The management of patients with long-term conditions


Summary
This article provides an overview of chronic disease management for patients. Background from the approach used in the United States is provided along with UK developments, and there is discussion about the role of the nurse in patient empowerment and the role of the community matron in case management.

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Aim and intended learning outcomes
The aim of this article is to give an overview of the system of chronic disease management for patients. The background to the implementation of this approach to care delivery is discussed, including learning from the approach used in the United States. Policy initiatives for chronic disease management and the UK model for health and social care are presented. Each level of care in the UK model is described. The patient experience to date is discussed together with the need for a more integrated care pathway for patients.

This article discusses the nurse’s role in, and the need for, informed choice for patients; the key role of the community matron in the implementation of a case management approach for patients with the highest burden of disease; suggestions in support of the unique contribution made by nurses in their role as care manager; and the need for self-care and rehabilitation across the spectrum of long-term conditions.

After reading this article you should be able to:
- Discuss the policy initiatives behind the chronic disease management approach to care.
- Identify the different levels of the case management model in the UK.
- Discuss the need for education and patient-centred care plans for patients with chronic conditions.
- Discuss how patients requiring case management can be identified in your local area.
- Discuss the role of the case manager/community matron.
- Outline why a multidisciplinary approach to case management is vital.
- Understand the Expert Patients Programme.
- Describe the contribution of the nurse as case manager.

Background
Seventeen and a half million people in Great Britain report a long-term condition such as diabetes, asthma or arthritis, and for some, especially older people with more than one condition, each day brings discomfort and stress.

Health and social care services contribute a large financial resource in terms of staff and non-staff costs to caring for these patients who occupy up to 42 per cent of all acute hospital bed days.
(Department of Health (DH) 2005a). Both of these issues indicate that we are not caring for patients with long-term conditions in ways that really meet their needs or the needs of the health system. Incidence of long-term conditions is high in disadvantaged groups and, as the population ages, the incidence of long-term conditions will continue to rise.

Patients with one long-term condition, such as heart disease, are already experiencing better management of their conditions (DH 2005a), but for patients with highly complex needs the situation has been different. These patients have experienced unco-ordinated care that can result in frequent admission to acute hospitals. Care has been ad hoc at best. By improving the care of patients with long-term conditions we can help them to stay in their homes and their communities longer.

The National Service Framework for Long-term Conditions (DH 2005b) focuses on the needs of people with neurological disease and brain or spinal injury, with some application to patients with other long-term conditions. Although there are attempts to manage long-term conditions better through the implementation of condition-specific National Service Frameworks (NSFs), Lewis and Dixon (2004) note that there is not one recommended model for all long-term conditions.

**The patient’s needs**

Nursing has traditionally developed as a discipline to care for the sick. The formation of medical specialties has often meant that patients with more than one long-term condition have experienced their illnesses being treated in isolation from each other. The philosophies of holistic and person-centred care are not in reality being practised.

When patients are told they have a long-term condition they begin to realise that there is no cure for them. Muncey (2002) states how, if a chronic disease is not to be considered a life sentence, the focus of care must concentrate on enabling the person to live an active and meaningful life within the constraints of their condition. Various demands are placed on a person with a chronic condition, including physical symptoms, emotional strain, changes in relationships and a sense of uncertainty and sometimes helplessness (Burks 1999). Nurses are ideally placed to encourage patients to take control of their situation, enable them to explore the full extent of their needs and wishes, and to develop care plans that take into account physical and other needs.

**Patient empowerment**

Nurses can help patients with long-term conditions attain a better quality of life through purposeful interventions that aim to minimise symptoms, reduce the intensity and frequency of acute exacerbations of the disease and enhance psychosocial wellbeing (Kline Leidy et al 1990).

The notion of patient empowerment is a relatively new concept for nurses and other healthcare professionals. It means that patients are provided with information about risk and benefits of treatment so they can make an informed choice and act on this choice. This could mean that a patient may choose not to take prescribed medications or to follow the advice of a nurse. Traditionally, such patients have received short change from professionals.

Where patients choose a course of action not in keeping with professional advice, it is important they receive continuing support. In many cases there should be further exploration of why the patient does not wish to comply, for example, poverty, side effects of medication and poor information, and the reasons should be fully understood by the nurse. Understanding why patients are non-concordant with professional advice may lead to a solution, thus avoiding the ‘short change’ by professionals. Kelly (2002) notes how concordance is value laden within health professions where compliance with advice is considered good and non-compliance is seen as bad. Better understanding of the reasons for non-concordance will help professionals to further assist the patient.

The nurse should develop further skills in areas such as listening and facilitation, and revisit previously held values and beliefs about non-concordance with advice from professionals. There can be a variety of reasons for non-concordance. Roberson (1992) noted how patients with chronic conditions may comply with advice which supports a feeling of apparent good health now but, as Kelly (2002) adds, this may ignore the long-term effects of the condition. This is especially pertinent if patients have limited knowledge about the long-term nature of their condition and the rationale for treatments. Kelly (2002) argues that a key point about empowerment and concordance with treatment regimens and advice is that the patient and the nurse should have the same perspectives and negotiated goals, especially about whether quantity or quality of life is most important to the patient.

It has been known for some time that nurses do not value working with patients whose conditions are not curable, resulting in nursing
interventions becoming aimless (Nolan and Nolan 1995). Reed and Watson (1994) revealed how nurses in acute settings found it difficult to keep a sense of therapeutic optimism with patients who had ongoing needs. The care of patients with chronic conditions provides nursing with a true challenge, but a challenge where important nursing values such as the nurse-patient relationship can be central to practice. Anecdotal evidence sums up how we can approach chronic disease management and see beyond the medical conditions the patient has and to understand the meaning of the condition for the patient in his or her everyday life. This simple philosophy supports nursing activity, to discover the person, to explore the meaning of living with the condition and to facilitate a future that is person-centred and holistic.

The US approach

The US and the UK are facing the same demographic challenges of increasing numbers of older people with chronic diseases. Examples of models of care for patients with long-term conditions in the US include Kaiser Permanente and Evercare. Evaluation of the Evercare model has demonstrated a 50 per cent reduction in unplanned hospital admissions without any detriment to health, a significant reduction in medications with benefits to health and high family and carer satisfaction (DH 2004a). Within both models, the most vulnerable patients with complex needs are cared for by a case manager. Kaiser Permanente achieves the minimum use of acute hospital beds as chronic disease management is facilitated by greater integration between generalist and specialist services. It embraces co-ordination between primary and secondary care to facilitate early discharge planning and is supported by well developed intermediate care services and a person-centred approach all of which are underpinned by an emphasis on self-care wherever possible (DH 2004b).

The Evercare model has a high clinical focus based on the development of enhanced nursing roles such as that of the advanced primary/practitioner nurses (APNs). The care or case co-ordinator role is based on the five Cs:

- Care orchestrator.
- Champion.
- Clinician.
- Coach.
- Communicator.

The most vulnerable patients are identified from the population and transfer to the care of a case manager. In the Kaiser Permanente model, the case manager co-ordinates services across primary and secondary care, while the Evercare case manager provides care management across the spectrum. Despite several differences, the principles of the models are similar, to provide a co-ordinated quality service to patients living with a long-term condition. The underlying principles of case management are:

- A personalised care plan based on need and reflecting patient choice.
- Providing patients with care in the least intensive suitable setting.
- Supporting effective primary care.
- Focusing on patients with the highest burden of disease.
- Partnership working with secondary care, social services and the voluntary sector.
- An integrated care pathway for the patient.

UK developments

The transferability of the US experience to the UK has some problems. There are different incentives for providers in the US making it harder to reproduce the espoused financial savings in the UK. Nursing education and nursing roles in the US are also different and patient selection for schemes is imprecise. This would make it difficult to be clear about which patients would benefit the most (King’s Fund 2004). However, the principles of the approach are sound and likely to enhance the quality of life of patients, even if the proposed financial gains are not as high as anticipated.

The integration of health services with social services is key to success, especially for older people. Introduced in 1991, the care programme approach (CPA) (DH 1991) in mental health has offered a similar approach to that aspired to for patients with long-term physical conditions. Individuals are prioritised for a standard CPA approach and are entitled to the following:

- A thorough assessment of their health and social care needs.
- A written care plan.
- A care co-ordinator from mental health services to monitor the plan.
- Regular reviews of the care plan.
The enhanced CPA focuses on individuals with multiple care needs who may have more than one clinical condition, who should be in contact with more than one agency, and who may pose a risk if they lose contact with services. A care co-ordinator is assigned according to the patient’s needs, for example, it could be a community psychiatric nurse, an approved social worker, an occupational therapist, a clinical psychologist or a nurse. There are parallels with a case management approach for long-term physical disease.

Recent developments of NSFs encourage the better management of single conditions such as heart disease. However, their weakness is the disease-specific approach which means people with multiple conditions, and some single conditions, are not yet included in a specific framework. However, this should not inhibit nurses from developing a broad approach to management of long-term conditions to benefit patients.

The government has set a national Public Service Agreement (PSA) target for improving outcomes for people with long-term conditions by offering a personalised care plan for the most vulnerable that aims to reduce emergency admissions by 5 per cent by 2008 through improved care in primary and community settings. Included in this target is an increase in the number of people aged 65 and over to be supported to live at home by 1 per cent a year by 2007-2008 (DH 2005b).

Regardless of the various models already tried, the cornerstone of the approach to the development of management of long-term conditions for the most vulnerable is case management. The underlying principle is that care is proactive, healthcare staff should aim to work with the patient to identify problems quickly and to remedy them, both for their health and social care needs. However, there are fundamentally three levels of care designed to meet the needs of patients.

Figure 1 represents the levels of intervention and support for patients with long-term conditions. Health promotion reflects the population’s desire for a healthier future and is particularly important for disadvantaged groups and areas, including initiatives such as healthy lifestyles and a healthy diet. In the future, all pharmacies will be encouraged to promote healthy lifestyles. Level 1 patients require more support in managing their condition so that they can take a more active role.

The patients represented at level 2 are those who are at high risk of complications from their condition and would benefit from the assistance of the multidisciplinary team. Specialist nurses and nurses in general practice can make a key contribution by helping the patient to proactively manage his or her condition and avoid future complications. The new General Medical Services contract (DH 2004c) rewards practices for the good care of patients requiring level 1 and level 2 care. The conditions covered are asthma, cancer, diabetes, epilepsy, heart disease, hypertension, hypothyroidism, lung disease, mental illness and stroke.

Level 3 represents those patients requiring a case management approach. These patients often have complex, multiple conditions and their needs require the services of a skilled, integrated team. Although health promotion is identified as a distinct level, health promotion must apply at all levels of the triangle. This is also true of self-care wherever possible. Self-care and rehabilitation strategies must be considered and negotiated with each patient regardless of his or her level of care for chronic disease management. The patient may occasionally choose not to engage in self-care or rehabilitation but these approaches should be discussed to enhance ability and independence in all but those situations where the patient is at the very end of his or her life. A national target for long-term conditions was set in National Standards, Local Action: Health and Social Care Standards and

**FIGURE 1**

Levels of need for groups of the population requiring long-term management of their conditions

<table>
<thead>
<tr>
<th>Level 3</th>
<th>Patients with highly complex conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 2</td>
<td>Higher risk patients</td>
</tr>
<tr>
<td>Level 1</td>
<td>70-80 per cent of patients</td>
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<td></td>
<td>Population-wide health promotion</td>
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(DH 2005a)
Planning Framework (DH 2004d). It states that a personalised care plan must be in place for patients and emergency bed days must be reduced by 5 per cent by 2008, compared with 2003-2004, as the result of improved primary and community care.

Making self-care a reality

To ensure that self-care is possible for patients, the nurse needs to act as a facilitator and providing information is essential. The nurse must acknowledge patients’ central role in their care and help them and their family to make informed choices. Information needs to be provided and easily understood with the opportunity for discussion. The implementation of monitoring strategies by patients gives them some control over their situation. This may include adjustment of medications and intensity of self-monitoring when needed, together with guidance on when to contact a health professional. There should be one key contact for the patient to avoid him or her having to negotiate complex systems.

The expert patient

Patients with long-term conditions should be empowered to live a life that is as independent and flexible as possible with their condition and not constrained by a rigid, paternalistic healthcare system. The expert patient programme (DH 2001) was launched as a response to the untapped knowledge of the patient and in an effort to help patients move from being passive recipients of care to being able to manage their own conditions (Tattersall 2002). The programme helps patients to develop working in partnership with health, voluntary and social services and to restore control over their lives. The programme aims to assist patients to reduce the severity of symptoms; increase their confidence; increase their resourcefulness and improve their self-efficacy.

The core elements of self-management skills are problem solving, decision-making, resource use, forming professional-patient partnerships and taking action.

Tattersall (2002) notes how a change in the attitudes of professionals and patients is needed to create a culture where patients with chronic conditions are empowered to be the expert.

Research indicates potential reductions in accident and emergency (A&E) attendances, appointments with GPs and other health professionals, and hospital admissions (DH 2001). Courses should be run in accessible venues, at convenient times and at an affordable price. Leaflets about courses should be available locally.

Case management

The first step towards case management is for each team to identify those most at risk in the local population. The guidance in the UK and US models of case management offered will help to do this but the guidance should be used flexibly. In North Hampshire Primary Care Trust, teams reviewed the guidance from various models and the criteria in Box 1 were used as a working template.

It is clear from Box 1 that communication across teams and agencies is key in the absence of the single assessment process and good information technology links. There is no doubt that, once established, communication across

<table>
<thead>
<tr>
<th>BOX 1</th>
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<tbody>
<tr>
<td>Stratifying the local population to identify those requiring proactive management in North Hampshire Primary Care Trust</td>
</tr>
<tr>
<td>The patient meets at least four or more of the following criteria:</td>
</tr>
<tr>
<td>➤ Three or more active acute or chronic conditions, including mental health needs.</td>
</tr>
<tr>
<td>➤ Two or more unplanned hospital admissions in the past 12 months.</td>
</tr>
<tr>
<td>➤ Two or more accident and emergency assessment unit attendances in the past 12 months.</td>
</tr>
<tr>
<td>➤ Four or more current medications, excluding dressings.</td>
</tr>
<tr>
<td>➤ In the top 3 per cent of frequent visitors to the practice.</td>
</tr>
<tr>
<td>➤ Frequent contact with community teams.</td>
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<tr>
<td>➤ Frequent attendance to outpatients.</td>
</tr>
<tr>
<td>➤ Home care package of ten hours or more per week.</td>
</tr>
<tr>
<td>➤ Significant impairment in one or more activities of daily living.</td>
</tr>
<tr>
<td>➤ In receipt of Attendance Allowance or Disability Living Allowance.</td>
</tr>
<tr>
<td>➤ Significant number of falls – two or more in last two months.</td>
</tr>
<tr>
<td>➤ Experienced major life change and at risk of decline such as bereavement/loss and living alone with minimal support mechanisms.</td>
</tr>
<tr>
<td>➤ Vulnerable families.</td>
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</tbody>
</table>

NURSING STANDARD
education and ensuring social support is adequate. The case manager aims to anticipate problems before they occur. This role may be taken by a community matron. The case co-ordinator approach can be seen as the task-focused approach. In both cases the aim is to provide continuity of care and a named person to contact when problems and issues arise.

The case manager can integrate the contribution of specialist and generalist expertise, minimise unnecessary visits and provide care in the least intensive setting. Although avoidance of unnecessary hospital admission is a key motivation when the patient can be cared for at home, sometimes 24-hour care provision is required.

The patient’s care plan should set out his or her objectives and needs. It should state what the patient will contribute to his or her care and what each professional and agency will contribute. The case co-ordinator should be aware of the range of services offered locally and be able to access these. Ideally, the patient’s care plan will include these in anticipation of need, with the aim of avoiding a health or social care crisis. This may mean providing the patient with the telephone numbers of key staff to contact over a 24-hour period if he or she feels there is a decline in his or her health or ability to manage his or her situation.

Case co-ordinators will be in a good position to advocate the development of adjusted or new services for their patients if they realise it would be of greater benefit to maintain these patients’ care at home. It is crucial that a case management approach also includes the needs of carers to provide support for them. There is also an ideal opportunity for health promotion activities with the patient and his or her family.

As the system of long-term condition management develops, nurses have a key role in a variety of settings. Sometimes a nurse will encounter a patient with several A&E attendances, who visits the practice nurse more regularly and starts to have frequent hospital admissions. In a busy, daily practice these patients may not be highlighted to community or primary care teams in a way that identifies a possible underlying issue. A phone call to a practice or team to discuss the patient may well highlight an underlying problem.

The DH suggests that the role of case manager can take two forms: role or task. In a task-focused approach, different professionals keep their current job titles and positions but undertake individual care co-ordination whenever appropriate. Case management as a role means that a professional holds a caseload of patients with complex needs. Their role is predominantly clinical providing regular monitoring, review of treatments and medications,

**Time out 4**
Consider patients you have cared for who have visited accident and emergency several times, who frequently visited the practice nurse and started to have frequent hospital admissions? What did you do? Would you do anything different in future?

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**Time out 5**
Think of a patient you have cared for who has been admitted to hospital. Could admission have been avoided? If so, what services were needed to assist them at home?

**BOX 2**

**Key principles of good case management**

- Enhancing the general practice team role through a multidisciplinary approach.
- Providing proactive care to patients in the community with the highest burden of disease.
- Working across boundaries and in partnership with secondary care clinicians and social services.
- Professional, usually clinical, case managers who develop a personalised care plan on the basis of need, choice and patient preferences.
- A team managing the patient journey proactively and seamlessly through all parts of the health and social care system.

(Dowse 2004)
The nurse case co-ordinator can also embrace key concepts in nursing practice into the role of case manager whether the case management is short or long-term, such as person-centred care, holistic practice and clinical leadership (Box 3).

**Community matrons in England**

The NHS Improvement Plan (DH 2004e) describes a new clinical role for nurses. The role is termed ‘community matrons’. These skilled nurses will act as case managers for those patients who require high intensity healthcare services. The community matron will assist the patient to remain at home for as long as possible and to facilitate choices in healthcare. The DH suggests that the community matron will extend the concept of case management by encompassing clinical interventions to assist the patient. The community matron will be able to secure services for patients, order investigations, make referrals and arrange admission for the patient (DH 2005a), and they will also be expected to be independent and supplementary prescribers. Development of the competencies to become a community matron will sit comfortably with The NHS Knowledge and Skills Framework (KSF) (DH 2004f). The KSF has been developed from an analysis of competencies for NHS roles, including those recognised by regulatory and statutory bodies.

The DH has a target of 3,000 community matrons to be in post by 2007 to provide case management for the most vulnerable. As with hospital modern matrons, it is unclear whether the title of community matron will be widely used. The role is outlined in Box 4.

**Workforce development**

Nurses who take on a case management role may need to develop new skills and expand their knowledge. Courses assisting the development of physical examination, history-taking skills and nurse prescribing may be required along with clinical courses focusing on the management of long-term and specific conditions. A key skill of a case manager looking after older people is the ability to understand the effects of the ageing process on the condition or conditions.

A multidisciplinary approach to the management of long-term conditions is vital. Clerical support is vital and may require additional resources, such as a new telephone line, computer stations and formal time for the team to review current and new patients.

Once a system is established it is important to continually review the training and development needs of the team for some years. As patients with more complex needs are cared for at home, there is a need to develop the skills of not only the more junior nurses, but of the whole multi-disciplinary team. Training in team building and understanding other roles is essential.

### BOX 3

**The nurse as case manager: the nursing contribution**

- A sustained nurse-patient relationship that brings about empowerment and informed choice based on genuineness.
- A trusted key contact for the patient.
- Sound clinical assessment skills and the ability to identify or predict when health or social care problems arise as the result of a sound relationship.
- A key support and liaison role for family and carers – with the patient’s consent.
- A practitioner who can embed the central and key concepts of nursing into the case management role, such as encouraging independence, hope and caring.
- A patient-led holistic assessment and care plan.
- A listener and counsellor.
- A skilled professional who can help the patient to explore the options available, while remaining non-judgemental about the patient’s choices if they conflict with professional advice.
- Someone who will travel with the patient.
- Someone who can assist the patient to work through competing needs and assess those that are the most important at a particular point in time.
learning zone chronic diseases

BOX 4
The role of case management by community matrons

- Help avoid unnecessary admission to hospital.
- Reduce length of necessary stay in hospital.
- Improve outcomes for patients.
- Integrate all elements of care.
- Improve patients’ ability to function and their quality of life.
- Help patients and their family plan for the future.
- Increase choice for patients.
- Enable patients to remain in their homes and communities.
- Improve end of life care.

(DH 2005a)

Conclusion

Patients with long-term conditions require better management at all levels so that they can maximise their quality of life and independence. The traditional paternalistic nature of the NHS is no longer suitable. Informed choice for patients is the key to success and means examining issues such as non-concordance, patient choice, risk-taking, processes and care pathways so that we create cultures and philosophies that support patients more adequately. The proposed model for the management of long-term conditions in England will require the development of new ways of working and thinking to enable the change. The development of case management requires new skills for nurses and the whole multidisciplinary team but promises improved quality of care NS

Time out 7
Now that you have completed the article, you might like to write a practice profile. Guidelines are on page 64.

References


