HEART VOICES

British Heart Foundation

Where you could make a difference

What's this fact sheet for?

Heart Voices is all about encouraging patients and carers to have their say to change their heart services for the better. This factsheet outlines some of the areas where your say could make a difference. Think of it as a starting point to give you some food for thought.

Why does Heart Voices matter?

In a survey of nearly a thousand BHF supporters, we found that 70% had no idea that they had a right to take part in health service discussions and decision-making. Even the people who knew they had a right to get involved were often put off because they didn't know what to say or where to start. We want to help everyone use their voice and experiences to shape NHS services.

What services could I affect?

The best place to start is to think about all the different heart health care services you have used, and then work out where you can contribute. Here are some suggestions for starting points. They include:

- Lifestyle advice
- Cardiac rehabilitation
- Follow-up appointments
- Care plan
- Palliative and end-of-life care
- Making sure services work together

Lifestyle advice

There are many things people living with heart disease can do to help themselves. They include increasing physical activity, changing diet, keeping a healthy weight, cutting down on alcohol and stopping smoking. These changes can help to lower both blood pressure, cholesterol and improve heart health.

Part of the role of doctors, nurses and other health care professionals is to encourage people to make these lifestyle changes, tell them about the benefits of doing so, and the risks of not doing so. You could check that health care professionals in your local services are offering lifestyle change information, support and signposting to services patients may benefit from.

You could suggest any ideas you have on how local programmes, such as Stop Smoking services, could be improved or promoted more effectively.

Cardiac rehabilitation

This is a service that every heart patient should be offered, as long as it's assessed as suitable for them and they want to take part. Evidence shows that it can improve quality of life, helping a patient understand their condition and take the right steps to reduce the risk of another heart event. It's also very cost-effective. The average cost is £600 per patient.

In the weeks after a patient leaves hospital, they should be assessed for participation in a cardiac rehabilitation programme, covering activities such as exercise training, relaxation techniques, lifestyle information and psychological support. The programme should be home-based, community-based or hospital-based – whatever suits the patient best. It should involve a wide range of health care professionals, including a cardiac rehabilitation nurse, dietician, physiotherapist, pharmacist, psychologist or smoking cessation adviser – but this varies locally.

According to the latest figures[1], just 44% of heart patients in England took part in 2011/12. In Northern Ireland, the figure is 40% and in Wales just 35%. In Scotland 65% of heart patients were referred for a rehabilitation programme in 2010/11[2].

- You could check whether cardiac rehabilitation services are available and easily accessible in your area. To find your nearest cardiac rehabilitation services, **click here**.
- You could also check that heart patients who have had a heart attack, stable angina, heart failure, coronary artery bypass grafting or coronary angioplasty, are being offered a cardiac rehabilitation programme.
- The British Association for Cardiovascular Prevention and Rehabilitation gives guidance on best practice for cardiac rehabilitation[3]. You could check that the programmes in your area meet these minimum standards.

Follow-up appointments

Some people with a heart condition need regular monitoring and treatment. This could involve hospital doctors and nurses, visits to the GP, or referral to a heart failure nurse in the community for assessment and support. Before a patient leaves hospital, a doctor or nurse should tell them about arrangements for future appointments and care.

Exactly how often people are seen depends on their condition. It might be more frequent following discharge from hospital, and then less often. The National Institute of Clinical Excellence (NICE) states that patients with heart failure should have follow-up appointments at least every six months to keep a check on their condition and medication. Those with coronary heart disease, discharged from hospital cardiology, should have at least an annual check-up with the GP surgery.

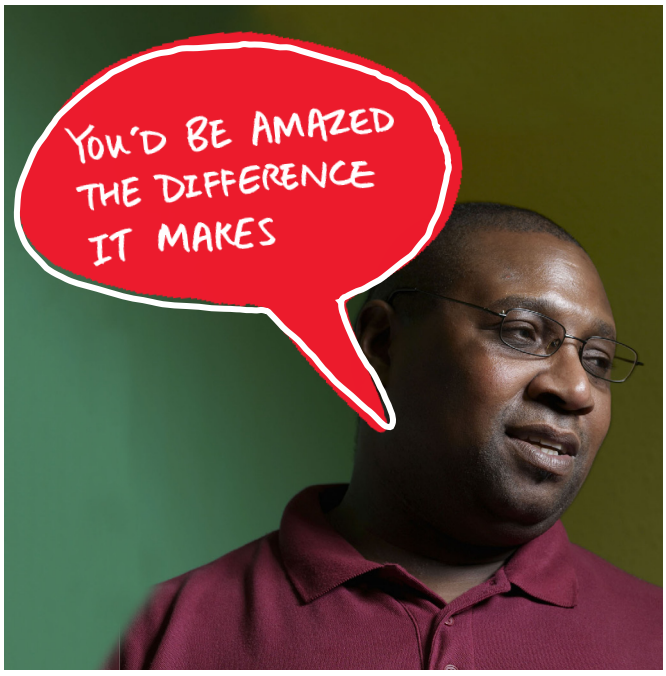
Surveys have found that only 20% of patients had planned specialist heart failure follow-up in England, Wales and Northern Ireland care in 2008[4] – and that under half of heart failure patients were referred to heart failure liaison services after they left hospital in England and Wales. In Scotland, an audit of cardiology services reported that the number of community heart failure nurses per 100,000 population has reduced from 50.7 in 2006 to 46.9 in 2011.

- You could check that heart patients in your area are offered appropriate support after they leave hospital, and that they have follow-up appointments to review their condition and medication.
- You could also check that there are community heart nurses available in your area to provide on-going support if needed.

Your care plan

A personal care plan is a written agreement between a patient and their health care professional to help manage their day-to-day health. It sets out what they should or shouldn't do to help their recovery, outlines their conditions, needs, and preferences for treatment and care. It should also cover relevant lifestyle changes including weight management, healthy eating, stopping smoking, medication compliance, physical activity and psychological support. A care plan is a good way to give people guidance and a feeling of control over their condition so they know what to do if they start to feel unwell again.

- You could check whether heart patients in your area have a personalised management and care plan, including regular face-to-face reviews, and that this plan is shared with all the health care professionals involved in their care.
- You could check whether people living with heart disease in your area have a single care plan that covers all their physical and mental health conditions.



Palliative and end-of-life care

Palliative care provides control of symptoms and maintenance of comfort for people nearing the end of their life with a condition for which there is no cure. The focus is always on quality of life, patient dignity and carer support.

Whenever a patient's condition becomes terminal due to heart failure, the heart failure team should discuss their care needs with them, and their family and carers. If necessary, they can refer patients to a team with specialist skills in this area, known as specialist palliative care.

Unfortunately, it's not always easy identifying patients in need of palliative care as the progression of heart failure can be hard to predict. However, it's important that palliative care is available for everyone who needs and wants it. Even taking into account the difficult prognosis, surveys have shown that people with heart failure often have very limited access to palliative care services or simply don't know they exist[567].

- You could check that heart patients in your area are referred to palliative care if and when they need it.
- You could also check that doctors, nurses and other health care professionals are making sure patients have the chance to discuss issues around end-of-life care.
- Whenever the symptoms of heart failure becomes more severe, patients and their carers should have access to a specialist in palliative care, such as a Heart Failure Palliative Care Nurse and a specialist palliative care service.

Making sure services work together

There are many different health care services for people with a heart condition. One of the big challenges is making sure they all work together. Different service providers need to talk to each other so that care is consistent. This is particularly important for patients with more than one condition, or older patients who may have more complex care needs.

- You could check that people living with heart disease are receiving properly 'joined-up' care and encourage coordination of care.
- You could also look into whether patients experience smooth transitions between different care settings. For example, when a patient leaves hospital, is the GP made aware of their condition and treatment in a timely manner?

[1] BHF (2011) National Audit of Cardiac Rehabilitation Annual Statistical Report 2010
[2] Information Services Division (2012) Cardiac rehabilitation in Scotland
[3] BACPR (2012) The BACPR standards and core components for cardiovascular disease prevention and rehabilitation
[4] Nicol, E.D et al. (2008) NHS heart failure survey: a survey of acute heart failure admissions in England, Wales and Northern Ireland
[5] Nicol, E.D et al. (2008) NHS heart failure survey: a survey of acute heart failure admissions in England, Wales and Northern Ireland.
[6] National Heart Failure Audit annual report 2010/2011 (2012). National Institute for Cardiovascular Outcomes Research (NICOR) University College London (UCL).
[7] Audit Scotland (2012) Auditor general for Scotland. Cardiology services