Encouraging and supporting patients living with long-term conditions to self-care

A programme of work by the Leeds Community Healthcare nursing teams to give self-care support to people who are living with long-term conditions

INTRODUCTION

With more than 15 million people in England living with a long-term condition (Department of Health, 2008a), there is a real need to address how patients can help to look after themselves and take joint responsibility for their healthcare in partnership with healthcare professionals.

At the time of the 2001 census (Office for National Statistics, 2001), there were more than 128,000 people in Leeds who considered themselves to have a long-term condition, equating to 18% of the resident population. Of these, 57,732 were of working age and the majority lived in the most deprived areas.

In addition, there were 70,446 carers providing unpaid care. This meant caring for people with a long-term condition was a key priority.

To address this, the Leeds Community Healthcare team developed a programme to integrate and promote self-care among its community healthcare professionals, driven by the long-term conditions nursing team and the community matron team. These form part of the Leeds Community Healthcare team.

Practice changing practice

Keywords Long-term conditions | Resource pack | Self-care

Practice Points

● Self-care is most effective when both health and social needs are considered.
● Having multidisciplinary teams of health and social care professionals working together reduces duplication of work.
● Many patients will need support to start on a self-care pathway and continuous encouragement.
● Practitioners should use national resources along with local service information.

Embedding the ethos of supporting self-care

The community matron and long-term conditions teams in Leeds have embraced the concept of self-care as part of patients’ everyday care. Together, they believe that enabling patients to self-care is an essential component of the nursing and matron role.

Professionals must promote independence to help patients take control and to ensure they play a crucial part in decisions made about their care. For the past four years, staff have been striving to ensure that this is integral to the work of all clinicians, working particularly closely with a number of interested GPs.

Partnership working to benefit patients has been one of the ways in which the Leeds team has been particularly successful. As well as working closely with other healthcare professionals, the community matron and long-term conditions teams work to ensure that self-care is integrated with social services.

All teams are conscious of prioritising patient needs and ensuring that patients receive information in an easy-to-use format, helping them make informed choices about their own health and social care.

Staff are mindful that they should not only concentrate on the health aspects of care delivery but also ensure they take a holistic approach, assessing patients’ health and social well-being, which often impact on each other.

Resources

The publication of the healthcare professional booklet Your Health, Your Way – A Guide to Long-Term Conditions and Self-Care (DH, 2009) has helped to focus the thinking of frontline nursing teams and to ensure nurses are tackling self-care issues with patients.

There is also an online resource pack, which brings together details of DH publications, national charities and other relevant organisations (see resources, p16).

As the Leeds teams work closely with social care staff, it is important that nurses have information about local social service provision. Therefore, as well as national resources, the teams use a Leeds City Council A-Z booklet, which outlines local services for older and disabled people, including neighbourhood networks, benefits advice and contact details for support groups.

Having local, up-to-date information enables nurses to help patients access all the relevant services from both a health and social care perspective.

The Your Health, Your Way booklet has also been useful for sharing information and ensuring that staff personal development is up to date.

NHS Leeds Community Healthcare brings frontline staff and senior management together regularly, through organisation-wide forums for all groups of nurses, allied health
A HOLIDISTIC APPROACH TO ASSESSMENT

As part of the Leeds Community Healthcare partnership with local social services, a holistic assessment takes place at the first meeting with each patient. This comprehensive assessment looks at both health and social care needs.

Health and social care professionals from both NHS Leeds and the local authority use the single assessment process. This same template ensures that all staff work consistently and that there is minimal duplication of work between multidisciplinary health and social care teams.

Patients’ home environments are also assessed, which may lead to them being referred to other services or professionals, such as occupational therapists, if a more detailed or specialist assessment is needed.

The general assessment helps nurses to decide the longer-term care planning needed. For those with impaired mobility, this might include help to enable them to use bathroom facilities more independently, such as walk-in showers, or referral for walking aids.

In some instances, people are able to walk very short distances around the house but cannot manage when outside. It may then be appropriate for them to have a wheelchair to enable family members to take them out and enable them to participate in organised outings from neighbourhood network groups.

These measures help people to remain independent for longer and reduce social isolation, which is a well-recognised cause of depression and anxiety.

The care plan may also cover referral to support groups or confidence-building courses such as the Expert Patient Programme (see www.expertpatients.co.uk).

Support that can be delivered includes referral to social services or referring patients to other services. This could include a referral to a local falls programme, run by dedicated staff, for those who are most vulnerable. The falls programme offers a structured exercise programme, which is individually tailored, along with advice on falls prevention.

As well as informing patients of the dangers inside and outside the home, this programme boosts confidence, allows patients to develop better mobility and balance and enables them to manage their own situation more effectively and safely.

Leeds dietitians also run a local nutrition service which the team uses. Food First is an educational resource for clinicians. It offers advice on nutrition for people with long-term illness, who have been assessed as being poorly nourished with weight loss, which is common in this group.

The service offers practical advice to tackle the issue on a long-term basis, with the team working with dietitians to advise patients on how to maintain weight, or gain weight by adding nutritional extra calories to their diet. This has proved to be more valuable than prescribing short-term supplements. These supplements do not have a long-term effect and often patients do not take them, which results in failure to improve nutrition and unnecessary expense for the PCT.

This new system has the positive effect of patients having a more enjoyable and naturally enhanced diet, while the PCT makes a cost saving that can be invested elsewhere.

For people with COPD, a local pulmonary rehabilitation class forms part of the PCT’s respiratory community service, giving information and support about living with the condition. The class incorporates a structured and individual exercise programme and is run concurrently with advice sessions, which explain the condition and tell patients how to manage it better.

When appropriate, self-management plans are agreed with patients. In those cases where they carry their own emergency antibiotics and steroids, this enables them to start treatment early, rather than waiting for a crisis. The team will be evaluating the effect of this on hospital admissions.

CHALLENGES OF SUPPORTING SELF-CARE

As self-care support has become an integral way of working with patients, the Leeds Community Healthcare team does not use a particular self-care pathway, but looks at various ways in which to engage and encourage patients.

The team finds that patient enthusiasm for self-care varies. Older people can find it more difficult to embrace, as culturally they are used to health care being delivered in a top-down way, without questioning provision. This can mean it takes time for them to accept that they could be in control of their health care.

The team has found living with a long-term condition can result in patient anxiety and depression, and so realised that psychological needs had to be addressed before patients would feel motivated to take a more active role in decisions about their health and care.

Patients often feel vulnerable when nurses first start to see them but, as relationships build over time, nurses find it easier to encourage them to take a lead in their care.

This may not happen instantly; education and reassurance is therefore an ongoing
Process, reinforcing the benefits. However, most of the patients who have started on the self-care path and can see the benefits want to do more.

Many with COPD will have previously been admitted to hospital with exacerbations. When a patient with COPD has left an exacerbation until crisis point, a doctor is called, and the patient becomes anxious and frightened, which leads to more breathlessness and an ambulance being needed.

Once the crisis is over and the patient is back at home, the community nursing team visits and encourages them to report their symptoms earlier. The patient sees the benefit of earlier treatment and therefore earlier recovery, which often prompts them to take action much sooner when they experience symptoms.

The team then finds that patients are much keener to follow a self-care pathway, and are keen to understand their medication and learn about early symptoms to look out for and when to start treatments.

Patients are encouraged to telephone at any time, to build their confidence in self-management. Over time they generally need less support as their confidence increases. Some people need more of a guiding hand than others and this often depends on where they are on their healthcare journey.

It can be more difficult to educate people with well-established illness who have lived with this for many years than someone closer to their initial diagnosis. This highlights the need to start empowering patients as soon after diagnosis as possible.

Nurses can be at the forefront of building relationships with patients that will benefit every subsequent interaction with healthcare professionals.

When it comes to supporting self-care and care planning, the Leeds Community Healthcare team strives to treat everyone as an individual, learning how individual patients prefer to be approached, understanding how they respond to information and how to take it forward with them. They understand there is no such thing as one size fits all.

CONTINUOUS LEARNING AND EVALUATION

The team has successfully integrated self-care into its patient care philosophy, but is continuously striving for improvement.

All health and social care professionals in Leeds use the single assessment process to record patients’ general health, care requirements and any social needs such as providing home carers.

Leeds Community Healthcare is developing a universal template for healthcare professionals to capture condition-specific information as part of the assessment process.

This assessment will record patients’ specialist requirements, including disease-specific medication and attendance at rehabilitation courses.

Sharing patient information between healthcare professionals on one form will help staff avoid duplication and save time, and patients will not have to repeat their medical history when seeing a different member of staff.

The Leeds Community Healthcare team is planning to develop a universal self-care framework to help all healthcare professionals across the PCT provide quality care and to encourage and support patients to self-care.

CONCLUSION

Nurses and community matrons at NHS Leeds have embraced the benefits of supporting self-care and care planning. With the involvement of local social services, it is a holistic approach, which looks at patients’ wider needs.

In 2007, as part of a review of the community matron service, patients were asked how the service had had an impact on their care. Patients said that community matrons had ‘improved [their] quality of life’, ‘helped [them to] cope with [their] disabilities’ and ‘take time to explain things’.

While this is only anecdotal evidence, the Leeds team will be working closely with health and social care partners to evaluate the wider long-term benefits, both to patients and the local service.

REFERENCES


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