

The expert patient: good thinking or a cross to bear?

The concept of chronic disease self-management programmes together with the emerging expert patient has not been widely studied in the context of heart disease. But many of our patients with chronic heart disease are already experts. The knowledge and experience held by the patient has been untapped as a healthcare resource. Research from Stanford¹ has shown that lay people with chronic conditions – when given a detailed leader's manual – can be as effective as professionals in managing their disease and its impact on their daily life. It has also been acknowledged in the report 'The expert patient: a new approach to chronic disease management for the 21st Century',² which recommends action over a six-year period to introduce lay led self-management training programmes for patients with chronic diseases within the NHS in England. A pilot phase between 2001 and 2004 will evaluate local programmes; between 2004 and 2007, programmes will be mainstreamed within all NHS areas.

The user-led, self-management programme has been the predominant model developed and evaluated over the last 20 years in certain areas, such as rheumatology. (In asthma and diabetes many self-management programmes for patients are led by professionals.) Professionally trained instructors with chronic disease, educate and train course volunteers with illnesses such as arthritis, diabetes, HIV, stroke and heart disease. There are UK pilots now implementing this phase of the programme for coronary heart disease (CHD). The pilot course is run over six consecutive weekly sessions of 2.5 hours each week and is highly structured, delivered from a scripted manual covering topics including relaxation, cognitive symptom management, exercise, fatigue, nutrition, problem solving, action planning and communication, and healthcare professionals. Review of the evidence on self management as a whole,³ conducted by Professor Julie Barlow of Coventry University, has shown that the benefits of self management include:

- reduced severity of symptoms
- significant decrease in pain
- improved life control and activity
- improved resourcefulness and life satisfaction.

A five-year research project has evaluated the chronic disease self-management programme in a randomised study⁴ involving more than 1,000 patients and found that the intervention group improved their health-giving behaviours, health status and decreased days in hospital. The key to effective self management is the change in the individual's confidence and belief that

they can take control over their life despite their disease.

CHD initiative

We should embrace this initiative for heart disease patients but with careful adjustment of the manual so that patients do not play down symptoms that merit ischaemic reassessment, either in their CHD Primary Care Register Clinic or with their cooperative record into secondary care. The programme requires qualification and specific development for application in cardiological patients. Whilst heart failure is clear to sufferers as a chronic disease, many CHD patients do not see themselves as chronic disease sufferers for much of their lives – nor should they except in acknowledging that they should follow a healthy lifestyle and maintain preventive measures and activities. Their lives, however, may be interrupted by acute crises and the appropriate management of these should be clearly addressed as a core requirement of training. The 'Heart manual' is quoted in the publication but this is essentially a rehabilitation at-home guide, albeit inclusive of some important self-help advice. Enthusiastic facilitation is essential to its successful use.

Key issues will include integration of the self-help programmes into all local NHS services with joint working with social care providers and community (including voluntary) groups, plus the flexibility to offer and evaluate variations to meet specific needs, e.g. of older people. Significant improve-



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ment can be made to services by ensuring adequate investment. In the UK we must ensure that the expert patient strategy does not shift investment away from the real requirement – more psychiatrists in manic depression, more neurologists for multiple sclerosis, and more rheumatologists for arthritis care, for instance. The poetic justice which may arise from the expert patient programme is that the true need for specialist advice will be defined.

Patient organisations

It is acknowledged that patient organisations have a vital role to play in partnership with the NHS and the Government in developing a national expert patients' programme. Patient involvement in the NHS generally and developments in cardiology are tackling the issue on a wider front. 'The expert patient' is only one concept of the contribution patients can make to the health service in heart disease. Many patients have already shown innovation in developing programmes themselves – they may provide access to a larger pool of potential lay tutors. A recent national survey by the British Heart Foundation of its Heart Support Groups⁵ has shown that less than 2% of likely CHD patients in the UK actually belong to any group and their main reason for attending is to receive educational support and practical advice. Only a minority had an interest in providing support to others by improving services.

The National CHD Patient and Carer Survey⁶ has highlighted the issues of communications and information. Although patients' willingness to undergo formal training and then teach is not yet known, the British Cardiac Patients Association have informally done much for their members. There are a wealth of focus groups for a multiplicity of conditions in cardiology. All share an agenda of common experiences and a desire to support others; their leaders are committed to form a new Heart Care Partnership with health professionals from the British Cardiac Society for all those "who live with heart disease". The theme of improving communications is a focus for everyone in early joint meetings. The wish for more education appears universal amongst 'thinking' patients who not only want empowerment through information but also want to share ideas in their treatment and care. The way forward may be to follow on formal programmes – such as the Phase IV maintenance phase of CHD Rehabilitation and Prevention – with a chronic disease self-management programme for those able to follow it. Talented patients could be stretched further by nomination for 'patient expert' training. They would then be able to contribute to the peer-review process, for instance.

Support from health professionals

Primary care also encourages these endeavours⁷ citing the example of the charity, Diabetes UK, as a model of professionals and patients working together. The patient perspective in the current

Fifth Joint Report⁸ on the provision of services for patients with heart disease has emphasised that the patient has a right to a specialist cardiological opinion when and where appropriate, and that health professionals treating patients with heart disease should have relevant training in the specialty. The issues of good communication and provision of understandable information should be better addressed under such circumstances. The patient:professional interface is ripe for development and the British Cardiac Society/British Heart Foundation initiatives are broadly welcomed among patient representatives.

The Department of Health's Expert Patients' Programme may well have a central role in transforming patient empowerment. This concept needs to be adapted and extended to be of relevance to all heart patients and their carers. The appreciation of the importance of maintaining a good lifestyle during the prevention phase of CHD, which is only briefly interrupted by acute coronary episodes, is vital. The ability of people to help monitor their own surveillance by shared care records may be expanded. We wish to go further and provide a focused partnership for patients, families, doctors and other health professionals to collaborate in management, mutual support, dissemination of knowledge, and research – and through mechanisms such as the British Cardiac Society Peer Review and British Heart Foundation's committees contribute to the development of services for all who live with heart disease. When this century's history of medicine is written, perhaps it will be entitled: 'Patients' progress: health professionals and patient carer partnerships in the 21st Century'.

Jane Flint

Consultant Cardiologist

Dudley Group of Hospitals,

Wordsley Hospital, Wordsley,

Stourbridge, West Midlands, DY8 5QX.

email: jane.flint@dudley.goh-tr.wmids.nhs.uk

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