

Decision-making
SELF-ESTEEM
PAIN RELIEF
EMPOWERMENT
User-led
Better Quality of Life
medication knowledge

The Expert Patient:

**A New Approach to Chronic Disease
Management for the 21st Century**

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Foreword



The Government is committed to helping everybody enjoy more years of healthy and active life. This includes people who live with chronic medical conditions. We know from the findings of research that such people are often in the best position to know what they need in managing their own condition. We also know, however, that in the past too little has been done to support them. An Expert Patients Task Force was set up in late 1999 with a remit to design a new programme that would bring together the valuable work of patient and clinical organisations in developing self-management initiatives. The outcome of this work and the recommendations are set out in this report.

On a personal note I am delighted to have had the opportunity to work closely with the Task Force in putting together this exciting programme. It has been a challenging but very rewarding exercise, and I am extremely grateful to the members of the Task Force for their time, commitment and contribution.

Professor Liam Donaldson
Chief Medical Officer

Executive Summary

- The second half of the 20th Century and the beginning of the new century has been a period in which many more people have lived into their seventies, eighties and beyond. This greater longevity has brought with it an increased burden of heart disease, stroke, cancer, arthritis, diabetes mellitus, mental illness, asthma and other conditions. As a result, the predominant disease pattern in England, and most other developed countries, is one of chronic or long-term illness rather than acute disease.

The Challenge: Chronic Disease and its Effects

- In Great Britain, at any one time, as many as 17.5 million adults may be living with a chronic disease. Older people suffer more with up to three quarters of those aged 75 years and over falling into this category.
- Living with long-term conditions for the individuals affected and their families can often mean physical and psychological difficulties, socio-economic problems, reduced quality of life and sometimes social exclusion.
- People have problems specific to their individual illness but there is also a core of common needs: for example knowing how to recognise and act upon symptoms, dealing with acute attacks or exacerbations of the disease, making the most effective use of medicines and treatments, accessing social and other services, dealing with fatigue, managing work and developing strategies to deal with the psychological consequences of the illness.
- Traditionally these problems faced by a person with chronic disease have not been comprehensively dealt with by health care providers in the NHS, the social services providers or the employment services.

The Concept of Expert Patients

- An observation often made by doctors, nurses and other health professionals who undertake long-term follow-up and care of people with particular chronic diseases like diabetes mellitus, arthritis or epilepsy is “my patient understands their disease better than I do.”
- This knowledge and experience held by the patient has for too long been an untapped resource. It is something that could greatly benefit the quality of patients’ care and ultimately their quality of life, but which has been largely ignored in the past.
- The emphasis is beginning to shift. Research and practical experience in North America and Britain are showing that 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.

The Expert Patients Initiative

- The idea of developing a major initiative on Expert Patients was set out in the Government's 1999 White Paper, *Saving Lives: Our Healthier Nation*. A further commitment to implementing a formal programme was made in *The NHS Plan* published in July 2000.
- In taking this idea forward and setting out the proposals contained in the strategic document, the Government's Chief Medical Officer, Professor Liam Donaldson, has been supported by a Task Force (membership set out in the Appendix).

A shift of emphasis necessary for the NHS

- The experience of people with chronic disease in using health services is very variable. In the better services people are given advice and information and their questions are answered. But few go beyond this to ensure that a patient's growing knowledge of his or her condition is developed to a level whereby self-management, within the boundaries of a medical regime, becomes a real option. The impact of this has been considerable. Individuals have experienced unnecessary pain and discomfort along with a severe limitation to their quality of life. There is also an economic cost to society from avoidable absence from work and inflated health and social service costs.
- 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.
- Patient self-management programmes, or Expert Patients Programmes, are not simply about educating or instructing patients about their condition and then measuring success on the basis of patient compliance. They are based on developing the confidence and motivation of patients to use their own skills and knowledge to take effective control over life with a chronic illness.

Chronic Disease Self-Management Programmes

- User-led self-management programmes have been developed over the last twenty years. These move beyond the purely medical view to look at how the illness impacts on daily life. The leading international authority in this field is Professor Kate Lorig of Stanford University, California, USA and the Chronic Disease Self-Management Programme (CDSMP), developed at Stanford, recognises that people with chronic illness deal with common issues such as pain management, stress and a need to develop coping skills, on a daily basis. The course is highly structured and is led by teams of trained volunteers all living with a long-term condition. Topics covered include cognitive symptom management, exercise, nutrition, problem solving and communication with professionals. A key element to the programme is the use of trained lay people with chronic illness as tutors.
- A number of similar programmes have been developed by patient groups and representative organisations in this country:

Self-Management in Arthritis: 'Challenging Arthritis' is the name given by Arthritis Care to the Arthritis Self-Management Course (ASMC), a user-led programme in which all senior staff, self-management trainers and volunteer course leaders are people with arthritis. In randomised controlled trials the ASMC, and modified versions of it, showed consistent improvements in knowledge, self-efficacy and the use of self-management behaviours, notably exercise.

Self-Management Training Programme (SMTP) for Manic Depression: begun by the Manic Depression Fellowship in 1998. It is entirely user-developed and user-led. The programme has been designed to enable individuals with a diagnosis of manic depression to gain confidence in their own capacities and to take control of their lives. This programme was developed from a course that originated in Ohio. It is currently the subject of a randomised controlled trial (RCT) with good outcomes to date, including improvements in mood sustained 3–6 months after completion of the course.

Self-Management in Multiple Sclerosis: The Multiple Sclerosis (MS) Society has this year begun to train tutors to deliver structured self-management courses based on the Lorig model. The tutors themselves have MS. The course content includes choosing treatment, managing fatigue, problem solving, accessing health services and communicating with health care professionals.

- A review of the research evidence of self-management programmes was conducted for the Task Force by Professor Julie Barlow of Coventry University. The review concluded that tangible benefits include:
 - reduced severity of symptoms;
 - significant decrease in pain;
 - improved life control and activity;
 - improved resourcefulness and life satisfaction.
- Research outcomes also demonstrated the potential of self-management programmes to enhance the quality of the doctor-patient relationship. Patients regularly reported improved communication with physicians and other health care providers.
- It is important to recognise that an Expert Patients Programme is not an anti-professional initiative. It is based on partnership. The expertise of professionals is no less essential in treating chronic disease when patients are involved in self-management. The knowledge and skills achieved by such training programmes should serve to promote the most appropriate use of the available health care.

A Vision of Success

- Ultimately if the Expert Patients Programme is successful the future role of patients with chronic disease will be very different. Some of these differences will show as:
 - 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 are less severely incapacitated by fatigue, sleep-deprivation, low levels of energy and the emotional consequences of their illness;
 - patients with chronic diseases are effective in appropriately accessing health and social care services and gaining and retaining employment;

- 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 contribute their skills and insights for the further improvement of services and as advocates of others.

The Proposals: Action to Create an Expert Patients Programme

- The report 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 and between 2004 and 2007 programmes will be mainstreamed within all NHS areas.
- The eight specific recommendations of the report are:
 - i) Promote awareness and create an expectation that patient expertise is a central component in the delivery of care to people with chronic disease.
 - ii) 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.
 - iii) 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.
 - iv) 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.
 - v) Ensure that each Primary Care Trust area has arrangements for user-led self-management programmes for key chronic conditions to be delivered or commissioned.
 - vi) Expand the practical support for user-led programmes provided by patients' organisations in partnership with health and social care professionals.
 - vii) 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.
 - viii) 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.
- In the implementation of this new programme it will be essential that the NHS works closely with the leading patient representative bodies and the main health professional bodies, and that the approach is consistent with the principles being developed within the National Service Framework for Long-Term Health Conditions.

Conclusion

- 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.
- The evidence, experience and views gathered during the preparation of this report leave no room for doubt that the people in this country living with a chronic disease are central to this transformation.
- The proposals set out in this report have the potential to create a cadre of expert patients – people who have the confidence, skills, information and knowledge to play a central role in the management of life with chronic diseases and to minimise the impact of disease on their lives.
- To enable people to achieve good quality of life despite having a chronic disease is the fundamental goal of the change being sought by this report. It is a big challenge for the NHS but also an enormously exciting opportunity – to work with patients and the organisations that represent them to move into a new era in the management of chronic disease.

1. The Vision

This chapter introduces the concept of expert patients – who enjoy good quality of life despite chronic disease; who have the confidence, skills, input and knowledge to play a central role in the management of life with chronic disease, and to minimise its impact on their day-to-day living. It sets out the background and scope of the task, which was to ensure that the NHS has an effective programme in place to help and support people with a wide range of chronic diseases in becoming ‘experts’.

- 1.1 Over the last three years, new policies to modernise the NHS have consistently emphasised the importance of the patient in the design and delivery of services.
- 1.2 These patient-centred policies, developed further in *The NHS Plan*, are now in the process of being implemented. They aim to introduce:
- clearer national standards through National Service Frameworks and the National Institute for Clinical Excellence (NICE) so that patients can see what to expect from high quality services;
 - comprehensive programmes of clinical governance in all local services to assure and improve quality and create a safer environment for patients;
 - greater flexibility and choice in accessing services, for example through the nurse-led telephone service (NHS Direct), Walk-in Centres and the NHS website;
 - a more positive and systematic approach to questions of consent including the use of patient information;
 - greater influence by patients over the quality and content of services;
 - more power for patient representatives and advocates when there are complaints and concerns about standards of care.
- 1.3 These fundamental changes to the way the NHS operates as it moves into a new century are serving to empower patients and are based on recognition of the fact that patients and professionals each have their own area of knowledge and expertise and need to work together.

Sharing Expertise

Patient

- Experience of illness
- Social circumstances
- Attitude to risk
- Values
- Preferences

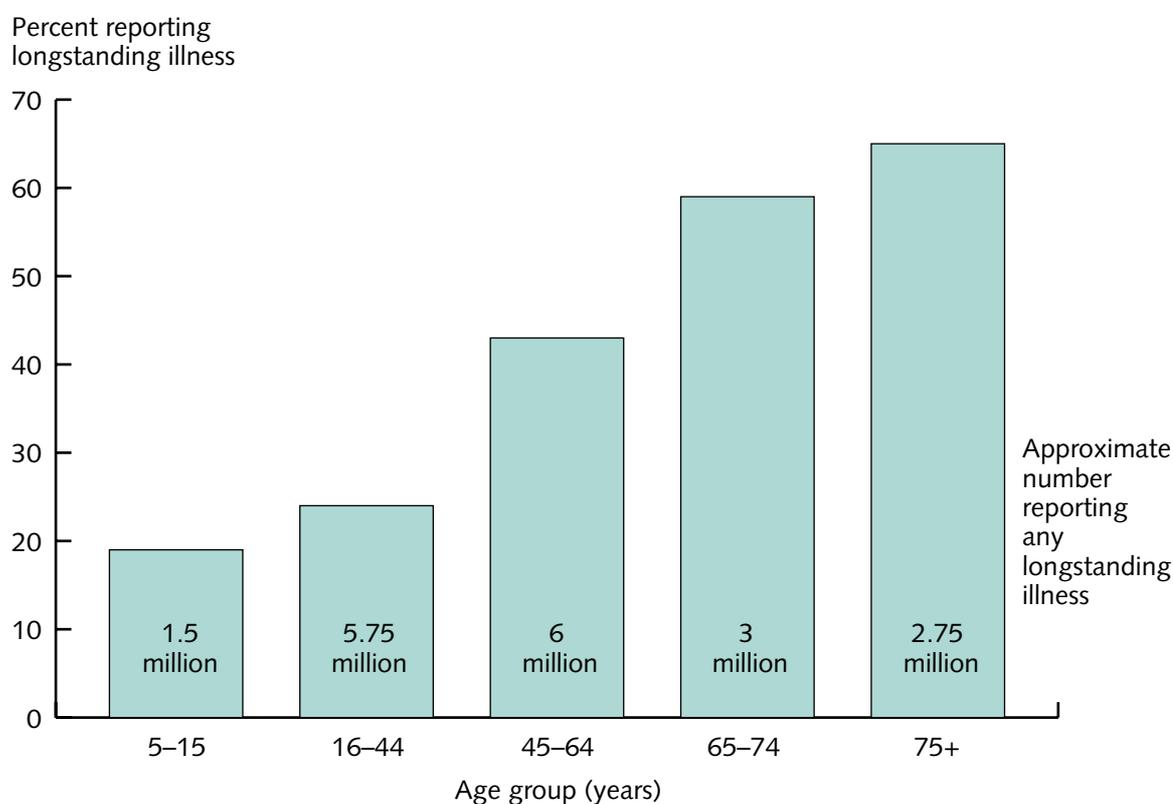
Clinician

- Diagnosis
- Disease aetiology
- Prognosis
- Treatment options
- Outcome probabilities

(Source: Coulter, A, Picker Institute, 2001)

- 1.4 The era of the patient as a passive recipient of care has been challenged by many examples of innovative practice, and is being replaced by a new emphasis on the relationship between the NHS and the people whom it serves: 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, without fear of intimidation or ridicule; one in which expert patients actively contribute – from their knowledge and experience – to further improvements in the quality of tomorrow's health service.
- 1.5 This vision for a new, more patient-centred NHS must embrace the fact that 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.

Numbers of people reporting that they suffered from a longstanding illness, Great Britain



Source: ONS. General Household Survey 1998

“When acute disease was the primary cause of illness, patients were generally inexperienced and passive recipients of medical care. Now that chronic disease has become the principal medical problem, the patient must become a co-partner in the process.”

Holman and Lorig, *British Medical Journal* 2000;**320**: 526-7.

- 1.6 Living with long-term conditions for individuals and their families has become a strong feature of our modern society. Physical and psychological difficulties, socio-economic problems, and social exclusion can lead to a reduction in the quality of life, perhaps because of limitations on mobility, restrictions to work and leisure activities – all can be part of living with a chronic disease.
- 1.7 Support for people with chronic disease is a major part of the work of social services departments. Much of the depression identified by community psychiatric social workers and day centres for ‘older people at risk’ can be tracked back to ineffectively managed chronic disease.

Some common experiences of patients

- Not enough involvement in decisions
- No-one to talk to about anxieties and concerns
- Tests and/or treatments not clearly explained
- Insufficient information for family/friends
- Insufficient information about recovery

(Source: Coulter, A, Picker Institute, 2001)

- 1.8 Health and social services around the world have been slow to recognise the emerging evidence that patients can play a powerful role in the management of their own chronic disease.
- 1.9 An observation made frequently by doctors who undertake long-term follow-up and care of patients with particular chronic diseases like diabetes mellitus, arthritis or epilepsy is “my patient understands her disease better than I do”.
- 1.10 They are, in fact, “experts” in their own right for they have acquired the life skills to cope with a chronic condition and have the potential to be confident partners with professionals in their care.
- 1.11 After acute care many people transfer to social care in the community provided by social services departments. The ambition of a seamless service needs to be maintained to ensure that, following an acute episode, people requiring rehabilitation and follow-up care for a chronic condition receive these services to a high-standard.
- 1.12 There is increasing evidence that certain systematic approaches whereby patients – with proper support – take a lead in managing their chronic condition can help to improve health, quality of life, and reduce incapacity. For this reason the White Paper *Saving Lives: Our Healthier Nation* introduced the concept of an Expert Patients Programme. *The NHS Plan* therefore announced the further development of the Programme to build on such experience and to bring it into the mainstream of the NHS and related services.
- 1.13 The work was assisted by a Task Force (for membership, see Appendix) to design the new Programme. The remit was:
- to look at the role of patients as experts in managing their chronic disease;
 - to set out the relationship between self-management programmes and the support required from the NHS;
 - to design and oversee a pilot programme;
 - to provide advice on actions required to implement and mainstream the programme.

- 1.14 Ultimately, if the Expert Patients Programme is successful there will be a wide range of improvements in the lives of current and future generations of patients with chronic diseases.

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.

2. The Challenge

This chapter establishes that the number of people who could be helped by a new approach to the management of chronic diseases is very great – an estimated 17.5 million adults living in Great Britain suffer from a long-term condition. It describes the size and nature of this pool of disease and identifies the range of needs which people with chronic diseases have.

- 2.1 In most industrialised societies and in many developing countries chronic diseases now predominate among the leading causes of death¹. They are also the cause of much poor health and disability. In this country, at least one person in three suffers from a chronic disease². The trend is rising. In 1996, 43 per cent of the population aged over sixteen years reported that they were suffering from a longstanding illness. In 1997 the proportion had risen to 44 per cent and this was also the level in 1998, showing no difference by gender³.

Arthritis, in some form, affects about 8.5 million people in the UK. Approximately half below and half above the age of 55. This includes some 14,500 children.

Asthma is estimated to affect over 3.4 million people in the UK, including 1.5 million children (aged 2–15).

Back Pain lasting more than a day was reported as having occurred in the previous twelve months by forty percent of adults in 1998. Fifteen percent of back pain sufferers said they were in pain throughout the year, and approximately forty percent of back pain sufferers consulted a General Practitioner for help.

Diabetes Mellitus prevalence estimates vary but there are thought to be in the region of 1.5 million doctor-diagnosed cases of diabetes in the UK.

Epilepsy is the commonest serious neurological disorder affecting more than 420,000 people or one in 130 of the UK population. Epilepsy can affect people at any age and from any walk of life.

Heart Failure in the UK, based on morbidity studies in general practice, has been estimated to affect about half a million people.

Multiple Sclerosis (MS) is one of the most common diseases of the central nervous system. It is estimated to affect between 80-90,000 people in the UK. It usually strikes people when they are young adults. MS affects women more than men in the ratio 3:2.

- 2.2 Chronic diseases are more common among older people. Approximately two-thirds to three-quarters of all people aged over 75 years suffer from one or more longstanding illnesses – three times more than people aged 16 to 24 years. There are inequalities between social groups: for example, significantly more unskilled men (46%) reporting a longstanding illness than their professional counterparts (40%). For women the contrast is even greater, with 49% of unskilled women reporting a longstanding illness compared with 38% of their professional counterparts³.

| Longstanding illness by social class | | |
|--------------------------------------|-----|-------|
| Social Class | Men | Women |
| I | 40% | 38% |
| II | 42% | 40% |
| IIINM | 42% | 45% |
| IIIM | 46% | 43% |
| IV | 46% | 49% |
| V | 46% | 49% |

- 2.3 People with chronic disease are affected in different ways. Some are severely restricted in performing basic activities of daily living, for example people suffering from Parkinson's disease, depression, chronic bronchitis or arthritis. Others experience intermittent episodes of ill-health of varying intensity and duration. Yet others are hampered by the daily distress and limitations imposed by problems such as colitis or incontinence.
- 2.4 The degree of pain and discomfort also varies from one chronic disease to another. In some cases pain can be constant, as with some types of arthritis; with sickle cell disease the pain associated with an acute phase is extreme. For others there is also the embarrassment caused by the symptoms of disease and their impact on others, for example the sudden epileptic seizure.
- 2.5 Faced with these physical, mental and social restrictions it is not surprising that people with chronic disease often experience anger, bitterness, depression and despair.
- 2.6 The experience of people with chronic diseases in using health services is very variable. The doctor or nurse may discuss with the patient the nature of the treatment and care that he or she needs and agree a plan for managing the disease. In other situations most attention may be given to the technical aspects of care with inadequate attention paid to the social or emotional consequences of the disease. Too often people with chronic diseases are left to cope with the illness on their own ("you'll just have to learn to live with it"), sometimes feeling – as well as becoming – quite isolated. It is vital that their confidence in their ability to cope is built up at this point not eroded. Support from another expert patient may prevent some of these emotions, and this also helps to build 'self-efficacy'⁴ and a sense of control over one's life.
- 2.7 Age Concern England has been developing Ageing Well – a programme in which older volunteer health mentors support fellow members of day centres and projects. For the most part acceptance into day centre programmes requires the recommendation of social services departments.

Chronic diseases can...

...be disabling:

for example

- Manic-depression and chronic depression
- Chronic glaucoma
- Deafness
- Chronic heart failure
- Chronic bronchitis/asthma
- Arthritis

...cause intense pain:

for example

- Arthritis
- Ulcerative colitis
- Endometriosis

...cause embarrassment:

for example

- Psoriasis
- Incontinence

...cause stigma:

for example

- Epilepsy
- Schizophrenia

2.8 Although people have needs specific to their individual disease, they also have a core of common requirements, for example:

- knowing how to recognise and act upon symptoms;
- dealing with acute attacks or exacerbations of the disease;
- making most effective use of medicines and treatments;
- comprehending the implications of professional advice;
- establishing a stable pattern of sleep and rest and dealing with fatigue;
- accessing social and other services;
- managing work and the resources of employment services;
- accessing chosen leisure activities;
- developing strategies to deal with the psychological consequences of the illness;
- learning to cope with other people's response to their chronic illness.

2.9 Traditionally these generic problems faced by a person with a chronic disease have not been comprehensively dealt with by health care providers in the NHS, the social service providers or the employment services.

2.10 The impact of those shortcomings is considerable. For the individuals there is the pain and discomfort of their condition, and the limitation which it places on their activity. There are also the more profound consequences for their quality of life and their ability to function within society.

2.11 There is also a cost to society: an economic cost, through avoidable days lost from employment and the associated personal expenditure, and a social cost through the risk of isolation and social exclusion. And there are the extra health and social service costs that arise from these broader costs to society.

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.

3. The Current Position

The NHS cares for hundreds of thousands of people with chronic disease every day in primary care, in hospital outpatients and after admission to hospital. In this chapter the scope of present services for people with chronic diseases is outlined and the extent to which those services currently address the range of needs identified in the previous chapter is assessed.

- 3.1 Despite the growing proportion of NHS care that is provided to patients with an underlying chronic disease (many of them older people), the focus of health services provision is still very heavily on the care of acutely ill people.
- 3.2 Yet many people who fall acutely ill are those with an underlying chronic problem. In a proportion of these, better management of the underlying chronic disease may prevent or reduce the chances of an acute episode occurring.
- 3.3 Local NHS services are the primary route through which people with chronic disease receive support. Increasingly, this is provided in a primary care setting with back-up and specialist help from hospital services. Increasingly also it is provided by teams of individuals representing different health professions. For example someone suffering from diabetes mellitus could expect to see not just a doctor, but a dietician, a nurse, a chiropodist, an optometrist and other health professionals as well. The secondary route is through social services departments. Here too, new sensitivities are required. All too often the services can only react to emergencies.
- 3.4 In the better services patients are given advice, information and their questions are answered. However, few go beyond this to ensure that the patient's growing knowledge of his or her condition is developed to a point of expertise where he or she is genuinely empowered to take much of the control for its management with confidence. Taken in the round, the NHS is not nearly as strong as it could be in meeting the needs of people with chronic diseases.
- 3.5 Some of the organisations that represent patients with particular diseases have drawn attention to some of the problems with present provision. For example:
 - fewer than 50% of people with asthma had received basic information from their health care professional such as how to recognise an impending attack, how to avoid asthma triggers or the importance of stopping smoking;
 - up to 20% of patients with epilepsy may be misdiagnosed and receive inappropriate and unnecessary treatment;
 - it is estimated that 20% of the child and adolescent population suffer from mental health problems, with 10% having more serious conditions such as conduct disorders, depression and hyperactivity; demand is increasing and currently exceeds service capacity.
- 3.6 Increasingly, when people become ill they expect to play a much fuller part in decisions about their illness and their treatment than would have been the case in the past. There are many driving forces for this. For example:

- the increasing availability and accessibility of information about health and health care;
- developments in medical technology – devices that will make it easier for patients to monitor the progress of a disease;
- a greater willingness of people to accept responsibility for their own health;
- education and training programmes for health professionals which emphasise the importance of forming a relationship where patients are partners in planning their care;
- increased public awareness of the limitations of traditional treatments and the demand for unproven remedies and alternatives.

3.7 These driving forces are starting to create a vision of patient care for the future that is very different from the present. One in which the patient:

- has a self-confident relationship with their medical advisors;
- is much better informed;
- may have explored the options for the diagnosis and treatment of their condition prior to formal consultation with the NHS;
- may have very specific requests of the health professional caring for them.

Ways in which people can access health information

- General Practitioners' surgeries
- Hospital Clinics
- Health Authorities
- Health professionals in other spheres
- Pharmacies
- Pharmaceutical companies
- Charities and voluntary organisations
- Public libraries
- Citizens Advice Bureaux
- Internet web-sites
- Telephone help-lines
- Magazines, newspapers, posters
- Television, radio, and other media
- Family, friends, colleagues, peers with similar experiences
- Schools and colleges

3.8 The Government's White Paper *Saving lives: Our Healthier Nation* recognised that trend and acknowledged the growing evidence of an effective role for patients with chronic disease in the management of their own condition. In July 2000 *The NHS Plan* took forward this initiative through the promise that the "Expert Patients" Programme would be extended, and through a range of specific commitments to shape the health service around the convenience and concerns of patients, including:

- More information for patients
- Greater patient choice
- Patient advocates and advisers in every hospital
- Patients' forums and citizens' panels in every area
- A new national panel to advise on major reorganisations of hospitals
- Stronger regulation of professional standards.

3.9 Already the NHS has put in place a wide range of measures to help to support a new style of service that is more flexible, more diverse in its points of access, more effectively linked to the variety of local services, and more supportive to the new role of patients. These include:

- National Service Frameworks for Mental Health, Coronary Heart Disease, Older People, and the *NHS Cancer Plan*
- NHS Home Health Care Guide
- *NHS Direct* helpline
- Public Health Electronic Library
- Patient Partnership Strategy
- Healthy Living Centres
- Health Improvement Programmes
- Healthy Schools Initiative
- Health Action Zones
- Life Skills Courses and Programmes
- Emphasis on Skillmix
- Healthy Workplace and Healthy Neighbourhood Projects.

3.10 Yet despite these factors that are driving towards greater self-care there are also factors that constrain its growth or impede its appropriate development. For example:

- **Professional attitudes, skills and time** – a need for greater recognition of health care professionals' important role in supporting people in taking responsibility for their own care.
- **Patients' attitudes and skills** – a need for greater understanding that improvements in health can be achieved by people themselves.
- **Dedicated services** – a need for increased provision of, and equitable access to, services for people with chronic diseases.
- **Service quality** – a need for consistently high quality, accessible services focused on the patient.

3.11 To help overcome those obstacles the concept of self-management has been developed. The term self-management was first used in the 1960s and 1970s in the context of the self-care movement. At that time it was seen as a way of seeking better solutions to illness and enabling people with chronic ill-health to take more control of their lives by relinquishing involvement with organised health care systems.

3.12 Today, self-management has a different emphasis and aims to be an integral, even central, part of the system of care provided to people with chronic diseases. It is a term that is typically applied to any formalised patient education programme aimed at providing the patient with the information and skills necessary to manage their condition within the parameters of the medical regime (this reflects the related concept of “concordance”, details of which are set out in the box below). Some models extend the use of self-management skills to enable individuals to take control of the emotional and social consequences of living with long-term illness.

Concordance

Concordance is an agreement reached after negotiation between a patient and a healthcare professional, that respects the wishes and beliefs of the patient in determining whether, when, and how medication is to be taken.

Concordance assures the patient a proactive role in treatment decisions, and a central theme in the partnership with the prescriber and pharmacist is an understanding of the patient's beliefs and expectations for the treatment.

3.13 Patient self-management or Expert Patients Programmes are not simply about educating patients about their condition or giving them relevant information. Neither are they based on a model of care whereby a health professional educates or instructs a patient and then measures success on the basis of patient compliance. They are based on developing the confidence and motivation of the patient to use their own skills, information and professional services to take effective control over life with a chronic condition.

3.14 There are two main types of self-management programme⁵. Those which concentrate upon improving people's ability to adhere to their treatment regime are usually condition-specific, and led by health professionals. The others are user-led and move beyond the medical view, often using the patient's perceptions as a starting point. They look at how the illness impacts upon daily life and the ways in which people can take greater control over their condition on a day-to-day basis.

3.15 It is the user-led self-management programme that has been the predominant model developed and evaluated over the last twenty years in certain areas such as rheumatology (though in other areas such as asthma and diabetes many self-management programmes for patients are led by professionals). The

leading international authority in this field is Professor Kate Lorig of The Patient Education Research Center, Stanford University, California.

“...little has been done to prepare patients for long-term management of their diseases. They face many challenges in coping with discomfort and disability and carrying out treatment programmes on a regular basis. They need to modify behaviour to minimise undesirable outcomes, adjusting their social and work lives to accommodate their symptoms and functional limitations and deal with the emotional consequences. For their care to be effective, they must become adept at interpreting and reporting symptoms, judging the trends and tempo of their illness and participating with health professionals in management decisions.”

Lorig K, et al. *Medical Care* 1999; **37(1)**:5-14

- 3.16 The chronic disease self-management programme (CDSMP) was developed at Stanford following some twenty years of work with arthritis. Professionally trained instructors with chronic disease educate and train course volunteer tutors with illnesses such as arthritis, diabetes, HIV, stroke and heart disease.
- 3.17 It shows that people managing long-term conditions share more commonality than differences. A key point is that these benefits are all additional to the benefits being derived from the treatment plans, and that the healthy way to live with chronic illness is to work at overcoming the physical and emotional problems caused by the disease. The CDSMP recognises that people with long-term conditions are dealing with similar issues on a daily basis, such as pain/symptom management, stress, low self-image and a need to develop coping skills.
- 3.18 The course is run over 6 consecutive weekly sessions of 2.5 hours each week. The course is highly structured and delivered from a scripted manual covering topics including relaxation, cognitive symptom management, exercise, fatigue, nutrition, problem solving, action planning and communication, and health care professionals.

The Chronic Disease Self-Management Program (CDSMP) was developed at Stanford University Patient Education Research Center as a collaborative research project between Stanford and the Northern California Kaiser Permanente Medical Care Program. The primary developers of the program are Kate Lorig, Virginia González and Diana Laurent.

Several assumptions underlie the CDSMP:

- People with chronic conditions have similar concerns and problems.
- People with chronic conditions must deal not only with their disease(s), but also with the impact these have on their lives and emotions.
- Lay people with chronic conditions when given a detailed leader’s manual can be as effective as professionals.
- The process or way the CDSMP is taught is as important, if not more important, than the subject matter that is taught.

- 3.19 The CDSMP is in use in Australasia, Europe, USA and recently in China. Within Britain these ideas have been taken forward by a number of patient bodies and used to design practical user-led delivery programmes. They have also been used by other non-governmental organisations in the development and provision of services, for example by Northamptonshire County Council.

Examples of user-led self-management programmes in England.

Self Management Training Programme (SMTP) for Manic Depression, begun by the Manic Depression Fellowship in 1998. It is entirely user-developed and user-led. The programme has been designed to enable individuals with a diagnosis of manic depression to gain confidence in their own capacities and to take control of their lives. This programme was developed from a course that originated in Ohio. It is currently the subject of a randomised controlled trial (RCT) with good outcomes to date, including improvements in mood sustained 3-6 months after completion of the course.

Challenging Arthritis (CA) is the name given by Arthritis Care to the arthritis self-management course (ASMC) originally developed at Stanford in 1979. The Challenging Arthritis course was launched in 1994. It too is a user-led programme in which all senior staff, self-management trainers and volunteer course leaders are people with arthritis. Over 100 peer-reviewed articles on ASMC have been published since 1980.

The **Multiple Sclerosis Society** has this year begun to train tutors to deliver structured self-management courses based on the Lorig model in 2½ hour sessions over a six-week period. The tutors themselves have MS. The course content – which follows the Arthritis Care model of ensuring quality – includes problem solving, dealing with emotions, managing fatigue, choosing treatment, accessing health services and communicating with health care professionals.

- 3.20 One innovative approach, developed by the British Epilepsy Association in co-operation with Leeds Metropolitan University, has been the introduction of a vocational certificate in epilepsy to reflect the skills and information required to manage the condition. A more generic programme, run by Changing Faces, provides courses for people living with a range of disfiguring conditions (however caused) and is aimed at challenging public perceptions about appearance.

The Heart Manual

Origin: The Heart Manual was developed by The British Heart Foundation Rehabilitation Research Unit at the University of York and is administered under licence by the Astley Ainslie Hospital NHS Trust, Edinburgh.

Content: The Heart Manual system has three elements:

- A professionally facilitated introductory session;
- A workbook divided into 6 weekly sessions, with a phased programme of home based exercise, stress management and written information;
- Two audio tapes. One a programme of relaxation training and the other a scripted interview between a doctor and patient aimed at helping the patient and their significant others understand what has happened.

Current use: The Heart Manual is now used by 70 healthcare providers, reaching approximately 5,000 patients each year. Around 1,500 health professionals have been trained to administer the manual. It is estimated to be providing 10% of all the cardiac rehabilitation in the UK. It is currently on trial in the USA, Italy and Holland.

4. Evidence and Experience

This chapter sets out some of the evidence for the efficacy of self-management programmes and demonstrates that their benefits cover both patient outcomes and satisfaction as well as improvements in their interactions with health care professionals.

- 4.1 The Expert Patients Programme holds out the promise of thousands of confident and more informed patients and large numbers of lay people involved in evidence-based self-management programmes of one kind or another. This will need a major shift in cultural attitudes, and this in turn will depend in part on convincing patients and professionals of the value of this approach.
- 4.2 The implications for Social Services of developing Expert Patients Programmes are also significant. If people with long-term illnesses have more opportunities to maintain their independence, then there are considerable opportunities for care to be released for other people in need.
- 4.3 There is a growing body of evidence to show that, compared to no intervention (i.e. “standard” care), self-management approaches **can** provide important benefits for participants. For example, in a number of evaluations of Chronic Disease Self Management Programmes (CDSMP), sustained improvements have been obtained in individuals’ skills in self-management and in disease outcomes. For example, in a five-year research project, the CDSMP was evaluated in a randomised study involving more than 1000 subjects. This study found that people who took the program, when compared to people who did not, improved their healthful behaviours (exercise, cognitive symptom management, coping, and communications with physicians), improved their health status (self-reported health, fatigue, disability, social/role activities, and health distress), and decreased their days in the hospital⁶.
- 4.4 The five core self-management skills in the CDSMP are:
- problem solving;
 - decision-making;
 - resource utilisation;
 - formation of a patient-professional partnership;
 - taking action.

However, the evidence shows that none of these is in itself the key to effective self-management. The key is the change to the individual’s confidence and belief that they can indeed take control over their life despite their disease. These five skills comprise the toolkit for the patient to deploy as required.

- 4.5 Similarly the Heart Manual referred to in the previous chapter has been proven to be clinically effective in three randomised controlled trials demonstrating improved psychological adjustment, fewer visits to General Practitioners and significant reductions in re-admission to hospital in the first six months following the heart attack.

4.6 A review of the evidence on self-management as a whole, conducted for the Task Force by Professor Julie Barlow of Coventry University⁷, 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.

Evidence for effects of self-management programmes on health

| Health Problem | Effectiveness of self-management programmes |
|--|---|
| Asthma | reduction in quantity of medication used ⁸ |
| Arthritis Asthma Diabetes HIV/AIDS Other chronic illnesses | reduction in symptom severity ⁹⁻¹³ |
| Arthritis Other chronic illnesses | significant decrease in pain ^{12,13} |
| Arthritis | improved relaxation and exercise ¹² |
| A range of chronic illnesses | improved social function ¹⁴ |

4.7 Thus giving people with chronic diseases the skills to manage their illness can have a major beneficial impact on their lives. Their own knowledge and experience of their illness, and that of their peers, can help and support them to develop the confidence necessary to become active in the self-management of their condition.

4.8 The published literature does not always describe interventions in sufficient detail to permit a thorough understanding of the findings. It is sometimes difficult to tease out within a specific programme the precise factor or factors leading to change among participants. That may not matter, however, because the programme will usually be designed to increase the participants’ overall self-management skills within the realities of living with a chronic condition.

4.9 Other than the work done by Professor Julie Barlow at Coventry, there is as yet little exploration of the potential of self-efficacy evaluations of UK patient education interventions. However, the extensive collaboration behind the Stanford work has attracted world-wide interest.

The Living with Long-Term Illness (Lill) Project

The three-year Lill action research project – begun by the Long-Term Medical Conditions Alliance (LMCA) in September 1998 – has been the central vehicle for increasing the number of user-led self-management programmes available to people with chronic long-term conditions. It has succeeded in facilitating an increase in the number of organisations delivering programmes from two in 1998 to thirteen in 2001.

Lill has brought about positive benefits for participants, tutors and for participating organisations. In addition, it has provided the basis for research into the CDSMC in the United Kingdom, and has laid the foundation for the development of generic user-led programmes.

Evidence for selected disease-specific self-management programmes

Self-management in asthma

- 4.10 The evidence is now very strong in favour of the wider use of self-management by people with asthma, and shows a reduction in morbidity and reduced demand on health service resources. Studies by the National Asthma Campaign (NAC) show that people with asthma want more information about their condition, more involvement in treatment decisions and greater control of their own condition¹⁵. National and international guidelines all promote the concept of self-management.
- 4.11 Several randomised controlled trials of self-management using plans very similar to that produced by the National Asthma Campaign have shown that, when given to adult out-patients with asthma, there is a resultant reduction in symptoms due to asthma, and of emergency visits to General Practitioners, hospitalisation, and days off work¹⁵. Benefits have previously been demonstrated six and twelve months after the issue of such plans and more recently have been shown to have lasted for at least two years. Such interventions may take a little time to teach but cost-effectiveness studies demonstrated overall savings.

Evidence for benefits of self-management plans in asthma

- Reduction in asthma symptoms
- Improvement in lung function
- Reduction in attack frequency
- Reduction in requirement for reliever and steroid treatment
- Reduction in inappropriate use of antibiotics
- Improvements in compliance
- Improvements in quality of life

Source: *National Asthma Campaign*, 2001

Self-management in arthritis

- 4.12 The literature on self-management in arthritis relates mostly to the **Arthritis Self-Management Course (ASMC)**. This is a community-based, group approach led by lay tutors and accompanied by a manual for participants and tutors. In randomised controlled trials the ASMC itself, and modified versions of the programme, showed consistent improvements in knowledge, self-efficacy, and the use of self-management behaviours, notably exercise. Studies by Professor Kate Lorig and her colleagues at Stanford University suggest a reduction in physician visits of 42–44% can be achieved, and significant cost savings made by using volunteers with arthritis, rather than health professional leaders.

Self-management in diabetes mellitus

- 4.13 Randomised controlled trials in the field of diabetes showed self-management approaches to be effective in increasing the use of self-management behaviours, particularly monitoring (for example of blood glucose). One of the aims of the forthcoming Diabetes National Service Framework will be to enhance peoples' personal control and management of their diabetes with appropriate education, designed around the needs of the patient rather than of the service.

Diabetes: The DAFNE project

Patient education is widely acknowledged as vitally important in facilitating appropriate management of diabetes. DAFNE – Dose Adjustment For Normal Eating – is a patient education model which involves a structured training programme in intensive insulin therapy and self-management. Patients with Type 1 diabetes are taught to match their insulin dose to food intake on a meal-by-meal basis. The aim is to enable patients to maintain healthy glycaemic control without an increased risk of severe hypoglycaemia (low blood glucose levels that can lead to loss of consciousness and, occasionally, convulsions), and with minimal support from health care professionals.

A one-year feasibility study of DAFNE started in February 2000 at three English centres. Final data from the study are expected soon. However, preliminary results have shown:

- reduced blood glucose levels, with no increase in severe hypoglycaemic attacks
- a marked improvement in quality of life
- a significant increase in satisfaction with treatment.

The National Institute for Clinical Excellence (NICE) will be evaluating patient education models for diabetes as one of the appraisal topics in its work programme announced on 31 July. The DAFNE model is expected to be among the approaches that NICE examines.

Self-management and use of health care

- 4.14 These potential benefits extend to the NHS itself by providing opportunities to strengthen the traditional bond between health professional and patient.
- 4.15 For example, research outcomes demonstrate the potential of self-management programmes to enhance the quality of the doctor/patient relationship. Participants in research studies regularly report improved communication with physicians and other health care providers. The skills and expertise of professionals are no less essential in treating and helping to manage chronic diseases when patients are involved in self-management.
- 4.16 Moreover a number of studies suggest that user-led self-management programmes lead to a considerable reduction in visits to General Practitioners and other health professionals. There is also strong anecdotal evidence that some of the people coming through these programmes become valued members of consultative arrangements in both health and social services.
- 4.17 Collectively these studies suggest that, rather than becoming more demanding, “expert” patients are in general more likely to make more effective use of available services.
- 4.18 Over the years the main connections and initiatives with voluntary organisations have been through specialist units in hospitals, and this of course continues. *The NHS Plan* also placed great emphasis on the role of primary care, for example, and the part to be played by Primary Care Groups and Trusts

which would need to work with representatives from other sectors, including voluntary organisations concerned with user-led self-management. Such partnerships would help to ensure that programmes were tailored to local conditions and that facilitators received suitable support appropriate to their particular needs. Overall, the research evidence and practical experience suggest that self-management interventions can have a beneficial effect on the well-being of participants. Most interventions achieve their aims of increasing participants' self-efficacy, knowledge and use of self-management techniques.

- 4.19 Where previous evaluations have sought to address or assess psychological well-being, findings were consistent in showing an improvement in mood. This is important given that annually about 1 in 4 of the population visit their General Practitioner with some form of mental illness, most commonly depression. It is also the predominant reason for people coming to the attention of social services, being identified as 'at risk' and in need of services. The evidence provides a good foundation on which systematic expansion of user-led self-management approaches for people with chronic conditions in the NHS and associated evaluations can be based.

Evidence for impact of self management programmes on service use

| Health Problem | Impact of self-management programmes on care services |
|---------------------------------|---|
| Chronic Pain Arthritis | Reduction in number of visits to health professionals up to 80% ^{12,16} |
| Arthritis Insomnia Asthma | Reduction in number of general practitioner visits up to 44% ¹⁷⁻²¹ |
| Sickle Cell Disease Asthma | Reduction in number of hospitalisations (up to 31%) and length of stay (up to 50%) ^{22,23} |
| Insomnia | Reduction in number of visits to specialists by 15% ²¹ |
| Sickle Cell Disease Asthma | Reduction in number of accident and emergency department visits up to 39% ^{22,23} |

5. The Programme

This Chapter sets out the recommendations and the actions that need to be taken to implement self-management programmes. It highlights the vital role of patient organisations in such programmes, and refers to the National Service Framework Programme and, specifically, the National Service Framework for Long-Term Health Conditions that is being developed.

- 5.1 Based on the comprehensive review undertaken by the Task Force a clear model has emerged of the major potential benefits of self-management programmes.
- 5.2 In July 2000, part way through its work, the Task Force held a special conference in London to hear a wide range of stakeholder and specialist views on the need for an Expert Patients Programme. This proved very valuable in confirming the strong commitment to moving forward with a comprehensive programme as well as identifying the main issues and challenges.

Key points from Expert Patients Stakeholder Conference in July 2000

- **User-led self-management has real value**
 - Self-management helps people with a long-term medical condition to take responsibility for their own lives. It addresses the “whole person” and not just their illness or disability. It is about people with chronic disease becoming able to gain greater independence and live healthy, confident lives.
 - Self-management could help reduce visits to General Practitioners and better equip people to manage their own conditions with appropriate professional support.
- **Self-management programmes need to reach the right people**
 - It is particularly important to reach individuals and groups who have difficulty in gaining access to services:
 - People living in a rural location
 - People whose ethnicity, culture or language may present barriers
 - People with low education or literacy levels
 - People who might not see themselves as able to be partners in their own care.
- **The right messages about self-management need to be sent**
 - Courses should be appropriate and accessible. Possible delivery tools include
 - one-day, lunch-time or evening courses
 - digital television
 - internet web-sites
 - related personal and social education in schools
- **Partnerships between patients and professionals are essential**
 - A cultural change is needed so that user-led self-management can be fully valued and understood by healthcare professionals.
 - Education about the concept of self-management is important throughout all stages of training for healthcare professionals.
 - User-led self-management programmes should be mainstreamed within existing policy frameworks. Resources need to be committed on a long-term basis to ensure the sustainability of self-management programmes. However, planning will need to ensure that development is in line with resources.
 - Primary Care Groups and Trusts should have a key role in commissioning self-management programmes.

- 5.3 Patient organisations have a vital role to play in partnership with the NHS and the Government in developing national Expert Patients Programmes. This is because:
- many have already shown innovation in developing programmes themselves;
 - they have a good understanding of, and commitment to, assuring quality and consistency in programmes;
 - through them there is access to a large pool of potential lay tutors;
 - effective networks and partnerships have already been established within and between voluntary organisations – these have the potential to support a growing self-management network;
 - they can act as consultants to other organisations wishing to develop programmes;
 - they can act as advocates for people who otherwise would not have a say in their own care.
- 5.4 There are a number of National Service Frameworks (NSFs) to which Expert Patients Programmes are relevant, for example: those on Coronary Heart Disease (including congestive heart failure), Mental Health, Older People, the *NHS Cancer Plan*, and the forthcoming NSF on Diabetes. In addition, in February 2001 the Secretary of State for Health announced a new National Service Framework for Long-Term Health Conditions. It will be drawn up in partnership with the Long-Term Medical Conditions Alliance, the Neurological Alliance, and their member organisations. It will have a particular focus on the needs of people with neurological disease and brain and spinal injury, and will include a number of generic standards intended to improve the quality of life of all people with long-term conditions. It will include services for people with epilepsy, multiple sclerosis, Parkinson's Disease, motor neurone disease and other similar conditions.
- 5.5 This report builds on the prospect of a new National Service Framework by setting out the case for systematically promoting self-management programmes as a part of health service and related provision.
- 5.6 *The NHS Plan* placed great emphasis on the role of primary care, and the part to be played by Primary Care Groups and Trusts. These bodies will need to work with representatives from other sectors, e.g. voluntary organisations concerned with self-management. Thus neither patients nor professionals should see self-management as a replacement for medical care – indeed, many self-management programmes cross the professional-led/user-led spectrum.

Key issues in the design of programmes

- Affordable programmes and flexibility to include those on the lowest incomes
- Recruitment of self-management tutors from all sections of the community
- Simple materials in a variety of forms to suit the needs of different people, e.g. large print, use of audio tape
- Wider access including, through training, encouragement to new technologies such as the internet for those (e.g. some older people) who may be wary of such media
- Accessible venues for self-management programmes
- Joint work with community groups and voluntary organisations to make programmes widely known within all sections of the community
- Joint work with social care providers
- Respect for the evidence on what works in self-management with flexibility to offer and evaluate variations to meet specific needs e.g. for specific linguistic and cultural minorities, for women as well as men, and for older people
- Use of complementary therapies that encourage self-management, where there is evidence that such therapies were effective.
- Understanding of medication, to get the best outcomes

5.7 There are a number of key principles which should drive the introduction of an Expert Patients Programme:

Key principles

- The expertise of patients themselves is a largely untapped resource in the effective management of chronic disease
- 'Expert Patients' must become an integral part of the design and functioning of all local NHS services, not just of a few innovators
- User-led self-management programmes are the principal route for creating a new generation of expert patients
- It is the responsibility of the NHS to ensure that these programmes are in place, that they are developed and sustained over the long-term
- New provision must be integrated with the work of other statutory providers such as education and social services
- All programmes must be firmly rooted in good evidence governing their design and implementation
- Feedback, evaluation and assessment of outcome should be a routine part of the operation and development of the programme.

Recommended action

5.8 Action in the following specific areas is recommended:

- i) **Promote awareness and create an expectation that patient expertise is a central component in the delivery of care to people with chronic disease.**
- ii) **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.**
- iii) **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.**
- iv) **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.**
- v) **Ensure that each Primary Care Trust area has arrangements for user-led self-management programmes for key chronic conditions to be delivered or commissioned.**
- vi) **Expand the practical support from the NHS for user-led programmes provided by patients' organisations in partnership with health and social care professionals.**
- vii) **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.**
- viii) **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.**

Proposed Timetable

5.9 It is proposed that the programme should be implemented in full over a six year period with the following milestones:

- 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.

References

- 1 Davis RM, Wagner EG & Groves T: editorial in *British Medical Journal*, special edition on managing chronic diseases, 7234, 26 February 2000.
- 2 *National Survey of NHS Patients: General Practice 1998*. NHS Executive, 1999.
- 3 Erens, B and Primatesta, P.(eds.). *Health Survey for England. Cardiovascular Disease '98*. London: Stationery Office, 1999.
- 4 Bandura A (1977). Self-efficacy: Toward a unifying theory of behavioural change. *Psychological Review*, 84, 191-215.
- 5 A full directory of self-management programmes is available under the “People and Communities” section of the *Our Healthier Nation* website: www.ohn.gov.uk
- 6 The British Liver Trust. *Living a Healthy Life with Long Term Illness. LEADERS MANUAL*. The Board of Trustees, Leland Stanford Junior University, 1999.
- 7 Barlow JH *et al.* *Self-management literature review*. Psychosocial Research Centre, Coventry University, July 2000.
- 8 Gillies J, Barry D, Crane J, Jones D, MacLennan L, Pearce N, Reid J & Toop L (1996). A community trial of a written self management plan for children with asthma. *New Zealand Medical Journal*, 109(1015), 30-33.
- 9 Horan P P, Yarborough M C, Besigel G, Carlson D R (1990). Computer assisted self control of diabetes by adolescents. *Diabetes Educator*, 16(3), 205-211.
- 10 Allen R M, Jones M P & Aldenburg B (1995). Randomised trials of an asthma self-management programme for adults. *Thorax*, 50, 731-738.
- 11 Gifford A L, Laurent D D, Gonsales V M, Chesney M A & Lorig K R (1998). Pilot randomized trial of education to improve self management skills of men with symptomatic HIV/AIDS. *J of AIDS*, 18(2), 136-44.
- 12 Barlow J H, Williams B & Wright C C (1999). ‘Instilling the strength to fight the pain and get on with life’: learning to become an arthritis self-manager through an adult education programme. *Health Education Research*, 14(4), 533-44.
- 13 Coleman E A, Grothaus L C, Sandhu N & Wager E H (1999). Chronic care clinics, a randomised control trial of a new model of primary care for frail older adults. *J of the American Geriatric Society*, 47(7), 775-783.
- 14 Lefort S M, GrayDonald K, Rowat K M & Jeans M E (1998). Randomized control trial of a community based psycho-education program for the self management of chronic pain. *Pain*, 74(223), 297-306.

- 15 Gibson PG, Coughlan J, Wilson AJ, Abramson M, Bauman A, Hensley MJ, Walters EH (1999). *Self-management education and regular practitioner review for adults with asthma*. The Cochrane Library, Issue 1, 1999, Oxford Update. Also see the National Asthma Campaign website at www.asthma.org.uk/
- 16 Cole J D (1998). Psychotherapy with the chronic pain patient using coping skills development: outcome study. *Journal of Occupational Health Psychology*, 3(3), 217-226.
- 17 Lorig K & Holman H R (1989). Long-term outcomes of an arthritis self-management study: effects of reinforcement efforts. *Social Science and Medicine*, 29(2),221-4.
- 18 Charlton I, Charlton G, Broomfield J & Mullee M A (1990). Evaluation of peak flow and symptoms only self management plans for control of asthma in general practice. *British Medical Journal*, 301(6765), 1355-9.
- 19 Lorig K R, Mazonson P D & Holman H R (1993). Evidence suggesting that health education for self-management in patients with chronic arthritis has sustained health benefits while reducing health care costs. *Arthritis and Rheumatism*, 36(4), 439-46.
- 20 Fries J F, Carey C & McShane D J (1997). Patient education in arthritis: randomized controlled trial of a mail-delivered program. *Journal of Rheumatology*, 24(7), 1378-83.
- 21 Oosterhuis A & Klip E C (1997). The treatment of insomnia through mass media, the results of a televised behavioral training programme. *Social Science and Medicine*, 45(8), 1223-9.
- 22 Thomas J E, Koshy M, Patterson L, Dorn L & Thomas K (1984). Management of pain in sickle cell disease using biofeedback therapy: a preliminary study. *Biofeedback and Self Regulation*, 9(4), 413-20.
- 23 Choy D K, Tong M, Ko F, Li S T, Ho A, Chan J, Leung R & Lai C K (1999). Evaluation of the efficacy of a hospital-based asthma education programme in patients of low socio-economic status in Hong Kong. *Clinical and Experimental Allergy*, 29(1), 84-90.

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