

Expert patients usher in a new era of opportunity for the NHS

The expert patient programme will improve the length and quality of lives

This patient knows more about her disease than I do." This passing remark was made more than 30 years ago to a group of new medical students as we stood around the bedside of a woman with longstanding diabetes mellitus. It is a sentiment that has probably been expressed or felt by doctors many thousands of times since.

Yet until recently the wisdom and experience of the patient has been only a tacit form of knowledge whose potential to improve the outcome of care and quality of life has been largely untapped. In England alone, there are now nearly 10 million people with a chronic disease. It has been estimated that non-communicable diseases account for almost 40% of deaths in developing countries and 75% in industrialised countries.

Strong evidence that the expertise of patients could be harnessed to play a part in addressing the challenge of this shifting burden of disease came from Professor Kate Lorig and her colleagues at Stanford University, California. She started to develop and evaluate programmes for people with arthritis and side stepped the traditional model of professionals educating patients. By means of a more radical and innovative solution, using trained lay leaders as educators, she equipped people with arthritis and other chronic diseases with the skills to manage their own condition. She found that, compared with other patients, "expert" patients could improve their self rated health status, cope better with fatigue and other generic features of chronic disease such as role limitation, and reduce disability and their dependence on hospital care.¹

The Lorig approach created a clearly defined chronic disease self management programme (CDSMP) that was used in the 1990s by patient organisations, such as the Long-term Medical Conditions Alliance, in the United Kingdom.²

The government moved to make an expert patient programme a centrepiece of the NHS approach to chronic disease management in the 21st century. The public health white paper, "Saving Lives: Our Healthier Nation" set out the commitment³; formal proposals were made in a chief medical officer's report⁴; and a commitment to implement was made in the 10 year NHS Plan published in 2000.⁵

The expert patient programme is already being piloted in more than 100 primary care services in England and there are plans to implement it throughout the NHS between 2004 and 2007. Feedback such as, "It

gave me new ways of analysing and solving some of my problems ... I believe that this is one of the most important initiatives for those with long-term chronic conditions"; "The expert patient programme has really helped me to take more control of not just my arthritis, but also my life"; "I have learnt that I need to take responsibility for my health instead of leaving it all to the GP"; "Coming on the programme has given me real confidence to move on, plan for the future without fear, because I can now plan and pace—really good teaching" is typical of what patients think about the programme.

This is in keeping with what we know from experience elsewhere: those patients who are confident in their ability to manage their condition are the ones who are likely to have the best outcomes. When patients succeed in resolving problems which they have themselves identified it enhances their sense of self efficacy. Quality of life improves when the patient rather than their disease is in control.

Self efficacy also predicts a healthy lifestyle.⁶ The philosophy which underlies the expert patient programme has implications for the ways in which people live their lives beyond just the management of chronic disease. Those who are able to deal successfully with the problems posed by a chronic illness, and those who avoid illness through a positive lifestyle, may have a great deal in common. Such people live longer and healthier and are an example of how more assertive engagement with one's own health and with the healthcare system can improve both the length and the quality of people's lives.⁷

The expert patient programme is one of the best examples of how a true partnership between the public and health professionals can be formed. If successful it will slow, arrest, or possibly even reverse the progression of the chronic diseases of thousands of patients. It will give those affected the power to manage their conditions more effectively. The patient as expert and partner in care is an idea whose time has come and has the potential to create a new generation of patients who are empowered to take action to improve their health in an unprecedented way.

A true partnership will be achieved only with a significant change in the attitude of both patients and healthcare professionals and the way in which they interact with one another.⁸ Even if self management courses are delivered by lay educators, patients should

be encouraged to enrol by the professionals who care for them.⁹ In spite of this not all patients will come forward; although formal evaluation is underway, anecdotal impressions so far suggest a level of commitment and enthusiasm from patients, healthcare professionals, and managers which will carry the management of chronic disease into a new era of optimism and opportunity.

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