CONTINUING PROFESSIONAL DEVELOPMENT

Improving self-management for patients with long-term conditions


Summary
An increasing number of people are living with long-term conditions. These conditions cannot be cured, but can be managed through education, health promotion, medication, therapy and self-management. Self-management involves people taking responsibility for their own health and wellbeing, as well as learning to manage any long-term illnesses. Nurses play a pivotal role in providing advice, guidance, education and support to people living with long-term conditions. Self-management is important as it not only benefits the patient, but also provides wider opportunities for community and specialist nurses to use and develop their clinical and interpersonal skills.

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Aims and intended learning outcomes
This article aims to explore some of the nursing implications associated with the rapid increase in the number of people living with long-term conditions, as well as addressing the nurse’s role in supporting patients to self-manage their conditions. After reading this article and completing the time out activities you should be able to:

> Understand the personal and economic burden of long-term conditions.
> Recognise the benefits of self-management in enhancing the patient’s quality of life.
> Identify your role in supporting patients in self-management.
> Implement strategies that will support government initiatives aimed at enhancing self-management skills.

Introduction
The British Medical Association (BMA) says that people with a long-term condition should “own and control their condition” rather than have the condition dictate how they lead their lives (BMA 2007). In England, an estimated 15.4 million people have a long-term condition (Department of Health (DH) 2009a). Long-term conditions may include diabetes, asthma, arthritis, hypertension, some respiratory conditions and some mental health problems, such as depression and schizophrenia. It is estimated that 85% of deaths in the UK are from long-term chronic diseases, with 36% of all deaths resulting from cardiovascular disease and 7% from chronic respiratory disease (European Cardiovascular Disease Statistics 2008).

The personal and economic burden of long-term conditions is exacerbated by additional health and lifestyle factors. People with two or more long-term conditions are more likely to be obese, eat less healthily and smoke than people with one or none of these conditions (Maskell 2007, Scottish Government 2007). Such co-morbidities affect individuals’ quality of life, and lead to huge cost to the NHS. Furthermore,
condition self-management can become a more fundamental part of their everyday lives, to ensure independence, self-worth and the ability to lead an active life as possible. For high-risk patients with such illnesses, self-management is essential to prevent further complications. This has been acknowledged within government policy, with initiatives being put in place to enhance the self-management skills of people with long-term conditions, such as the expert patient programme (DH 2001). Nurses are well placed to implement this policy, promote self-management and educate patients on the quality-of-life benefits of self-management. Training packages are available for health professionals to help them develop key skills in self-management promotion (Working in Partnership Programme 2010). Taking part in these training courses can be incorporated into continuing professional development (CPD), with CPD credits being provided for participation.

To describe government self-management initiatives, the prime minister made a commitment in January 2008 to develop a patients’ prospectus outlining how people with long-term conditions in England can access a range of self-management services. The Patients’ Prospectus – ‘Your Health, Your Way – A Guide to Long Term Conditions and Self Care’ (DH 2008a) set out the support that patients with long-term conditions could expect from April 2009.

From April 2009, people with long-term conditions in England could expect local services to be provided by their primary care trusts (PCTs) and local authorities, if they were not already available. As a minimum, patients have a right to receive the right information when they want it, support with making small lifestyle changes, access to structured courses designed to provide the skills to self-manage, the opportunity to talk to other people about their condition.

Self-management

Self-management involves individuals taking responsibility for their own health and wellbeing. For people living with a long-term condition self-management can become a more fundamental part of their everyday lives, to ensure independence, self-worth and the ability to lead an active life as possible. For high-risk patients with such illnesses, self-management is essential to prevent further complications. This has been acknowledged within government policy, with initiatives being put in place to enhance the self-management skills of people with long-term conditions, such as the expert patient programme (DH 2001). Nurses are well placed to implement this policy, promote self-management and educate patients on the quality-of-life benefits of self-management. Training packages are available for health professionals to help them develop key skills in self-management promotion (Working in Partnership Programme 2010). Taking part in these training courses can be incorporated into continuing professional development (CPD), with CPD credits being provided for participation.

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and access to self-management aids for daily living or to improve their functional ability at home. This is not a new policy, but provides an opportunity to draw together all of the resources that are already available. It is applicable to all long-term conditions, which cover the four pillars of existing DH policy on support for self-management (Table 1).

These pillars complement the desires of people living with long-term conditions, since research has demonstrated that these patients would like to be more involved in their health care. Studies by the National Asthma Campaign have demonstrated that people with asthma would like more information about the condition, more involvement in treatment decisions and greater control of their illness (Gibson et al 2003). Studies with people with cancer have also shown similar findings (Davies and Thomas 2007, Davies et al 2008).

Doctors, nurses and other health professionals who undertake long-term follow up and care of people with long-term conditions often observe that the patient understands the disease better than they do (DH 2001). This knowledge and experience held by the patient has been referred to as an untapped resource that could benefit greatly the quality of patient care and ultimately the individual’s quality of life (DH 2001).

### TABLE 1

<table>
<thead>
<tr>
<th>Policy</th>
<th>Explanation</th>
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<tr>
<td>1. Information: more informed patients are more empowered people.</td>
<td>Information to support self-management should be at the centre of the choices offered to people with long-term conditions. This can include advice on how best to access health and social care services as well as broader advice on voluntary services, housing and education. By directing people to the right information about their conditions, and providing them with the confidence to use this information, people can gain more control of their illness and thus feel more empowered to live independently.</td>
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<td>2. Skills and training: helping people to take care of their condition better.</td>
<td>Healthcare professionals, especially nurses, have a pivotal role in teaching people the skills to take control of their long-term conditions. This can be done by encouraging people to attend training courses.</td>
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<td>3. Tools and devices: helping people to monitor their condition and control their medications.</td>
<td>Healthcare professionals have a duty to be aware of the tools and devices, both technological and non-technological, that can be used to self-manage long-term conditions. With the appropriate support, these interventions can have a significant effect on a person’s quality of life and ability to live independently with such illnesses.</td>
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<tr>
<td>4. Support networks: boosting confidence and getting involved in the community.</td>
<td>Involving people with long-term conditions in their needs assessment and care planning is one of the most important ways in which health and social care services can be transformed into integrated services with the individual or his or her carer at the centre of the care plan. Directing people to relevant support groups could make the difference between someone living independently with a condition, or just living with it.</td>
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(DH 2009a)

Established user-led self-management programmes

Along with existing policy and patients’ wish to be involved in personal health care, there has been a rise in the number of self-management programmes available. These programmes can take a variety of approaches, but are primarily user-led. One of the leading authorities in this field is Kate Lorig of Stanford University in the United States, who developed a community-based generic self-management programme known as the chronic disease self-management...
In a five-year research project, the chronic disease self-management programme was evaluated in a randomised study involving more than 1,000 participants. This study found that people who used the programme, compared with those who did not: improved their healthy behaviours, for example exercise, cognitive symptom management, coping and communications with physicians; improved their health status, such as self-reported health, fatigue, disability, social activities and health distress; and decreased the time they spent in hospital (British Liver Trust 1999).

Based on this approach and success of the initiative, the expert patient programme (EPP) was introduced in England in 2001 (DH 2001). The EPP is a lay-led self-management programme that aims to improve quality of life by developing the confidence and motivation of people to use their own skills and knowledge to take effective control over living with a long-term condition. The programme is based on the assumptions that people with long-term conditions need to:

- Know how to recognise and act on symptoms.
- Make effective use of medications and treatments available.
- Understand the implications of professional advice.
- Access social and other services (including transport).
- Manage work and access the resources of the employment services.
- Access chosen leisure activities.
- Develop strategies to deal with the psychological effects of illness.

As with the chronic disease self-management programme, those who have participated in the EPP have reported improved health, better coping with fatigue, fewer limitations in their activities of daily living and less dependency on hospital care (Richardson et al 2008). After successful piloting, approximately 12,000 EPP course places are available per year, which are now being made available through PCTs.

The effectiveness of lay-led self-management programmes in improving patient outcomes is outlined in Table 2 and improvements in health service use are outlined in Table 3.

The nurse’s role in self-management

While self-management is fundamentally a personal and independent journey, interactions between healthcare professionals and the ‘expert patient’ are critical for the exchange of information and decision making. The Health Foundation uses
the term ‘co-creating health’ to describe an active and collaborative partnership between patients and health professionals (Coulter and Ellins 2006). For guided self-management to be successful, a positive patient-professional relationship has been shown to be a key factor (Coulter 1997, Clark and Gong 2000, Holman and Lorig 2000). It has been reported that this enhances patient motivation (Hibbard and Cunningham 2008) and increases self-efficacy (Cimprich et al 2005), both of which are implicated in self-management.

Self-management programmes for people with long-term conditions not only offer benefits to the patient and the healthcare service, but also to individual healthcare workers. Family doctors, practice nurses and other primary and community clinicians will have greater opportunities and incentives to advise people on the measures they can take to improve their health.

Nurses, in particular, are at the forefront of a national shift towards self-management promotion. Indeed, specialist nurses are shown to provide efficient and cost-effective advice and care for people with progressive conditions such as multiple sclerosis and Parkinson’s disease (Freeman and Thompson 2000, Evans et al 2002). Furthermore, several initiatives highlight the contribution of nurses to support the delivery of the national service framework for people living with long-term conditions (DH 2005) (Box 2).

The vast array of clinical and interpersonal skills held by nurses is particularly pertinent in meeting the self-management needs of individuals with complex problems arising from three or more long-term conditions. Nurses who work in this area of self-management promotion are known as community matrons, whose primary role is to work with patients to assess their personal and support needs. They act as a fixed point of contact for the patient. Self-management becomes feasible by nurses overseeing and co-ordinating particular care needs while also acting as an educator and model to the patient. Not only does this approach to community nursing reduce hospital admissions, but it also fits in with the preference of the vast majority of patients to remain at home. Where possible, patients are able to choose where and when they receive care, including telephone contact, digital television, telecare and the internet.

Personalised care planning is an effective approach that nurses can use to identify the self-management needs of patients, as well as the level of support required by health professionals.

### Table 2

<table>
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<tr>
<th>Programme</th>
<th>Outcome</th>
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<td>Challenging arthritis is a user-led programme developed by Arthritis Care (2009) in which all senior staff, self-management trainers and volunteer course leaders have arthritis.</td>
<td>In randomised controlled trials consistent improvements in knowledge, self-efficacy and the use of self-management behaviours have been reported (Barlow et al 1999). Other arthritis programmes have reported reductions in symptom severity, especially pain (Barlow et al 1999).</td>
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<td>The self-management training programme developed by MDF The Bipolar Organisation (formerly the Manic Depression Fellowship) (2009) has been designed to enable individuals with a diagnosis of bipolar disorder to gain confidence in taking control of their lives.</td>
<td>Improvements in mood sustained three to six months after completion of the course have been reported (Department of Health 2001).</td>
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<tr>
<td>Self-management in multiple sclerosis (MS) has been developed by the MS Society (2009), and all tutors have MS.</td>
<td>In 2009 the MS Society began to train tutors to deliver structured self-management courses based on the Lorig et al (1999) model. Outcomes are still to be measured.</td>
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<tr>
<td>Asthma self-management (Asthma UK 2009).</td>
<td>Programme outcomes include reduced symptom severity (Allen et al 1995) and reduced quantity of medication used (Gillies et al 1996).</td>
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</table>

**Time Out 5**

- **Identify any generic and condition-specific self-management groups available in your local area.**
- **Place a list of these groups on a staff noticeboard or other visible location within your practice.**
- **Ensure these lists are regularly updated.**
- **Make a conscious effort to inform one or more patients of a relevant self-management group available to them in their local area.**
Personalised care planning

Personalised care planning has become increasingly critical to effective self-management partnerships between healthcare providers and people with long-term conditions. Personalised care plans have been created to ensure that people with long-term conditions receive more individualised care and services to help them manage their conditions better and achieve the outcomes they want for themselves. In *High Quality Care for All* (DH 2008b) the government said that ‘over the next two years, every one of the 15 million people with one or more long-term conditions should be offered a personalised care plan, developed, agreed and regularly reviewed with a named lead professional from among the team of staff who help manage their care’.

*Supporting People with Long Term Conditions* (DH 2009b) was developed to ensure that this vision for the use of personalised care plans becomes more widespread.

It is envisaged that care planning will take place mainly in primary and community care and will involve staff such as GPs, practice nurses, community matrons, allied health professionals and social care workers. It may also take place in secondary care and involve specialist staff such as specialist nurses or consultants. It has been emphasised within the *Supporting People with Long Term Conditions* (DH 2009b) guidance that all NHS staff need to be aware of personalised care planning and their role in delivering these plans.

Personalised and integrated care planning is essentially about addressing individuals’ full range of needs, taking into account their health, personal, family, social, economic, educational, mental health, ethnic and cultural background, and circumstances. It is a holistic approach recognising that there are other issues in addition to medical needs that can affect a person’s overall health and wellbeing. Providing people with quality, timely and relevant information is crucial, as is self-management advice. Risk management and crisis and contingency planning are central to the process. The key elements of personalised care planning are outlined in Box 3.

### BOX 2

**Nurse delivery of the national service framework for people living with long-term conditions**

- Making a Difference: Strengthening the Nursing, Midwifery and Health Visiting Contribution to Health and Healthcare (DH 1999) highlights the positive contributions nurses make to improving people’s lives.
- The NHS Plan: A Plan for Investment, A Plan for Reform (DH 2000) requires NHS employers to empower appropriately qualified nurses, midwives and therapists to undertake a wider range of clinical tasks that enable self-management.
- Liberating the Talents: Helping Primary Care Trusts and Nurses to Deliver the NHS Plan (DH 2002) describes continuing care, rehabilitation, managing long-term conditions and delivering the national service frameworks as core functions for all nurses in primary and community care.
- The NHS Improvement Plan: Putting People at the Heart of Public Services (DH 2004) identifies community matrons as key to delivering the targets for long-term conditions using case management techniques for planning and co-ordinating care.

### TABLE 3

**Improvements in service use as a result of self-management programmes**

<table>
<thead>
<tr>
<th>Long-term condition</th>
<th>Outcome</th>
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<td>Chronic pain</td>
<td>Up to 80% reduction in the number of visits to health professionals</td>
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<tr>
<td>Asthma</td>
<td>Reduction in the number of hospitalisations (up to 31%) and length of stay (up to 50%)</td>
</tr>
<tr>
<td>Sickle cell disease</td>
<td>Reduction in the number of specialist visits by 15%</td>
</tr>
<tr>
<td>Asthma</td>
<td>Up to 39% reduction in the number of emergency department visits</td>
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### Time out 6

**List the potential benefits of personalised care planning for**

- People living with long-term conditions.
- Carers of people with long-term conditions.
- The healthcare workforce, particularly nurses.

Share your thoughts and ideas with colleagues. Can they make any additions to your lists?

### Conclusion

The personal and economic burden of living with a long-term condition is vast. The ageing
population and subsequent increase in the number of people living with one or more long-term conditions exacerbate this burden. Government initiatives are in place to enhance quality of life for people with long-term conditions by developing their skills and confidence to self-manage such illnesses. Nurses have a central role in caring for people with long-term conditions, as well as educating and promoting self-management practices. Although nurses have always contributed to self-management awareness, their role has become more explicit and the opportunities to use a vast array of clinical and interpersonal skills are at the forefront of this work.

**Box 3**

**Key elements of personalised care planning**

- Place the individual, his or her needs and health choices at the centre of health care.
- Focus on setting goals and outcomes that people want to achieve.
- Take into consideration the needs of carers.
- Offer anticipatory and proactive health care via contingency (or emergency) self-management during crisis episodes.
- Promote choice and control by putting the person at the centre of the process and enabling better management of risk.
- Ensure that people with long-term conditions receive co-ordinated care packages.
- Provide information that is relevant and timely.
- Provide self-management support to prevent deterioration.
- Support multidisciplinary working between health professions and agencies.
- Conclude with a single care plan that is owned by the person, but can be accessed by those providing direct care and/or services, enhancing patient-provider partnership.

**References**


