

• **SELF-MANAGEMENT FOR LONG-TERM CONDITIONS**

Patients' perspectives on the way ahead

Sara Corben and Rebecca Rosen

managing
long-term
conditions

Self-management for Long-term Conditions

PATIENTS' PERSPECTIVES ON THE WAY AHEAD

SARA CORBEN
REBECCA ROSEN

This paper reviews patients' perceptions about managing their own long-term conditions, and identifies how primary care trusts and other health and social care providers can support patients, in line with their individual needs. It sets out three key areas for service development: improving health professionals' skills to support self-management; improving the provision of information and signposting; and increasing the flexibility in service provision to fit in with patients' other commitments.

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Foreword

This report sets out the three key challenges for PCTs in supporting people to self-manage long-term conditions: developing the skills of professionals to support self-management; improving the provision of information about long-term conditions and the local services available; and increasing the flexibility of service provision to fit in with patients' other commitments.

The LMCA welcomes this work by the King's Fund to identify the way forward for local services. Self-management will become increasingly important as people live longer, many with at least one long-term condition.

Self-management means different things to different people. For most people, it means developing an understanding of how their condition affects their lives and how to cope with their symptoms. People report that it helps them live better lives, and puts them in control of their condition.

But there is no single approach to self-management, and neither should there be. This research shows above all that people are individuals, with different reactions to receiving a diagnosis and different ways of coping. Not everyone wants to be more actively involved in managing their own condition, but for the growing number of people who do, more support is needed from the professionals involved in their care.

People increasingly expect to work in partnership with health and social care professionals. To make this happen, professionals need to see their patients or clients first and foremost as individuals. They need to make time to listen to people's concerns, and to understand their values and their goals. They also need to ensure that people have access to the information they want. PCTs must use every lever at their disposal to support self-management – commissioning, workforce development and above all leadership – to ensure that the following recommendations are implemented.

David Pink
Chief Executive, LMCA

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Arthritis Care
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Epilepsy Action
MS Society
National Association for Colitis and Crohn's Disease
Parkinson's Disease Society
Positive East
Public Health Network (e-group)

Introduction

Millions of people in the UK are living with long-term conditions such as asthma or diabetes. Up to a quarter of those affected have more severe symptoms and are at higher risk of hospital admission. Most, however, are leading full and active lives with only occasional contact with health professionals and provide much of their care themselves, altering drug doses and adapting their lifestyles in response to subtle changes in symptoms. These decisions and behaviours constitute 'self-management' of long-term conditions and affect a patient's overall health and well-being significantly. The role of health professionals in ensuring that patients understand their condition, and supporting them to self-manage it, is crucial but often neglected.

Recent government policy on long-term conditions identifies support for self-management as one of three key approaches to improving services and maintaining good health (Department of Health 2005a). There is evidence that effective self-management can reduce hospitalisation and accident and emergency attendances (Gibson *et al* 2004; Newman *et al* 2004). Currently, the Department of Health is leading work to promote self-care – a wide spectrum of activity that includes preventing illness, treatment of minor injuries, and self-management of long-term conditions (Department of Health 2005b). This paper focuses on self-management. Primary Care Trusts (PCTs) are working hard to implement and deliver the Expert Patient Programme to support self-management, although a variety of other innovative practices have also been established (Department of Health 2005c).

How can the NHS and other organisations build on existing good practice and develop comprehensive strategies to support people living with long-term conditions to manage their lives and their symptoms with greater skill and confidence? What will be of greatest value to patients and what will achieve the most in terms of improved health and reduced hospitalisation?

Why is the King's Fund interested?

This King's Fund working paper has been written in response to growing interest among policy-makers, clinicians and patients in self-management of long-term conditions. It forms part of a wider programme of work on long-term conditions covering:

- the identification of people at highest risk of ill health
- the effectiveness of case-managing people at high risk of hospital admission
- qualitative studies of health care use by people with long-term conditions
- work on the impact of current incentives on people with long-term conditions.

Aims of this working paper

This working paper reviews patients' opinions about self-management and identifies how primary care trusts (PCTs), health and social care providers and other organisations can best develop support for self-management in line with patient expectations. The focus of this analysis is on health services, but we recognise that solutions emerge from agencies and organisations working together.

A central issue to emerge from this work is that receiving and adjusting to a diagnosis is a process that takes place over time. People's ability to self-manage develops as part of this process. We identify three key areas of service development that planners and providers must address to support this transition:

- improving health professionals' skills to support self-management
- improving the provision of information about long-term conditions and the local services available
- increasing the flexibility of service provision to fit in with patients' other commitments.

Methods

We reviewed recent literature on self-management of long-term conditions, focusing specifically on studies of patients' perspectives about self-management.

Working with the LMCA (Long-term Medical Conditions Alliance), we also interviewed nine people about their experiences of living with different conditions. Interviewees were recruited through charities and support groups for selected conditions and, although not a representative group, the interviewees do represent a range of conditions, ages, ethnic groups and geographical spread. The men and women we interviewed have lived with their condition for varying lengths of time – from two to more than forty years. All names have been changed.

We convened an e-reference group of six people who work in different aspects of long-term conditions policy and service development, and asked them to comment on the issues emerging from this work. Their feedback has been incorporated into this paper.

Living with a long-term condition

When people are diagnosed with a long-term condition, they must make a series of adjustments to their lives. Our literature review and interviews with patients identified a process that people typically go through, with a variety of individual responses that change over time. Three themes emerged as particularly important in shaping these responses:

- the different ways in which people receive the diagnosis
- the fact that different people have different responses
- the fact that people's ability to self-manage changes over time.

Receiving a diagnosis

People receiving a diagnosis of a chronic, long-term condition begin to make a series of adjustments over time (Kralik *et al* 2004). Structured self-management education programmes will not necessarily result in immediate behaviour change and 'adherence to prescribed medical treatment plans' (*ibid*), because people's responses are linked to their social, cultural, emotional and psychological needs (Pooley *et al* 2001). Furthermore, for some of our interviewees – for example, those with diabetes or asthma – diagnosis was straightforward and clear, while for others – for example those with Parkinson's disease – it took many years to get a definitive diagnosis. People's responses to diagnosis are therefore unique.

Different people, different responses

Participation in active self-management of a condition is influenced by many factors, including length of time since diagnosis, severity of the disease, age, social support and level of education. Not all people want to – or can – self-manage a long-term condition.

Bill, for example, does not want information about his chronic obstructive pulmonary disease, and does not want to discuss his care any more than he needs to. He describes one of his regular visits to the hospital for management of his long-term condition:

They take your blood, there's no discussion, they're too busy, just a bloke with a machine. Then the nurse tells you there's no change this time, that things haven't altered. I don't want to know more. The GP – we work together – he tells me what to do – but he's the doctor, that's what he gets paid for, and what I paid in for, for all those years.

Bill, 79, chronic obstructive pulmonary disease

For Bill, and others like him, management of their condition will continue to be what the doctor decides and does (Sims 1999). By contrast, Debbie came around slowly to the idea that she had to live with and manage her diabetes:

[I was] searching on the internet and found Diabetes UK. It took a while to sink in. I was too frightened to find out, [and I] didn't know the GP or nurse at the time. I felt like I was being stupid, then I was in denial. It took me a long time to get to grips with it. There is an education day at the hospital, [and I've been] waiting for ages to get referred to the hospital that runs this.

Debbie, mid-20s, diabetes

Participants in self-management are more likely to be younger, female, middle-class and better educated. Some people with long-term conditions would like to be more involved in managing their own condition, but find that services are not flexible enough to allow this (as in the case of epilepsy services discussed by Elwyn *et al* 2003). Those who lack basic literacy skills in English, or who don't read their own language, may be less likely to self-manage well.

The changing nature of self-management

An individual's involvement in self-management is likely to fluctuate over time: it may increase but it may also decrease. Vicky, who was diagnosed with asthma ten years ago, describes her experience of living with the condition:

You have to feel you have some sort of control over it, how to deal with it. It's to do with accepting your condition. When I was first diagnosed I used my inhalers, but I thought it was all in my mind, and gave up my medicine, and then I ended up in hospital again. My turning point – acceptance – was to say to myself, 'It's not going to be easy, but I'm going to be an active part in dealing with it'. My new consultant is really positive about managing it myself and having a say in it. Since I've seen him I've got my own nebuliser at home. He trusts that I won't leave it too late and end up in A&E. I now have a management plan agreed with my consultant and GP as a result of my last admission. I take it on holiday with me, in case I need to go to hospital while I'm away.

Vicki, mid-20s, asthma

The stage of life when a person is diagnosed with a chronic condition also influences how they will engage with self-management and with health services. A chronic condition is only one part of a person's life. Being a parent and/or having a job will influence how much time and importance a patient can – or wants to – give to self-management of their long-term condition. Ruth describes how she manages her rheumatoid arthritis as well as a full-time job:

I see the rheumatologist every four months. My GP prescribes my drugs. I need a chiropodist, but no one even knows how you make an appointment with them. I'm loosely attached to an occupational therapist who I can call if I need anything. I also have a cleaner who does the cleaning and ironing – I pay for this myself. In the past I used a physiotherapist. I've seen a neurologist – for complications with drugs. I've also seen a urologist – again, for drug complications. I co-ordinate it all myself. My job is unstructured, so I can plan my visits to hospital around my work.

Ruth, mid-50s, rheumatoid arthritis

While many of the people we spoke to have had to make considerable changes to their lives, including, for some, giving up work, a long-term condition will not always take

priority. For example, a young person may be more influenced by their peer group than their condition, and refuse to allow their life to be dominated by illness. Support from parents, nurses and doctors – and a feeling that the condition is not a threat to social well-being – influence how young people will comply with advice for ongoing self-management (Kyngas 2000). Russell, who was diagnosed with epilepsy in his 20s, continued to live a life as similar to his peers as possible, drinking with friends, for example:

As you get older, you learn to deal with things; you begin to notice things more. It hadn't occurred to doctors to tell me not to drink. I read the drug information and realised, at about 22, 23, that I shouldn't be drinking.

Russell, 33, epilepsy

People's responses to diagnosis with a long-term condition, and their approach to self-management, are unique. Their responses may not be immediate and their approach may change over time. Some people will not wish to self-manage their condition, while others will be more likely to do so. Most people find a way to incorporate the condition into their life over time, but the level of self-management may vary.

How should service providers support patients to self-manage?

Three key themes emerge from our literature review and interviews about how service providers can support self-management in the most effective way:

- the importance of good relationships between professionals and patients
- the need for patients to have clear information about their condition and guidance on how to access it
- the need for flexibility in service provision to fit in with patients' other commitments.

Good relationships between professionals and patients

A good relationship between professionals and patients is key to ensuring that patients are supported in their efforts to self-manage. Understanding how patients perceive their condition is important, but helping them become more active in their own care is the real goal (Michie *et al* 2003). A patient's encounter with a health professional will be enhanced considerably if the professional:

- has the ability to listen
- identifies the patient's main concerns
- allows time for discussion
- understands how the patient experiences their condition
- ensures that the patient contributes to the planning of their care.

Some of our interviewees' stories reflect the importance of their relationships with health professionals. For example, Toby, who has chronic back pain, explains his relationship with his GP:

He turns away from the computer screen, has been known to take my hands in his, and says, 'Right then Toby' – we are on Christian-name terms – and asks how I'm coping – hands on. Not the sort of thing we come to expect from the younger doctors, maybe more from the older doctors who didn't want computers in their consulting rooms. He doesn't just get out his prescription pad.
Toby, late 70s, chronic back pain

Doctors who find it difficult to listen to patients, understand their preferences and involve them in their care may need additional training in the competencies for shared decision-making (Coulter 2002).

Planning with patients, not for them

Patient non-compliance is frequently cited as a central problem in the management of long-term conditions (Carter *et al* 2003). Closer investigation may reveal that both patients and professionals have similar understandings of the condition, and patients may already

have the information they need (Hunt and Arar 2001). However, professionals favour clinical models, and may fail to ground their recommendations in the reality of patients' lives. Patients' responses are shaped by many factors, including experience and new information, as Fred, who is HIV-positive, demonstrates:

I read a lot. I'm aware of new drugs coming out, complementary therapy, herbs. I feel very comfortable that when I go to my doctor I can discuss articles and suggest things I want to try. I don't feel I'm challenging him, but giving him my opinion. Before we used to have an argument, now it's more of a conversation. I've reached the point where I try to be aware of new developments, but I still respect the decision of my doctor. I've seen results, I'm pleased with what's happened but, in the end, I'm the one who's responsible for me.

Fred, early 20s, HIV

Both Fred and Toby demonstrate how their relationships with health professionals have developed over time, and how their doctors have listened to their patients, and acknowledged that their patients' experiences are an important part of self-management.

Clear, accessible information and signposting

From the point of diagnosis – or even before – people are faced with an array of different services and many have little idea of how to choose between them. They need support to understand their conditions and to understand the services available. Two key themes emerge:

- the importance of providing enough information
- the importance of signposting and key workers.

Providing enough information

Responses from our interviewees and findings from the literature review suggest that, when first diagnosed, people are often not given much information about their condition – whether leaflets or sources of further information. Information is needed in many formats, and as early as possible (Hussein and Partridge 2002). People can, and do, seek out their own sources of information, but our interviewees suggested that the NHS is providing them with little. However, voluntary organisations' websites were commonly cited as reliable sources of information, as were information leaflets included in drugs packaging.

Signposting and key workers

People living with long-term conditions may have contact with several different health professionals in the course of their regular care. Acute and community nurses are in touch with people on a regular basis and can play a part in facilitating self-management (Kralik *et al* 2004). The burden on GPs could be lessened through broader thinking about the role of care co-ordinators, involving nurses, information officers or fellow patients in care-giving (Coulter 2002).

Sally, who has Parkinson's disease, thought it would be a good idea to have someone to direct newly diagnosed patients to services, including those provided by the voluntary sector, and point out sources of information about the disease:

If I'd had a key worker, or someone at the beginning, that would have helped enormously. I was on my own and floundering. I didn't start on proper medication for years. Everything was self-taught. Had there been somebody to turn to, to signpost – a nurse – then you can go away but at least you know they are there when you need them, when you have questions.

Sally, mid-50s, Parkinson's disease

Ruth, who has rheumatoid arthritis, felt that a referral to a team of disabled people based in the hospital would provide the best access to information, citing the local, experiential knowledge that peer groups have that would help a patient to understand and negotiate the hospital system. Such a group could tell the patient about voluntary organisations and benefits, as well as providing support when a patient has just been given a diagnosis.

Flexibility in service provision

We have highlighted the fact that patients want different types of support at different times of their lives and at different stages of their condition. Our literature review and interviews emphasise that the following issues are important:

- the value patients attribute to continuity of care
- the importance of professionals having enough time to talk to patients
- the importance of patients being able to fit contact with professionals into the rest of their lives
- the difficulties for patients in finding out-of-hours support
- the potential role for assistive technologies (ranging from adaptations of the home, to use of email, text messaging and internet-based health services) to facilitate self-management across many different age groups.

Continuity of care

Our literature review suggests that patients are concerned about, and want, continuity in their care. However, this is not always easy to achieve within a highly pressured service and a flexible workforce. Where patients do have access to individuals or, more realistically, to a team of people with whom they have built up relationships over time, their sense of satisfaction – and their belief that the health professionals are taking an interest in them – is high.

Enough time to talk

A common concern emerging from the literature on self-management is that doctors' time is at a premium and patients should not waste it (Paterson and Britten 2000). But long-term conditions are not time efficient. The interwoven medical, social and psychological needs of a patient must be identified and managed by health professionals who often do not have the time for such in-depth assessment.

Research in diabetes has found that patients and professionals have very similar concerns (Pooley *et al* 2001). Lack of time – to deliver and receive quality care – is a recurrent theme from both perspectives. However, patients are realistic about what the NHS can and cannot do, and many accept that primary responsibility for their own health lies with themselves (*ibid*).

Service planning – fitting in with people’s lives

A real challenge for the NHS is to provide services that fit in with people’s lives. Targets that require GPs to be available to patients within 48 hours have often meant that practices are unable to offer pre-booked routine appointments to people who need regular care. Telephoning for a same-day appointment is not a realistic option for many, especially those with work and/or family commitments, transport difficulties or assistance needs. Ruth, who has rheumatoid arthritis, feels that the system has let her down when it comes to booking GP appointments:

My GP used to be good. The practice nurse ran a weekly walk-in clinic and I went at the end of the day, every week, for (gold) injections. If I wanted to see the GP, I could make an appointment. Now with government targets, if I want to see the GP I have to ring up at 9am on the day I want to see her – then at 2pm for the afternoon session. It causes absolute havoc – I can’t plan anything. I have to plan when I’m going to phone. I’ve written to the practice, I’ve written to the PCT. They did say they were going to change the system so that people like me, who have other commitments, can book in their appointments, but a year on, that hasn’t happened. It’s the doctor who wants to see me, not the other way round.

Ruth, mid-50s, rheumatoid arthritis

Out-of-hours care

Out-of-hours-care also emerged as an important issue for many of our interviewees, and was highlighted by two people as the single thing they would change to improve their care, which they described as otherwise largely excellent.

Vicky describes the process of trying to get out-of-hours care for her asthma. Her years of experience, and close working relationship with a team of health professionals, has led to a written management plan, agreed to by herself, her consultant and her GP. Vicky knows how to treat herself in a crisis and at what point she needs to be admitted to hospital:

I try to avoid hospital if at all possible. I try to time my crises for between 9am and 5pm, Monday to Friday. But sometimes I have to go in, out of hours, and A&E don’t know that. I need a red card system to get me through. I have a nebuliser at home. A&E will repeat what I’ve already done. I sit in the waiting room for three hours, getting more and more tired, and more stressed. The out-of-hours doctors know nothing about you and they can’t access your notes. We don’t want to be in hospital, we don’t want to abuse the system. COPD have an early discharge system – if you’re ill within three weeks of being discharged you can go straight back in, but they won’t do that for asthmatics. There must be some way of allowing access to your notes – the out-of-hours docs don’t know me from Adam.

Vicky, mid-20s, asthma

Using assistive technologies

Although recent literature on self-management of long-term conditions does not refer to assistive technologies (by which we mean a broad range of technologies that includes home adaptations as well as newer electronic technologies such as email and text messaging), we asked our interviewees if they made use of them at all in the self-management of their conditions.

Some of our interviewees use email for rapid communication with consultants, while others receive telephone text messages from their clinic, for example, with their latest blood test results. Russell has invested in a smart phone, on which he can set reminders of daily appointments. Toby has an electric adjustable bed and various adjustable chairs, as well as nerve stimulators such as a TENS machine. Debbie has her own glucose monitor at home, and Vicky her own nebuliser. These devices contribute to patients' self-management on a daily basis, as well as their ongoing relationships with their health teams.

Some of these ideas, such as email contact with patients, save administration time in booking appointments and are undoubtedly cheap. They also free up time for both patients and professionals. Text messaging to patients who want to be contacted in this way is also a potentially cost-effective and fast way to send out results. Not all patients or health professionals will want to communicate in this way, but these methods are worth considering as part of an overall strategy.

Ways ahead

The issues raised in this discussion of how people self-manage long-term conditions have implications for service planners and providers. Much work is already in progress through the Expert Patient Programme, but this focuses primarily on how patients need to change rather than how services need to develop in line with people's needs and expectations. Other developments are also needed. Drawing on the patients' views described in this paper, we outline ways in which primary care trusts (PCTs) and strategic health authorities (SHAs) working in partnership with local authorities and the voluntary sector, can best support people to self-manage their long-term conditions.

Developing the skills of health professionals to support self-management

PCTs and acute trusts should:

- ensure that local education and training programmes equip health professionals to work with and manage patients within the context of their own lives, rather than a clinical model of care. PCTs could use Local Delivery Plans (LDP) to enhance education and training for health professionals through Workforce Development Confederations. They could also use the assistant practitioners' role and the 'skills escalator' opportunities of Agenda for Change to provide development opportunities for nurses and other health professionals. Continuing Professional Development (CPD) programmes could be used for GPs with special interests (GPSIs) to support self-management (*see*, for example, www.gmsa.nhs.uk/core/dtw/index.htm)
- support shared decision-making between doctor and patient, and use decision support services, learning from pilots such as Team Health in Haringey PCT (www.natpact.nhs.uk/news/index.php?article_request=1144), and the Shared Decision-making Project (www.modern.nhs.uk/action-on/8905/26892/IDM%20Presentation%20-%20RC.ppt#256,1,Informed Patient Decision Making Project)
- consider how to develop micro-incentives to reward health professionals for undertaking learning and skills development for long-term support of self-management.

Improving information and signposting

SHAs should:

- take responsibility for developing long-term-conditions information strategies and providing core information on health, social care and voluntary organisations. Ideally this should be done jointly with local authorities, and could involve:

- reviewing information in line with National Service Framework information reviews
- ensuring that information is available in different formats, electronically and in multiple languages, at the point of diagnosis and whenever the patient needs it subsequently.

PCTs, hospital trusts and social services departments should:

- use community matrons and community specialist nurse links with practices to ensure that every GP and specialist nurse has, and is using, a wide range of up-to-date leaflets in appropriate languages
- ensure that all clinicians with a special interest in managing long-term conditions (for example, practice nurses and specialist nurses) are aware of available services and develop advocacy skills to support people in gaining access. (This is a training and continuing professional development issue, *see* p 13.)
- train clinicians to direct patients towards decision support information (including leaflets, DVDs, audiotapes and internet web sites – *see*, for example, www.besttreatments.co.uk/btuk/howtouse/130.html and <http://decisionaid.ohri.ca/index.html>) to enable them to participate in shared decision-making
- work with local authorities to provide access to web-based information in public spaces (*see*, for example, www.escis.org.uk)
- develop ways to support people who are not being actively case-managed to navigate and gain access to information and services. This could include working with the local voluntary sector, or developing the care navigators or assistant practitioner role.

Ensuring flexibility in service provision to fit in with patients' other commitments

PCTs, working with social services departments, should use the commissioning process to develop flexible provision and monitoring arrangements that help people self-manage. This could include:

- working through existing service development groups, such as clinical networks and collaboratives, to encourage primary and secondary health care providers to develop the use of flexible forms of access for patients – including the use of email, telephone text messaging and assistive technologies (*see*, for example, <http://bmj.bmjournals.com> (vol 329, 21 August 2004, pp 439–42))
- developing personal health and social care plans in line with the recommendations in *17 Million Reasons* (Partnership on Long-term Conditions 2005) and the commitment in the Labour Party Manifesto 2005 (Labour Party 2005). This could help resolve the difficulty and confusion that many patients experience both during the day and out of hours.

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Millions of people in the UK are living with long-term conditions such as asthma or diabetes. Most of these people are leading full and active lives with only occasional contact with health professionals, by altering drug doses and adapting their lifestyles in response to subtle changes in symptoms. This paper reviews patients' perceptions about managing their own conditions, and identifies how primary care trusts and other health and social care providers can support them, in line with their individual needs. Three key areas for service development are:

- **improving health professionals' skills to help patients manage their own conditions**
- **improving the provision of information about long-term conditions and the local services available**
- **increasing the flexibility of service provision to fit in with patients' other commitments.**



