise your medicines in a way that makes them easier to take. For example, a list of which drugs to take when can be helpful. Alternatively, there are gadgets that you can use to help you take your medicines at the right time. Finally, it may be possible to change the times and doses of some medicines so that they can be taken with others – ask your doctor about this. It is also helpful if your family/carers can understand your medicines so that if you cannot remember which medicines to take when, someone else may be able to help.

Other treatments

Sometimes other treatments will also be used to help treat your heart failure, such as pacemakers, defibrillators and surgery. Your doctor may refer you to a specialist to see if you would benefit from these treatments.

Pacemaker

A pacemaker is a battery-operated device that stimulates the heart to beat and so can overcome problems with an irregular or too slow heart beat. The pacemaker is implanted in your chest (just under the skin) and has tiny cables (leads), which are placed in the heart. The pacemaker sends electrical impulses down the cables, and these impulses stimulate the heart to beat according to the rate set by the pacemaker. One of these devices may be considered for you if your heart is beating too slowly. Recently, more complicated ('biventricular') pacemakers have been developed which may help the heart pump better in some patients with heart failure.

Defibrillator

An implantable defibrillator is a battery-operated device that monitors the heart rhythm, and is just a little larger than a pacemaker. If the rhythm becomes dangerously abnormal the defibrillator automatically delivers a small electrical shock to the heart and this gets the rhythm back to normal. One of these devices may be considered for you if there is a problem with the heart's rhythm. Some people may have a combined pacemaker and defibrillator implanted.

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, heart transplantation can be considered. Naturally, this is a big step and your doctor will discuss with you the implications of suggesting this option. It is not an option that is open to everybody because of the risks of the surgery itself and its aftermath and because there is a shortage of hearts available to be transplanted.

Monitoring heart failure

The severity of your symptoms may vary from day to day or week to week. Sometimes you may suffer such severe symptoms that a period in hospital may be needed. However, if your condition is closely monitored your doctor may be able to adjust your medicines to control these changes in symptoms and perhaps prevent the need for a hospital stay. Therefore, your doctor will regularly assess your condition and the treatment you are receiving. How frequently your doctor will want to see you will depend on how stable your heart failure is. It may be as infrequently as every 6 months or as often as

every 2 weeks. If your medication has recently been changed your doctor may wish to see you every few days until the effect of the change in your medicines is clear.

In addition, you can monitor your symptoms and weight and alert your doctor to any changes. Your doctor will explain exactly how you can do this.

If you have to go to hospital

You may have to go to hospital for a variety of reasons.

- Your doctor is likely to want you to go to hospital for various tests to help to diagnose heart failure and possibly to monitor your condition. This may include taking X-rays, an echocardiogram (this uses sound waves to view your heart while it is beating), an electrocardiogram (known as an ECG or heart monitor) and blood tests.
- Your doctor may wish you to see a specialist for expert advice on how best to treat your heart failure, particularly if your heart failure is of an unusual type or is particularly severe, or if you have other conditions that could complicate your treatment or you experience severe irregularities in your heart beat.
- You may need to stay in hospital if your heart failure becomes worse. While you stay in hospital you will be able to receive more

powerful medicines than at home and be more closely monitored. Once your heart failure has become stable again, and you are confident about doing so, you will be able to go home.

Your GP will liaise closely with the doctors at the hospital and will be given information on any changes to your medicines, including changes in dose and timing of doses. It is very important that you take your medicines as instructed, so you should tell your doctor if for any reason you find it difficult to do so. Your GP or another member of your healthcare team may arrange for a nurse to see you quite frequently during the early days after you leave hospital.

Helping you cope with heart failure

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

You have the right to be fully informed and to share in decision-making about how your heart failure is treated and how that treatment is delivered. This should be the case whether you are being treated at home, in hospital or in a nursing

home. Doctors, nurses and other healthcare staff should answer any questions you or your family/carers have about your condition and its treatment simply, clearly and promptly. You should also be given written information to support the answers. Your doctors and the other healthcare staff you see should always listen to your concerns (and those of your family/carers) and take into account your wishes, beliefs and needs at all times.

Prognosis

Naturally, one question that you will want answered is that of prognosis (that is, how the heart failure will progress and what it means for you). Unfortunately, it is not easy for doctors to know exactly what will happen. Their answers may well not be as definite as you would like. However, your doctor should be open and honest with you. Some of the tests that may be done can give an indication of your likely prognosis, but even this will only be a rough guide.

Heart failure can be a life-threatening illness, but the outlook for an individual patient with heart failure depends on his or her age, the severity of the heart failure, overall health, and a number of other factors. Modern treatments for heart failure not only improve symptoms but extend life. Your doctor should give you guidance on living with the uncertainty even if he or she is unable to be definite about the prognosis.

If heart failure gets worse, the heart's reduced pumping ability may interfere with day-to-day life, and patients may become unable to care for themselves. If it is appropriate, the doctor should discuss the need for palliative care with the patient and his or her family and carer(s), and if necessary refer them to an expert. Palliative care aims to improve the quality of life for those patients with a potentially life-threatening illness. It seeks to accurately identify, assess and treat specific physical needs such as pain control. It also addresses patients' 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. If you choose to use 'complementary medicines' such as a herbal preparation to help you, be sure to tell your doctor as these medicines may interfere with the medicines for your heart failure. Contact with other heart failure sufferers through a support group can be a great help. Ask your doctor or nurse whether there are any local support groups. Details of local groups may also be available from your local library or Citizens Advice Bureau.

Further information

If you need further information about any aspects of heart failure or the treatment you are receiving, please ask your doctor or a relevant member of your health team. You can discuss this guideline with them if you wish, especially if you aren't sure about anything in this booklet. They will be able to explain things to you. If you want to find out more about heart failure, NHS Direct may be a good starting point. You can call NHS Direct on 0845 46 47 or view the NHS Direct website at www.nhsdirect.nhs.uk.

There may well be support groups for people with heart failure in your area. Your doctor or nurse should be able to give you more details. Details of local groups may also be available from your local library or Citizens Advice Bureau.

For further information about the National Institute for Clinical Excellence (NICE), the clinical guidelines programme, or other versions of this guideline (including the sources of evidence used to inform the recommendations for treatment and care), you can visit the NICE website at www.nice.org.uk.



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