

The Expert Patient: a briefing note

The Expert Patient, published in September 2001, sets out what it terms 'a new approach to chronic disease management for the 21st century. This notion was first put forward - in an official paper - in the white paper *Saving Lives: our Healthier Nation* and then reaffirmed in the NHS Plan.

It has two starting points:

First: the predominant disease pattern in this country is of chronic rather than acute disease. The second half of the 20th century and the beginning of this new century have seen a period in which many more people have lived into their seventies, eighties and beyond. But with this improvement in overall health status and greater longevity have come a major burden of diseases like cancer, heart disease, stroke, arthritis, mental illness, diabetes mellitus and asthma. These diseases can and do kill but increasingly they are a burden that people carry from the middle years of life into old age. (p 12)

Second: today's patients with chronic diseases need not be mere recipients of care. They can become key decision-makers in the treatment process. By ensuring that knowledge of their condition is developed to a point where they are empowered to take some responsibility for its management and work in partnership with their health and social care providers, patients can be given greater control over their lives. Self-management programmes can be specifically designed to reduce the severity of symptoms and improve confidence, resourcefulness and self-efficacy. (p 5)

The report goes on: The era of the patient as the passive recipient of care is changing and being replaced by a new emphasis on the relationship between the NHS and the people whom it services - one in which health professionals and patients are genuine partners seeking together the best solutions to each patient's problem, one in which patients are empowered with information and contribute ideas to help in their treatment and care. (p 9)

Against this background the paper states that: The challenge for the NHS, working in partnership with patient organisations and other government departments and agencies, is to bring about a

fundamental shift in the way in which chronic diseases are managed - a shift which will encourage and enable patients to take an active role in their own care. (p 6)

The key means of making the shift is to be self-management programmes. Some have already been developed in the US and also in this country by patients' organisations such as Arthritis Care.

The report makes eight specific recommendations:

- To promote awareness and create an expectation that patient expertise is a central component in the delivery of care to people with chronic disease.
- To establish a programme for developing more user-led self-management courses to allow people with chronic diseases to have access to opportunities to develop the confidence, knowledge and skills to manage their conditions better, and thereby gain a greater measure of control and independence to enhance their quality of life.
- To identify barriers to mainstreaming user-led self-management in the NHS and address these barriers, in the first instance, through existing National Service Frameworks and others that are planned such as that on Long-Term Health Conditions.
- To integrate user-led self-management into existing NHS provision of health care - e.g. into other National Service Frameworks, Healthy Living Centres and NHS Direct.
- To ensure that each Primary Care Trust area has arrangements for user-led self-management programmes for key chronic conditions to be delivered or commissioned.
- To expand the practical support for user-led programmes provided by patients' organisations in partnership with health and social care professionals.
- To build, as part of continuing professional development programmes, a core course which would promote health professionals' knowledge and understanding about the benefits - for them as well as for patients - of user-led self-management programmes.

- To establish a National Co-ordinating and Training Resource to enable health, social services and voluntary sector professionals to keep up to date with developments in the provision of self-management; patients should be part of the process of developing professional education programmes. (p 8)

The Benefits

The changes promoted by the new programme are expected to bring about health benefits and also gains in employment and a reduction in the use of health services. See Box:

A vision for a successful Expert Patients' Programme

- Many more patients with chronic diseases improve, remain stable or deteriorate more slowly.
- Many more patients can manage effectively specific aspects of their condition (such as pain, complications, medication use).
- Patients with chronic diseases who become expert are likely to be less severely incapacitated by fatigue, sleep disturbance, and low levels of energy.
- Most patients with chronic diseases have skills to cope with the emotional consequences of their disease.
- Many people with chronic disease gain and retain employment.
- Many more patients with chronic diseases successfully use health promoting strategies (for example improving diet, exercise, weight control).
- Most patients with chronic diseases are effective in accessing appropriately health and social care services.
- People with chronic disease make greater use of Adult Education and employment training programmes.
- Many more patients with chronic diseases are well informed about their condition and medication, feel empowered in their relationship with health care professionals, and have higher self-esteem.
- People with chronic diseases spend fewer days a year as hospital inpatients or attending outpatient clinics.
- People with chronic diseases contribute their skills and insights for the further improvement of services.
- People with chronic disease work as counsellors, information workers and advocates for others. (p 14)

Implications for the NHS

These recommendations represent a massive shift in the way that the NHS works and in the roles of the professionals within it.

2.12 The challenge for the NHS, working in partnership with patient organisations and other government departments (for example, the Department for Work and Pensions) and agencies, is to bring about a fundamental shift in the way in which chronic diseases and long-term conditions are managed - a shift which will empower and liberate patients to play a central role in decisions about their illness. (p.17)

Next Steps

The proposed timetable is as follows:

- Between 2001 and 2004: enough pilot schemes to cover all Primary Care Trust and Primary Care Group sites.
- Between 2004 and 2007: programmes to be mainstreamed throughout the NHS.

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30 October 2001