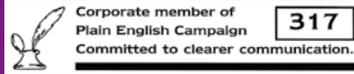


Chronic heart failure

A booklet for patients, their families and carers





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ISBN 978 1 909103 41 2
First published 2016

This booklet can be photocopied to be used in the NHS in Scotland.

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Cover illustration
Sebastian Kaulitzki / Science Photo Library

Who is this booklet for?

This booklet is for you if:



You have chronic heart failure.

Or



You are a friend, relative or carer of someone who has chronic heart failure.

This booklet explains:

- what chronic heart failure is;
- what causes it;
- what the symptoms are;
- how it is diagnosed;
- how it is treated; and
- what you can do to help yourself.

What is this booklet about?

This booklet explains the recommendations set out in a clinical guideline produced by us, the Scottish Intercollegiate Guidelines Network (SIGN), about the care you may need if you have chronic heart failure.

On pages 30 to 33 there are details of organisations who can give you information about chronic heart failure.

The clinical guideline we produced is based on what we know from current medical research. There is also some advice based on the opinion of health-care professionals who are trained on how best to manage your care.

On page 34 you can find out more about us at SIGN and how we produce guidelines.

There are four different types of recommendations in this booklet.



Strong recommendation
based on the
research evidence



Recommendation
based on the
research evidence



Recommendation
based on clinical
experience



Not enough research evidence
to tell us if something
is of benefit

If you would like to see the clinical guideline this booklet is based on, please visit www.sign.ac.uk

What is chronic heart failure?

Chronic heart failure describes what happens when your heart cannot pump blood around your body as well as it should. People with heart failure can get short of breath and tire very easily.

What causes chronic heart failure?

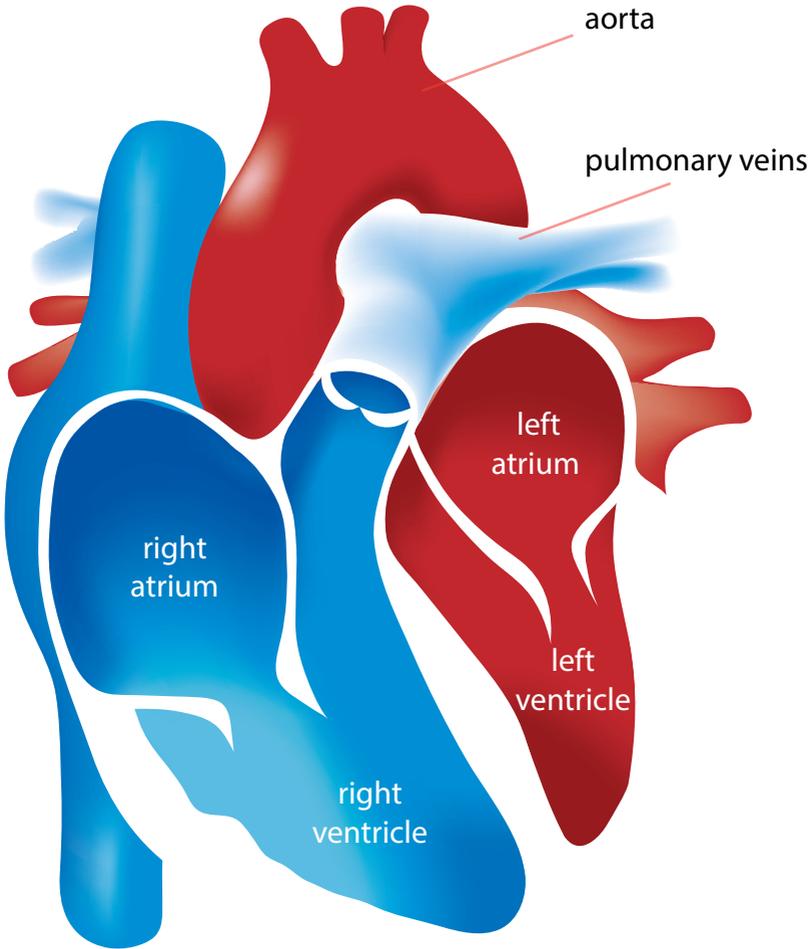
The most common cause of chronic heart failure is a heart attack, which causes damage to the muscle of the left ventricle (see the diagram on page 4).

But there are other possible causes, including the following.

- Narrowing of the arteries that supply blood to the heart muscle. This is called **coronary artery disease**.
- A previous heart attack (sometimes called **myocardial infarction**), which has left scar tissue that stops the heart muscle working normally.
- High blood pressure (**hypertension**).
- Diseased or damaged heart valves, which can affect the flow of blood in the heart.
- A disease of the heart muscle itself, called **cardiomyopathy**.
- **Congenital heart defects** (these are heart defects that were present at birth).
- Infection of the heart valves or heart muscle itself (known as **endocarditis** or **myocarditis**).

Sometimes the cause of chronic heart failure is unknown.

The heart



What are the symptoms of chronic heart failure?

The main symptoms of chronic heart failure are:



- Severe tiredness or fatigue



- Shortness of breath, sometimes known as **dyspnoea**



- Swelling of the ankles

These symptoms can also be caused by other conditions. Your doctors will do some tests to find out if you have heart failure. You can read more about the tests on pages 7 and 8. They will look at your symptoms to find out how serious it is.

How severe is my heart failure?

Doctors will assess your symptoms to decide how severe your heart failure is. The severity of heart failure is classified on a scale of 1 to 4 using the New York Heart Association (NYHA) scale.

Severity of heart failure

No limitations. Ordinary physical exercise does not cause undue tiredness, breathing difficulties or palpitations.

1

Slight limitation of physical activity. Comfortable at rest but ordinary activity results in fatigue, palpitations or breathing difficulties.

2

Marked limitation of physical activity. Comfortable at rest but less than ordinary activity results in symptoms.

3

Unable to carry out any physical activity without discomfort. Symptoms of heart failure are present even at rest with increased discomfort with any physical activity.

4

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www.heart.org

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What tests will doctors do?

Doctors will look at your symptoms and the results of some tests to find out if you have heart failure and to rule out other conditions.

Initial tests



Recommendation

Doctors will do some initial tests, including:

- taking your pulse;
- measuring your blood pressure; and
- taking some blood and urine to find out if you have anaemia, liver damage, kidney damage or thyroid disorder.



Strong recommendation

Your doctor will arrange for you to have a chest x-ray

“It is important to receive early diagnosis and treatment.” Patient

Further tests

ECG – electrodes are placed on your body and connected to a machine to measure the rhythm and electrical activity of your heart.

BNP is a blood test to measure the levels of the hormone B-type natriuretic peptide (BNP) in your blood. If you have heart failure, the level of BNP in your blood is increased.

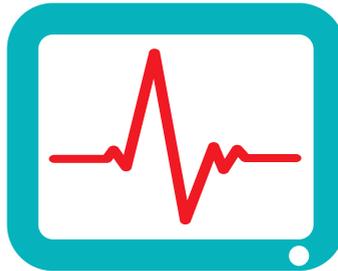


Recommendation

You may also be referred for an **echocardiogram**.

If, after the initial tests on page 7, your doctor thinks that you have heart failure, you may then have further tests, including:

- **electrocardiogram (ECG)** 
- **B-type natriuretic peptide (BNP)** 



Echocardiogram – a recorder is put on your chest wall and ultrasound is passed through your chest to your heart. The recorder monitors the echoes from your heart and displays them on a screen to show doctors how your heart is working.



What information should I receive when I am diagnosed with chronic heart failure?

Your doctor or nurse from your **cardiology team** should do the following:

- Explain what heart failure is.
- Give you information, spoken and written, explaining how you will be treated and cared for throughout the course of your treatment. Discussion should include:
 - treatment options;
 - side effects of treatment and how these can be managed;
 - treatment outcomes; and
 - referral to other specialists if necessary.
- Give you time to discuss the following issues:
 - The aims of treatment
 - The prognosis (that is, the likely course of the condition) and any **advanced-care planning**, if appropriate
 - Managing distress (including depression and anxiety).
- Refer you to a clinical nurse specialist for support, advice and information.
- Provide information on other sources of support.

Cardiology team – health-care professionals who diagnose and treat heart conditions

Advanced-care planning allows patients, their families and professionals to discuss and make plans about future health-care decisions.

How can I help myself?

There are some things you can do to slow down the progression of your heart failure.



Be more physically active



You should try some low-intensity physical activity such as walking. Even just a few minutes a day can help.



Monitor your weight



Weigh yourself every day and let your GP know if your weight changes by more than 3 to 4lbs (1.5 to 2kg) in two days.



Strong recommendation

Physical activity is beneficial for people with heart failure. You should be offered a supervised exercise programme to help to keep your condition under control.



Recommendation

Your doctor or nurse should encourage you to take regular exercise. They can talk to you about activities that are safe for you to do.



Reduce your fluid intake

This will help improve any swelling you have and will make you feel less tired. Your doctor will give you advice on how much fluid you should drink each day.



Cut down on salt

You should aim to eat less than 6 grams of salt a day. This will improve your blood pressure, which helps to reduce your heart failure. But don't use 'low salt' substitutes, as they have high potassium content, which your body may not be able to cope with. A high level of potassium in your blood can cause stomach cramps, diarrhoea, general weakness and muscle spasms.



Avoid:

- St John's wort
- cranberry juice
- grapefruit juice



Don't take St John's wort or cranberry juice as they interact with medicines such as warfarin and digoxin.

If you are taking the statins called atorvastatin or simvastatin, grapefruit juice can affect how well these medicines work.



Stop smoking

If you smoke you should give up. Your doctor should offer you advice and support to do this.



Drink less alcohol

You should try not to drink large amounts of alcohol. If your heart failure has been caused by drinking too much alcohol your doctor will encourage you to stop drinking alcohol altogether.



Can complementary therapies help?

Complementary therapies are used alongside medicine and other therapies to treat conditions.



Not enough research evidence

There is not enough evidence to tell us if the following can help.

- Tai chi
- Acupuncture
- Group relaxation therapy
- Meditation

How will I feel?

It is common for patients with heart failure to experience depression. You may want to discuss this with your doctor or clinical nurse specialist. They can answer any questions you may have. They can also talk to you about treatment options to help you to make an informed choice.

“I felt so low but I trusted my doctor, I had to. I wanted to still have a life.” Patient



Recommendation

If you and your doctor decide that antidepressants would be helpful, you should not be prescribed tricyclic antidepressants.

You will be prescribed another type of antidepressant.



Recommendation

Cognitive behavioural therapy (CBT), a talking therapy that can help patients to manage their problems by changing the way they think and behave, should be considered if you have depression.

What medication will I be given to treat my heart failure?

There are a number of medicines that may improve your condition including the following.

Medicine	How they work	Possible side effects
<p>Angiotensin converting enzyme inhibitors (ACE inhibitors)</p> <p>These should be used for all types of heart failure. You will be started on a low dose and your blood pressure will be monitored regularly.</p> 	<p>These lower your blood pressure and reduce the work your heart has to do to pump blood around your body. Your symptoms should improve within a few weeks to a few months of starting treatment.</p>	<p>Side effects can include:</p> <ul style="list-style-type: none"> • a cough; • low blood pressure and dizziness (hypotension); • kidney problems (renal impairment); and • high levels of potassium in your blood (hyperkalaemia). <p>A rare side effect is swelling under the skin around your eyes, lips and throat (called angio-oedema). This can be dangerous. If this happens, your ACE inhibitors will be stopped and you will be prescribed a different medicine. If you experience side effects from an ACE inhibitor you should be given an angiotensin receptor blocker (ARB) instead.</p>

Medicine	How they work	Possible side effects
<p>Angiotensin receptor blockers</p> <p>These can be used if the ACE inhibitors are giving you a cough.</p> <p>The doctor will start you on a low dose and will monitor your blood pressure and carry out regular blood tests.</p> 	<p>These lower your blood pressure and reduce the work your heart has to do to pump blood around your body.</p>	<p>Side effects are not common but can include:</p> <ul style="list-style-type: none"> • kidney problems (renal impairment); and • high levels of potassium in your blood (hyperkalaemia). <p>You may get low blood pressure and feel dizzy when you first start taking these.</p>



Recommendation

An ACE inhibitor, an ARB and an MRA (see page 17) should never be used together as side effects on kidney function outweigh the benefits.

Medicine	How they work	Possible side effects
<p>Beta blockers</p> <p>As soon as your condition is stable you should be prescribed beta blockers.</p> <p>If you have a history of asthma, heart block (abnormal electrical activity) or low blood pressure (hypotension) you should not take beta blockers.</p> 	<p>These block the action of hormones called noradrenaline and adrenaline, which normally increase your heart rate (make your heart beat faster). Using beta blockers slows down your heart rate and lowers your blood pressure.</p> <p>Symptoms may take three to six months or longer to improve. You should not stop taking your beta blockers without speaking to your doctor first.</p>	<p>In the short term, your symptoms may briefly worsen after starting to take beta blockers.</p> <p>It is important that you monitor your health during this time and tell your doctor if, for example, your symptoms of tiredness, fatigue and breathlessness get worse. These symptoms can usually be managed by adjusting your medication.</p>

Medicine	How they work	Possible side effects
<p>Mineralocorticoid antagonists (MRA)– spironolactone and eplerenone</p> <p>If the severity of your heart failure is 2, 3 or 4 (see page 6), you may be given a medicine called spironolactone or eplerenone.</p> 	<p>These treat the build-up of water in your body associated with heart failure but prevent too much potassium being lost. This helps to maintain the balance of salts in your blood.</p>	<p>Side effects can include:</p> <ul style="list-style-type: none"> • high levels of potassium in the blood (hyperkalaemia); • kidney problems (renal dysfunction); and • development of breasts in men (gynaecomastia). <p>Around 1 in 10 men develop gynaecomastia.</p> <p>If you develop gynaecomastia you should talk to your cardiology team. You will be prescribed eplerenone instead.</p>  <p>To reduce the risk of side effects, your blood will be monitored while you are taking spironolactone or eplerenone.</p> <p>You cannot take spironolactone or eplerenone if you have signs of kidney problems or high levels of potassium in your blood.</p>

Medicine	How they work	Possible side effects
<p>Angiotensin receptor/ neprilysin inhibitor – sacubitril/valsartan</p> <p>If you are taking an ACE inhibitor or ARB and your symptoms are not improving and:</p> <ul style="list-style-type: none"> the severity of your heart failure is 2 or 3 (see page 6), you should be given sacubitril/valsartan instead.  <ul style="list-style-type: none"> the severity of your heart failure is 4 you may be given sacubitril/valsartan instead.  <p>You should be seen by a heart failure specialist who is part of a multidisciplinary team before starting treatment with sacubitril/valsartan.</p> 	<p>These lower your blood pressure and reduce the work your heart has to do to pump blood around your body.</p>	<p>Side effects can include:</p> <ul style="list-style-type: none"> low blood pressure and dizziness (hypotension); kidney problems (renal impairment); and high levels of potassium in your blood (hyperkaleamia). <p>You should stop taking your ACE inhibitor 36 hours before starting sacubitril/valsartan to reduce the risk of swelling under the skin around your eyes, lips and throat (angio-oedema).</p> 

Medicine	How they work	Possible side effects
<p>Ivabradine</p> <p>You may be given ivabradine if:</p> <ul style="list-style-type: none"> • you are on the maximum dose of beta blockers and still have symptoms of heart failure; or • you cannot take beta blockers. 	<p>They work by slowing your heartbeat so your heart doesn't have to work as hard.</p>	<p>Side effects can include:</p> <ul style="list-style-type: none"> • a slow heart rate that makes you feel tired and unwell; and • problems with your eyes. <p>You cannot take ivabradine if you have an irregular heartbeat.</p>

“There is a need for doctors to give appropriate information and provide patients with a clear explanation of why they have been given these drugs. It is important that prescribed drugs are frequently reviewed.”

Patient

Medicine	How they work	Possible side effects
<p>Diuretics, (sometimes known as water tablets), you will be given water tablets if you have a build-up of fluid in your ankles and lungs. This swelling is common in people with heart failure.</p> <p>The dose you receive will depend on your individual needs and will reduce your fluid retention without causing dehydration or kidney problems.</p> 	<p>These increase the amount of water and salt in your urine. They remove excess fluid from the blood which means that your heart does not have to work as hard to pump blood around your body.</p>	<p>Sometimes diuretics can cause gout in patients with heart failure. Diuretics are vital to the treatment of heart failure and it is not possible to stop them, even if they cause gout. You should be offered pain killers called nonsteroidal anti-inflammatory medicines (NSAIDs), such as ibuprofen, or a medicine called colchicine, to reduce the inflammation.</p> <p>If you have diabetes, taking diuretics can increase the level of glucose in your blood.</p>

Medicine	How they work	Possible side effects
<p>Digoxin</p> <p>If you have heart failure and a normal, regular heartbeat (known as sinus rhythm), and you are still experiencing symptoms of heart failure despite treatment, you may be given digoxin on top of your other treatment (that is, as an add-on therapy).</p> 	<p>Digoxin works by increasing the strength of your heart's contractions and slows your heart rate.</p>	<p>Side effects can include:</p> <ul style="list-style-type: none"> • loss of appetite; • palpitations; • nausea; or • vomiting. <p>If you experience a slow heart rate (bradycardia) when taking digoxin and a beta blocker, the digoxin should be stopped.</p>  <p>You should not take St John's wort or cranberry juice if you are taking digoxin as they can interact with this medicine.</p>
<p>Hydralazine and isosorbide dinitrate (H-ISDN)</p> <p>You may be given these medicines if you cannot take ACE or ARB.</p> 	<p>These medicines are used in the same way as ACE inhibitors, but they are not as effective.</p>	<p>Isosorbide dinitrate and hydralazine may cause dizziness or light-headedness.</p>

Medicine Sick Day Rules

When you are unwell with any of the following:

- Vomiting or diarrhoea (unless only minor)
- Fevers, sweats and shaking

Then **STOP** taking the medicines listed overleaf

Restart when you are well (after 24-48 hours of eating and drinking normally)

If you are in any doubt, contact your pharmacist, GP or nurse



Medicines to stop on sick days

- ACE inhibitors: medicine names ending in “pril”
eg, lisinopril, perindopril, ramipril
- ARBs: medicine names ending in “sartan”
eg, losartan, candesartan, valsartan
- NSAIDs: anti-inflammatory pain killers
eg, ibuprofen, diclofenac, naproxen
- Diuretics: sometimes called “water pills”
eg, furosemide, spironolactone, indapamide, bendroflumethiazide
- Metformin: a medicine for diabetes

Initially produced by NHS Highland

Other management options



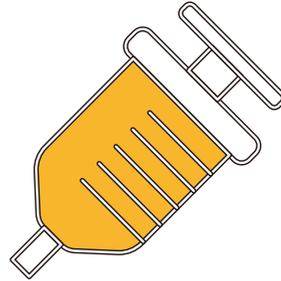
Intravenous iron

If the amount of iron in your blood is low, you will need to be given iron in a drip to increase it.

You need iron so your body can make new haemoglobin (the pigment in red blood cells) to carry the oxygen around your body.

When you have had intravenous iron, you should:

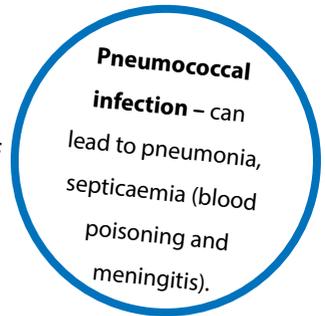
- feel less tired;
- have more energy; and
- be less breathless when you exercise.



Immunisation

If you have chronic heart failure you are at greater risk of developing a more serious illness such as flu.

It is recommended that you are given vaccinations for flu and pneumococcal infection. Your doctor should offer you this.





Cardiac resynchronisation therapy (CRT) or implanted cardiac defibrillator (ICD)

Patients who are severely ill with a specific type of heart failure should be considered for cardiac resynchronisation.

A special pacemaker will be fitted. This will help to co-ordinate the contractions of the left and right sides of the heart.

An ICD is a device which is implanted just under the collarbone. It monitors your heart rhythm and sends out an electrical shock if your heart rhythm becomes abnormal.



Heart transplant

If you have class 4 heart failure and your medication is not working you should be referred to specialist doctors who will assess you to find out if you are suitable for a heart transplant.





Information

Across Scotland there are cardiac support groups working with a variety of charity organisations such as Chest Heart and Stroke Scotland (CHSS). These self-help groups are run by people with experience of heart disease.

You and your family may find it helpful to meet and talk to people who have gone through similar experiences. You can refer yourself to one of these support groups if your health-care team hasn't already done so (details of CHSS are listed on page 31).

Support groups can give you and your family and friends:

- emotional and social support;
- help with rehabilitation (through a structured exercise programme);
- advice on preventing further heart problems; and
- information and education.

What ongoing support will I get?

Health-care staff should make arrangements for you to receive ongoing support and follow-up.



Strong recommendation

Follow-up should include support from a multidisciplinary team (a team of different health-care staff) including a nurse and a pharmacist.



Information

Health-care staff should explain the follow-up you should receive and the importance of going to follow-up appointments.

How can I plan ahead?

When you are living with heart failure you may wonder whether it will get better or worse.

You may have concerns and unanswered questions. It is difficult for health-care staff to know how the condition may progress (the prognosis). They will listen to your concerns and talk to you about these issues. They will offer support and guidance on living with uncertainty



Recommendation

If you continue to have symptoms or keep having to go into hospital, you may benefit from access to a collaborative cardiology and palliative-care approach to your care. This will involve your cardiology team and palliative-care team working together to provide care. This approach is designed to help manage your symptoms in ways that your cardiology treatments alone have not managed to. It also gives you the opportunity to talk about any concerns you and your family may have. It can be an opportunity to try to improve your quality of life but also to plan for a time where you may be less well and to identify your preferences and priorities of care.



Recommendation

As your condition changes, adjustments will need to be made to your treatment. Your treatment will be regularly reviewed and discussed with you to make sure that the treatment you have is in your best interests. If the treatment causes you more difficulty than good, it can be altered to what suits you best.

If you are mentally capable of making your own decisions about your care and treatment, you can refuse any medical treatment or ask for treatment to stop. This includes refusing implantable cardioverter defibrillators or having them removed. Your cardiology and palliative-care team will talk to you about any concerns you have with your treatment. They will give you the advice and support you need.

Deactivating pacemakers and ICDs

Your cardiology and palliative-care team will give you information about deactivating devices, and will be there to support you and answer any questions you may have.

Although conversations about this are difficult to have they are helpful to care for you in the best way and in a way that is most appropriate for you at a time when you are approaching the end of your life.



Strong recommendation

Your cardiology and palliative-care team will follow guidance from the Resuscitation Council UK on deactivating devices in patients with advanced heart failure who are near the end of their life.

- There may come a point where having treatment, including a pacemaker or defibrillator, is not in your best interests. The cardiology and palliative-care team will discuss deactivating your pacemaker or defibrillator.
- You and your family should be made aware that your pacemaker or defibrillator can be turned back on if your situation changes.
- You should have a defibrillator-deactivation plan as part of the 'thinking ahead process', but this plan does not necessarily mean that your device needs to be deactivated immediately. It is there to make sure your care is co-ordinated when you are less well. At this time the cardiology and palliative-care team will probably discuss resuscitation with you. This is a medical decision and the team will guide you and your family through this process.
- You must not assume that a 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR) decision means that your device should be deactivated, and a decision to deactivate your device does not mean that you have made a DNACPR decision.

What information should I receive?



Information

Your doctor or nurse should do the following.

- Offer to discuss end-of-life care with you when the time is right.
- Discuss the following with you.
 - The reason for and aim of palliative care
 - Who is likely to be involved in your care
 - How symptoms can be managed
 - Advanced-care planning if appropriate
 - Where you would prefer to receive care.

Where can I find out more?

NHS inform

NHS inform provides a health and care information service for the people of Scotland, including information on over 850 medical conditions such as heart failure, high blood pressure, depression and diabetes.

Phone: 0800 22 44 88 (8am to 10pm)

Email: nhs.inform@nhs24.scot.nhs.uk

Website: www.nhsinform.co.uk

The Support Service Directory section on the NHS inform website provides information on local groups and telephone helplines.

Organisations specific to heart disease

British Heart Foundation

The British Heart Foundation is the UK's heart charity and the largest independent funder of cardiovascular research. It provides vital information for patients and carers.

Phone: 020 7554 0000

Heart Helpline: 0300 330 3311

Email: bhfhi@bhf.org.uk

Website: www.bhf.org.uk

Chest Heart & Stroke Scotland

This is Scotland's health charity set up to improve the quality of life for people in Scotland affected by chest, heart and stroke illness. It does this through medical research, influencing public policy, and providing advice, information and support in the community.

Phone: 0131 225 6963

Advice Line Nurses: 0808 801 0899

Email: admin@chss.org.uk

Website: www.chss.org.uk

Other organisations

Action on Depression

Action on Depression can refer people to local support. They provide advice and information on low mood and depression.

Email: admin@actionondepression.org

Website: www.actionondepression.org

Active Scotland

This website provides information and ideas on a range of indoor and outdoor activities in Scotland.

Website: www.activescotland.org.uk

Blood Pressure UK

This is a UK charity dedicated to lowering the nation's blood pressure to prevent disability and death from stroke and heart disease.

Phone: 020 7882 6218

Email: help@bloodpressureuk.org

Website: www.bloodpressureuk.org/Home

Breathing Space

Breathing Space is a free, confidential telephone and online service for any person who is experiencing low mood or depression, or who is unusually worried and in need of someone to talk to.

Phone: 0800 83 85 87

Website: www.breathingspace.scot

Diabetes UK

Diabetes UK provides information, advice and support to help people with diabetes manage the condition well, and bring people together for support when it's needed most.

Phone: (Careline Scotland) 0141 212 8710

Email: careline.scotland@diabetes.org.uk

Website: www.diabetes.org.uk

Drink Smarter

This is a national charity working to reduce the harm caused by alcohol. It provides information on sensible drinking and easy ways to cut back.

Website: www.drinksmaarter.org

Eat Better Feel Better

This website provides recipes for healthier and cheaper meals, and information on improving cooking skills.

Website: www.eatbetterfeelbetter.co.uk

GOV.UK

This website provides government information and services.

Website: www.gov.uk/heart-failure-and-driving

Kidney Research UK

This organisation provides kidney-health information and support for patients, their families and carers, as well as medical professionals and researchers.

Phone: 0845 070 7601

Email: enquiries@kidneyresearchuk.org

Website: www.kidneyresearchuk.org

Smokeline

Smokeline is Scotland's national 'stop smoking' helpline, open every day from 8am to 10pm.

Phone: 0800 84 84 84

Email: smokeline@nhs24.scot.nhs.uk

Website: www.canstopsmoking.com

How are SIGN guidelines produced?

Our guidelines are based on the most up-to-date scientific evidence. We read research papers to find evidence for the best way to diagnose, treat and care for patients. If we cannot find this out from the research evidence, we ask health-care professionals to use their clinical experience and judgment to suggest treatments.



1

Identify questions



2

Search for evidence



3

Look at the evidence



4

Make judgements
and recommendations



5

Publish



6

Let everybody know
about our guidelines

You can read more about us by visiting www.sign.ac.uk or you can phone **0131 623 4720** and ask for a copy of our booklet 'SIGN guidelines: information for patients, carers and the public'.

The Scottish Intercollegiate Guidelines Network (SIGN) writes guidelines which give advice for health-care professionals, patients and carers about the best treatments that are available.

We write these guidelines by working with health-care professionals, other NHS staff, patients, carers and members of the public.

If you would like a copy of this booklet in another language or format, such as in large print, please phone **0131 623 4720** or email sign@sign.ac.uk

www.sign.ac.uk



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The Healthcare Environment Inspectorate, the Scottish Health Council, the Scottish Health Technologies Group, the Scottish Intercollegiate Guidelines Network (SIGN) and the Scottish Medicines Consortium are key components of our organisation.

