

## What models of care are effective for people living with long-term health conditions?

Health and social care provision must increasingly focus on the most effective ways of supporting those with long-term health conditions. New ways of working and an increasing emphasis on self management are being promoted. This OutLine reviews the evidence that is currently available to support the development of practice.

### What is a long-term condition?

Defined by the Department of Health as a condition 'that cannot, at present, be cured, but can be controlled by medication and other therapies', long-term health conditions (or chronic conditions) are usually complex, sometimes unpredictable, and can affect most, if not all, aspects of a person's life. The challenges for health and social care include medical crises, symptom control and social isolation.

Around six in ten adults report some form of chronic health condition. These adults account for around 80% of GP consultations, are twice as likely to be admitted as an inpatient, and also have longer average stays in hospital than those without a long-term condition. The number of people with long-term conditions is expected to rise as the population ages, with an extra one million people living with a long-term condition per decade. This has major implications for health and social care services.

### Socioeconomic factors

People with a long-term condition are more likely to be socially and economically disadvantaged: less likely to be employed (with those holding a job more likely to have a lower status position), have fewer formal educational qualifications, less likely to have savings and more likely to live in an area of deprivation. They experience restricted access to public transport, private cars and the internet. Even after controlling for socioeconomic circumstances, they are also more likely to be current and heavy smokers, less likely to be physically active and more likely to be obese (Loretto and Taylor, 2007).

### The policy context

The 2005 National Service Framework for Long-term Conditions aims to bring a person-centred approach to long-term conditions. This NSF, while focusing on neurological conditions, has a stated transferable value to other long-term conditions. Eleven 'Quality Requirements' are set out to put the individual at the heart of their care, while maintaining independence for as long as possible. This shift from hospital-based care is likely to put further pressure on social care.

Early signs on the implementation of the NSF have been mixed. The central support team for the NSF was abolished in 2007, with responsibility for policy implementation completely shifted onto localities. This has been coupled with reorganisation of Primary Care Trusts (PCTs) and Strategic Health Authorities (SHAs) that has arguably led to a refocus on areas of national priority like heart disease.

## Models of Care

There are several formal models of care and support strategies for people with long-term conditions. These seek to find the most effective and cost-efficient means of managing the population living with a long-term condition.

### Wagner's Chronic Care Model

Most developed countries have adapted this US evidence-informed model, the most well-known of all generic models for long-term conditions since its development in 1998. It advocates a whole systems approach to providing support for long-term conditions. Wagner's model shifts from a system that is reactive - responding when a person is in need - to one that is proactive, focused on keeping a person healthy and independent. This will require the service user receiving structured, planned interventions and making follow-up a standard part of care. More complex patients may need case management.

To implement a strategy for long-term conditions, the Delivery System must be supportive. Senior leadership must identify long-term care improvements as important and translate this into the frontline. Breakdowns in co-ordination can be prevented through agreements that facilitate communication, and by data sharing as service users move between sectors. Systems should look outside of themselves towards the wider community to avoid duplicating effort.

Wagner's model stresses Decision Support: treatment and care decisions supported by explicit evidence-informed guidelines, training and specialists. The evidence for decisions should be discussed with service users in order for them to understand the principles behind their interventions. Information systems should give access to data on individual patients, in order to plan and track care, and to data on the population that the system serves, to identify groups of patients needing care and to facilitate performance monitoring.

The model also places an emphasis on self-management support. This means patients should acknowledge their own central role in their care and have a sense of responsibility for their own health. Providers and service users work together to define problems, set priorities and create treatment plans.

Wagner's model has undergone a four year evaluation process in the US. The results suggested a formal implementation of the model led to better outcomes in care for both adults and children with asthma, diabetes, heart failure and depression. Changes in Delivery System Design and self-management support significantly improved processes and outcomes; Decision Support improved processes but not outcomes and there were no significant benefits from clinical information systems. There is evidence that this model is also cost efficient, reducing healthcare costs or use of services (Singh and Ham, 2006).

The WISE model (Whole-system Informing Self-management Engagement) advocates a similar whole-systems approach, indicating that a multifaceted strategy provides a more effective and enduring improvement in the quality of care for those with long-term conditions. Singh (2006) found favourable evidence of the WISE model, although most is US-based and studies generally did not unpack the model sufficiently to discover which elements of the WISE approach were most successful.

### The NHS and Social Care Model

Introduced in January 2005 alongside the NSF, this model outlines a needs-led model of care, and contains significant elements of Wagner's model. Its key components are: a systematic approach linking health, social care, service user and carer; identifying everyone with a long-term condition; stratification according to need; a focus on frequent users of secondary care services; community matrons to provide case management; developing local ways to support social care and expanding the Expert Patient Programme.

- *A three-tier model of care*

The bottom tier of the model, representing 70-80% of those living with long-term conditions, focuses on 'supported self-care'. The next tier up is 'disease management', for those in greater need. The apex of the pyramid is for service users with multiple or complex conditions. These service users will be eligible for intensive, pro-active community matron case management to avoid admission to hospital. Although the case management approach is well established in social care, this generic model is a shift from previous condition-specific healthcare approaches.

Two US models have been particularly influential in developing the three-tier model: Evercare and Kaiser Permanente. It has been questioned whether the positive US-based evidence is transferable to the UK (Hudson, 2005), although there is other evidence to suggest the UK model of 'risk stratification', as part of a wider systems approach, is robust (Singh, 2006).

- *Community Matrons*

It was proposed that by 2008 all Primary Care Trusts (PCTs) should have developed care management approaches to long-term conditions, with 3000 community matrons in post across England and Wales to care manage those in the top tier of need. Initial guidance suggested that a community matron would have a caseload of fifty (Department of Health, 2006a). Early feedback from the Community Matron initiative suggests recruitment to the role has been problematic and in some instances other professionals, including social workers, have been case managing those eligible for a high level of support.

The role of community matrons was not defined in day-to-day terms, but by principles - primarily to treat service users earlier and in their own homes. The wide remit of community matrons has led to a variety of responsibilities including clinical care, care co-ordination, education, advocacy and psychosocial support; they are well-liked by service users and carers. Evidence from Sargent (2007) showed community matrons successfully integrating and co-ordinating the journey of the service user through the health and social care system. Recent evaluation of the Evercare case management model in nine UK pilot sites also found that the additional contacts, monitoring and treatment case management provided popular with service users and carers, but there was no overall reduction of emergency admissions, emergency bed days or mortality, at odds with evidence from the US (Boaden et al, 2006). It may be that out of hours care in the UK is not sufficiently geared to keep people out of hospital. There is also inconclusive evidence as to whether nurse-led community-based case management is effective for those with moderate or severe COPD (Taylor et al, 2005).

- *The Expert Patient Programme*

Launched in 2002, the NHS's Expert Patient Programme (EPP) aims to help people living with long-term conditions manage their own care and is recommended in the NSF for the bottom 'tier' of those with a long-term condition. Its core component is a training course, led by a lay trainer. The courses are generic and aim to take a holistic approach - from management of symptoms including pain and fatigue, to health promotion messages.

Evaluations of the EPP in 2005 and 2007 (Griffiths et al, 2007) show an improvement in service user self-efficacy (confidence to manage their condition). Overall, however, use of healthcare services was not reduced, and may encourage consultations through teaching communication skills. There were no improvements in quality of life or psychological health status from the 2005 study (and only slight improvements in 2007), the two aspects of a long-term condition most likely to involve social care. Evaluation has been based on those who have volunteered for the EPP and may be predisposed to accept self-management of their condition, while those who drop out or refuse the EPP have not been evaluated (Wilson et al, 2007). It is not known whether the EPP will have a sustained effect on people living with a long-term condition, although there is some evidence to suggest that self-care groups can result in the formation of subsequent informal, independent support networks, contributing to healthier and more active communities in the long run (Department of Health, 2007a).

## Condition-specific models

The advantage of condition-specific self-management models is in their tailored condition management skills and specialist knowledge (Griffiths et al, 2007). Whether a generic or condition-specific approach is more effective may depend on the individual condition. A useful summary of the different outcomes self-care support for a range of long-term conditions has recently been published by the Department of Health's Research Evidence on the Effectiveness of Self Care Support (Work in Progress 2007a). This summary, evaluating both generic and specialist interventions, may be useful in assessing whether a service user could benefit from involvement in the EPP or from a more condition-specific form of self-care support. Service user preference is split between generic and specialist models, with some suggesting a generic model of self-management with condition-specific 'bolt-ons' (Scottish Executive, 2007).

Research suggests successful case management schemes for long-term conditions have close links with specialists that allow ready links to clinical assessments. However, it may be dependent on the type of specialist: Singh (2006) found evidence that supported the addition of physiotherapists but not necessarily epilepsy nurses, mental health workers or pharmacists.

## The service user as virtual care manager

Traditionally, it has been seen as a failure of the system for service users to point out gaps in their care. However, Lloyd (2000) found in her study of Parkinson's patients' self-awareness that they were the only ones who experienced all service deliveries and had a clear idea of their needs. The way that service users manage their conditions varies according to their background, socioeconomic circumstances, personal experience, local context and family arrangements, and self-management would support these variations.

Corben and Rosen (2005) identified three factors as important in supporting service users to self-manage - a good relationship with the professional in charge of their care; access to clear information on their condition, and the need for flexibility in service provision.

Changing service organisation to allow self-referral to services is a cornerstone of accepting the service user as the manager of his or her own care. However, such open access systems risk alienating those service users who appreciate the routine of appointments; some people do not like to ask for help and their needs may be missed. Professionals broadly value self-care, but it can raise tensions between service user autonomy and professional responsibility, including the delivery of evidence-informed practice.

## The 'Strengths' model

Suggested by social care perspectives, the 'strengths' model focuses on helping people draw on their talents and capacities, connecting them with resources to help achieve these goals. While there is evidence that this model can work in long-term mental health conditions, there is no evidence to suggest effectiveness as a generic long-term conditions framework (Singh and Ham, 2006).

## Harnessing the local community

A successful shift from hospital to community based care will often depend on local context and good communication, moving beyond formal structures and joint planning. Community and voluntary groups can provide services including detailed information on a specific condition, respite care, support for carers, peer networks and advocacy (Department of Health, 2006b). Singh (2006) noted evidence in favour of community-based 'befriending' schemes to improve clinical outcomes. Policy suggests stronger links with community pharmacists, often the most accessible healthcare professionals to someone living with a long-term condition; they can provide information and support locally and out of hours.

## Information and technology-based approaches

Many people living with a long-term condition feel ill-informed, and those in the greatest need may not ask for information (Consumers' Association, 2003). Good information improves knowledge and understanding, encourages confidence in decision-making with professionals and may indirectly improve health and well-being. Personalised information has the greatest effect on supporting behaviour and attitude change to a condition (Singh, 2006) and service users also value the exchange of experiences with others in their position (Department of Health, 2007b).

Professional follow-up by telephone after hospital discharge has been associated with reduced health service use and improved clinical indicators (Barlow et al, 2007). However, there is no clear evidence that substituting a telephone call for an appointment improves outcomes or reduces healthcare use, and there is inconsistent evidence about internet-based support. Socio-economic circumstances may lead to programmes relying on home access to technology proving problematic (Loretto and Taylor, 2007).

## Working across health and social care

Service users do not generally distinguish between health and social care given in the home (Audit Scotland, 2007). In addition, people living with more than one long-term condition are less likely to receive joined-up care. Service users themselves are scathing of professional territorialism, viewing it as hampering their choices.

People with long-term conditions may be treated first and foremost as medical patients, and the mechanisms of social care may not be activated until need is severe. Others have criticised the NSF for giving lip service to joint working with social care but referring to 'patients' throughout.

There is evidence that social care services can reduce, prevent or substitute for hospital services (Wanless Review Team, 2005), with clear benefits to be found in installing aids and adapting homes to maintain independent living (Department of Health, 2006b).

## Areas for further research

Present models may not adequately serve the needs of minority ethnic service users, and information is scant in this regard. Generic models for long-term care are still in relative infancy, particularly in a UK context, and Singh and Ham (2006) caution that there is only limited evidence about the effectiveness of any long-term conditions model.

## Useful links

Service user experiences of long-term conditions can be found at [www.dipex.org](http://www.dipex.org).

Wagner's Chronic Care Model is at [www.improvingchroniccare.org](http://www.improvingchroniccare.org)

UK policy, including the NSF, is at [www.dh.gov.uk/en/PolicyAndGuidance/HealthAndSocialCare/Topics/LongTermConditions](http://www.dh.gov.uk/en/PolicyAndGuidance/HealthAndSocialCare/Topics/LongTermConditions), and self-care information, including the summary of evidence for self-care interventions, is at <http://www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/Selfcare/>  
The Long-Term Conditions Alliance can be found at [www.lmca.org.uk](http://www.lmca.org.uk)

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