CARDIAC REHABILITATION... RECOVERY OR BY-PASS?

National Campaign for Cardiac Rehabilitation

BEATING HEART DISEASE TOGETHER
The National Campaign for Cardiac Rehabilitation has five aims:

1. that every heart patient who is suitable and wishes to take part is offered a rehabilitation programme

2. that patients should be offered alternative methods, such as home-based rehabilitation, if they prefer not to take part in a group programme or attend hospital as an outpatient

3. that efforts be made to ensure that rehabilitation programmes meet the needs of under-represented groups, particularly ethnic minorities and women.

4. that each programme should meet the minimum standards set out by the British Association for Cardiac Rehabilitation

5. that this be monitored through the National Audit of Cardiac Rehabilitation.
Championing the cause of cardiac rehabilitation

Cardiac rehabilitation is an inexpensive treatment that saves lives. Yet, in the UK, 60 per cent of the patients who need it do not have access.

As a response to this dire situation, we are forming an alliance of patient organisations, health professionals and heart charities and are, collectively, launching a National Campaign for Cardiac Rehabilitation. Because cardiac rehabilitation lacks a powerful voice, our alliance will champion the cause. Will you join us?

Does it matter if people don’t get rehabilitation?

Cardiologists and surgeons can only do part of the job of putting heart patients back on the road to recovery. Without cardiac rehabilitation, many lives are shortened and many heart patients join those who live an unnecessarily fearful, symptomatic and restricted life.

Some Facts

- More than 30 years of scientific research have proved that rehabilitation is one of the most effective life-saving treatments available. Heart patients who do not take part in cardiac rehabilitation are 25 per cent more likely to die in the following two to five years.

- Cardiac rehabilitation also helps people with a heart condition to look at their life, make any necessary changes, avoid further problems and to get back on their feet again – physically, emotionally, socially and vocationally.

- When provided by suitably staffed and resourced teams, underpinned by good clinical guidelines, cardiac rehabilitation can improve lifestyle, reduce hospital admissions, improve quality of life, and reduce blood pressure, cholesterol, anxiety and depression.

- Cardiac rehabilitation is not expensive.

“I found the whole thing absolutely wonderful – there was someone there that cared. I felt like it was all surreal, like I was falling – and they [rehab] were there to catch me. I thought I would come home and that would be it, but rehab really helped me. You don’t know what you can and can’t do when you get home, but she [rehab nurse] made me realise I was not an invalid. It is also good for the whole family – my husband got great benefit from it.”

Pauline, age 56, Cambridgeshire
So it’s mainly about keeping people alive longer?

No. Finding out that you’ve got a life-threatening illness – and coming close to death – usually comes as a heavy blow. Many patients also have to cope with frightening and distressing symptoms such as chest pain, breathlessness, lack of energy, poor sleep, sexual difficulties, stress, anxiety and depression.

Some Facts

- Rehabilitation helps with all of these things too.
- Rehabilitation identifies physical, emotional, psychological, educational, social and other problems which may be holding the patient back, addresses them with the patient and the patient’s family, and either helps directly or signposts people to the appropriate specialist service.
- As anyone who has experienced good quality cardiac rehabilitation will tell you, rehabilitation provides much more than extra years. Rehabilitation supports and encourages changes and helps people set and work towards realistic and achievable personal goals to “restore their health and return to normal life”.

Do health departments in the UK support cardiac rehabilitation?

Yes. The relevant authorities in each of the four countries of the UK have made statements supporting the use of cardiac rehabilitation but they have failed to ensure that it is adequately funded.

Some Facts

- Over the last 30 years many organisations – from the World Health Organization to the British Cardiovascular Society – have reviewed the scientific evidence for cardiac rehabilitation. All recommend it in the strongest possible terms.
- The National Health Service in England, Wales, Scotland and Northern Ireland all encourage the development of better services and have produced reports or guidelines urging local trusts to make it available.
• The National Institute for Health and Clinical Excellence (NICE), which makes recommendations for gold standard and cost-effective treatments in England and Wales, says that every patient who has a heart attack should be offered rehabilitation.

So why do we need a campaign?

Despite Government pronouncements, cardiac rehabilitation is still not accessible to 60 per cent of the patients who want to take part.

Some Facts
• The NHS has not lived up to its many promises for cardiac rehabilitation.
• In 2006, the Healthcare Commission, the independent inspectorate for NHS standards in England, declared cardiac rehabilitation a ‘Cinderella service’, poorly funded and poorly organised, denying access to patients in need.
• Even where it is available, many groups of patients who would benefit are not able to take part because of a lack of funding. They include people with angina, heart failure, arrhythmias or implanted cardiac devices.

Surely access to services must be improving?

Far from improving, the outlook in 2007 is even less secure than in 2006!

Some Facts
• Some programmes have closed. A few, supported and championed by ex-patients, have fought and survived. Many others still fear closure.
• In Northern Ireland, Scotland and Wales, money is provided to local NHS organisations to pay for rehabilitation but the amounts provided are generally inadequate. In England, cardiac rehabilitation is not funded separately: some trusts have allocated money while others have not.
• In a survey carried out in February this year, 50 per cent of programmes in the UK reported that they felt under threat. Programmes are usually led by nurses and physiotherapists who, like patients, do not have much ‘clout’ when money is being discussed.
• Even before this crisis, many rehabilitation programmes were struggling to provide even a basic level of care for many of their patients. Many know that they fall short of the clinical recommendations set out in national documents.
Perhaps cardiac rehabilitation just can’t be delivered?

Experience shows us that cardiac rehabilitation can be delivered very well. There are a number of excellent services which are well staffed and enthusiastically supported by their local Primary Care Trust.

Some Facts

- Patients face a postcode lottery. Their chances of taking part in a cardiac rehabilitation programme will depend on where they live.
- Their chance may also depend on who they are. Surveys show that women, older people, those in rural areas, people from ethnic minority groups, those who are depressed and smokers are all losing out.
- There is often a lack of understanding of the benefits of cardiac rehabilitation in acute and primary care organisations. However, when they do take an interest, they are capable of providing an excellent service.

Can the health service afford cardiac rehabilitation?

Cardiac rehabilitation is very cost-effective compared to other treatments.

Some comparative costs

The average cost per patient for cardiac rehabilitation in the UK in 2005–06 was £413.

Independent researchers have worked out that to meet the basic standard in clinical guidelines the cost per patient should be about £600.

To put the cost into a health service perspective:

- a single day in a coronary care unit costs £1,400
- an angioplasty (which does not reduce mortality) costs £3,000
- bypass surgery costs in the region of £8,000.

Can the health service afford not to have cardiac rehabilitation?

Well-delivered rehabilitation is highly cost-effective and can actually reduce health care costs.

Keith, age 60, Solihull

“...I used to be really fit before my heart attack. I’m still waiting for rehab due to lots of delays with the exercise test. I just don’t know how much I can or can’t do, and am really keen to access the rehab programme to find out.”

National Campaign for Cardiac Rehabilitation
What would have helped me feel any different? If the cardiac rehabilitation sessions had been more accessible and I had been able to access the follow up support on dietary advice, exercise and general support, then I may have developed a more positive attitude to my health and future. I will never know.

63 year old heart attack patient

Some Facts

- It is not just patients and their families who benefit from cardiac rehabilitation. We all do.
- Where rehabilitation needs are not met, the burden falls on other, usually less appropriate services and on family and carers.
- Heart patients who are left unsure, anxious and depressed have many more tests and investigations than those who are not. In one study, the costs were 400 per cent greater over the next year. However, none of these costs were spent on relieving the anxiety.

Does cardiac rehabilitation fit with long-term NHS aims?

All health departments in the UK have initiatives to improve the self-management of chronic illness but these initiatives have ignored cardiac rehabilitation – which is the most researched and proven method.

Some Facts

- Cardiac rehabilitation teaches people how to manage their condition, reducing their dependence on health services.
- Many of the aims for improving the self-management of heart disease could be achieved if rehabilitation services were better funded and integrated with chronic disease management in primary care.
- The Government wants to move to a ‘patient led’ health service. There have been several ‘listening exercises’ with groups of heart patients in which cardiac rehabilitation has always emerged as a patient priority. Yet this request has been ignored.
- High quality cardiac rehabilitation will help tackle inequalities. Surveys show that women, older people, people in rural areas, people from ethnic minorities and people who are depressed are all less likely to be offered cardiac rehabilitation.
- Providing a range of cardiac rehabilitation programmes moves patient care into the community, closer to where people live.
Who does get cardiac rehabilitation?

In 2004, the British Heart Foundation set up a National Audit of Cardiac Rehabilitation to measure in detail where in the country people are being disadvantaged and which groups of patients are not taking part.

Some facts from the National Audit of Cardiac Rehabilitation

- There are 360 rehabilitation programmes on the official register in the UK. Together, at best, they treated about 40 per cent of patients in 2005–06 who had a heart attack, angioplasty or bypass surgery.
- This is far short of the 200,000 or so new patients every year found to have coronary heart disease who would benefit if they were able to take part.
- Very few patients with angina, heart failure, implanted cardiac devices, some arrhythmias or congenital heart disease are offered help.

In Germany, every heart patient is offered a four-week residential rehabilitation programme in a special centre!

A separate leaflet is available giving more information from the Audit (download from www.cardiacrehabilitation.org.uk/campaign).

Why are services so poor?

In most cases, programmes have developed despite rather than because of NHS systems. Physiotherapists, nurses and other health care workers recognised the needs of their patients and they have found ways to meet those needs. Even today, 25 per cent still depend in part or in total on charity or local fundraising.

The British Heart Foundation has helped to finance over 180 of the UK’s 360 programmes. Although the traditional grants offered to set up cardiac rehabilitation services are no longer available, the Foundation recognises the need – and urgency – to support cardiac rehabilitation services.

“Everything about cardiac rehab was positive for me. It was just fantastic. Boosting confidence was a great thing – it allows you to think about the future. Spin offs are also beneficial for the family too. On the social side, it’s great to see lots of people enjoying themselves.”

Noel, Aldershot
Some Facts

• Cardiac rehabilitation is not included in medical education so very few doctors are aware of how powerful the benefits of cardiac rehabilitation are and how much scientific evidence there is to support it.

• Very few cardiologists are interested in cardiac rehabilitation, no drug companies promote it and no-one makes money from it privately so it lacks a powerful champion to fight for it.

Can a campaign really change anything?

We believe that this crisis of care – and crisis of caring – has arisen because of a lack of awareness about cardiac rehabilitation and the benefits it can deliver, so we hope to educate health care professionals and, most importantly, the public.

We believe that when the public become aware of the loss of life and suffering that result from a failure to implement the recommendations on cardiac rehabilitation, people in a position to influence policy will act to remedy the situation.

Rehabilitation fulfils so many of the governments’ aims for the health of the population that it would be extraordinary if they let it disappear.

For all of these reasons we believe a campaign of publicity and education will be effective. If it is not, cardiac rehabilitation in the UK may eventually disappear or be available only to those who can afford to pay.

If you feel that cardiac rehabilitation is treated unjustly, we hope you will support our campaign. You can be the champion cardiac rehabilitation so badly needs.

How can I become a champion for cardiac rehabilitation?

The campaign committee will be raising awareness at the national level but we need you to champion the cause locally.

Why not contact your local rehabilitation programme and ask if they have any problems you could publicise for them? You can find them by typing your postcode into this webpage www.cardiac-rehabilitation.net, or if you do not have access to the internet by phoning the British Heart Foundation on 020 7487 7110.

Your local paper may be interested in hearing about any difficulties and running an article or campaign.

You could help by raising awareness by writing or speaking to those people who could help.
Apart from the six months appointment after discharge, there was no follow up after being in hospital. Before leaving hospital, I’d been told about a cardiac rehabilitation course … but the venue is miles away. I don’t drive and there is no good public transport so I couldn’t get there. No further advice was offered, no alternative. I felt very disappointed, and again very isolated and quite depressed.

63 year old heart attack patient

In England
Your primary care trust, strategic health authority, cardiac network, local papers, MP and the Secretary of State for Health.

In Northern Ireland
Your health and social services board, cardiac network, local papers, MLA, MP and Health Minister.

In Scotland
Your NHS board, managed clinical network manager, local papers, your MSPs, MP and the Minister for Health at the Scottish Executive.

In Wales
Your local health board, cardiac network, local papers, your local Assembly Member and Health Minister.

You can find their addressees in your local phone book.

If you would like to know more about cardiac rehabilitation – or to be able to give other people more information about the scientific evidence for it – we have produced another campaign briefing, called Cardiac Rehabilitation… recovery or bypass. The Evidence, which gives more detailed information, references to the evidence and further sources of information.

You can get a copy by contacting BHF Orderline
0870 600 6566
(Ref code is M101)

or downloading it from:
www.cardiacrehabilitation.org.uk/campaign
This report was prepared by the British Heart Foundation, the BHF’s Care and Education Research Group at the University of York and the British Association for Cardiac Rehabilitation. It makes the case for improved access to cardiac rehabilitation services for people living with heart disease. The report was edited by Helen Martins from Portfolio Publishing and published by the British Heart Foundation. More detail on the evidence for cardiac rehabilitation is available in the Road to recovery …or by-pass? The Evidence for a National Campaign for Cardiac Rehabilitation.

This campaign is supported by: