

CONNECT: NEWS AND VIEWS FROM LMCA (LONG TERM CONDITION ALLIANCE) Issue 32, Winter 2006/7

Time to take stock - Elizabeth Wincott

Self-management is what people with long-term conditions do all the time. Behind all the initiatives is the fact that the person living with the long-term condition is the only person who truly knows what it is like to live with that condition. What interventions like the Expert Patients Programme (EPP) and other self-management programmes should do is to contribute to enabling people to live more comfortably and knowledgeably with their condition. It is moving away from a 'done to' approach that can lead to passivity and dependence or even distress.

Individuals and organisations have been practising forms of self-management long before Arthritis Care and LMCA brought Kat Lorig's model over from Stanford.

The aim should be to create a variety of innovative ways of delivering self-management programmes; building on what already works well and developing new and creative approaches tailored to local and individual need.

For these initiatives to be successful, we must ensure that we continue to change the culture in some parts of the health service and truly acknowledge that people with long-term conditions have a great deal of knowledge themselves.

Self-management: what works? - Angela Coulter

Too often, the way in which clinicians and patients interact tends to promote passivity and dependence instead of self-reliance, sapping patients' self-confidence and undermining their ability to cope.

People in oldest age groups, those with lower levels of educational attainment, those with certain long-term conditions such as depression, chronic pain or digestive problems those from minority ethnic groups, and those with very poor health - struggle to know how best to look after themselves. These people need targeted education and support to learn how to interpret the symptoms and changes in their condition, to help them develop strategies for coping with physical and emotional problems associated with their illness, and to inform them about where to find specialist help when necessary and how to access it.

Information on its own appears to have little effect, but educational and self-help programmes that are actively supported by clinicians have been found to have a beneficial effect on health outcomes.

Brief stand-alone self-management courses such as those promoted through the Expert Patients Programme, have been shown to improve knowledge, coping behaviour, adherence, and self-efficacy, but the effects tend to diminish over time. Efforts should be

focused on providing opportunities for patients to develop practical skills and the confidence to self-manage their health. Hands-on participative learning styles are better than traditional didactic teaching. It seems that the role of health professionals in guiding patients through this process is essential. The goal is patient autonomy, but responsibility for achieving this must be shared by patients and health professionals alike.

How best to empower patients? - Sarah Clarke

Self-management support should not end at the close of each programme. We need to achieve a policy where programmes act as a start, but from where individuals can access appropriate information, therapy and equipment to help them with their life requirements.

The message gets put to budget holders, and other stakeholders that we are in the business of delivering quality and tailored self-management services. And that the voluntary sector reaches hard-to-reach groups and provides services welcomed by many thousands of individuals living with a long-term condition.

Three views on self-management

Penelope Doue

Key to the success of the courses is the fact that the tutors themselves have long-term conditions. This peer- or lay-led approach facilitates participation by people who may be intimidated by a health professional or an 'I know best' approach by someone who does not have a long-term health condition.

For too long there has been too much emphasis on wonder drugs and treatment, whilst the estimated 15 million people (and rising) in England who live with long-term conditions struggle in their day-to-day lives.

Judy Wilson

There is no clear policy on whether doctors should 'refer' to courses, or simply offer them as an option. There is a lack of appreciation by some doctors of the huge impact of the loss of self-confidence and need for interventions to restore it. Many focus more on improved technical management of specific medical conditions rather than general self-efficacy.

Kitty FitzHerbert

Self-management covers all the ways in which people living with long-term conditions take responsibility for protecting, maintaining and safeguarding their health and managing (or even improving) the effects of their condition.