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## **Managing Long-term Conditions in Primary and Community Care'**

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### **Abstract and keywords**

'District nurse', 'community nurse'; 'Long-term conditions'; 'chronic illness'; 'primary care; 'community care'

Health care policy in the UK continues to focus on provision of care in the community. For people with LTCs it has long been accepted that care should be focused in the primary/community care setting with a focus on case management for those with complex needs. Community nurses are ideally placed to provide care to all people with LTCs, from health promotion, prevention and encouraging self care to caring for people with more complex needs and co-morbidities and end of life care. Community nurses are an essential element of the multi-disciplinary team and should take the lead in delivering complex care at home to people with LTCs, whilst maintaining a focus on developing self-care, empowerment, community engagement and acting as an advocate for clients and their carers.

### **Main body**

#### **Introduction**

A number of definitions exist in the literature to describe the umbrella term long-term conditions (LTCs). Interchangeable terms for LTCs include chronic conditions, chronic illness and chronic disease as well as the term favoured by the World Health Organisation (WHO) (2015), non –communicable disease (NCD). The Department of Health (DH) (2010 p.4) defines a long-term condition as:

one that cannot currently be cured but can be controlled with the use of medication and/or other therapies.

The Department of Health, Social Services and Public Safety (2012), use a World Health Organisation (WHO) definition, stating simply that an LTC is:

A disease of long duration and slow progression (p.4)

Whatever term is used the message is consistent, the burden created by the rise in prevalence of LTCs is one of the greatest challenges to face health care systems globally in the twenty-first century, this burden resulting from the marked success in reducing deaths from acute illness (Nolte and McKee 2008). The Royal College of Nursing (RCN) (2013) note that there is an increasing need for district nursing expertise to meet emerging demographic, social and disease challenges, including the rise in the number of people with LTCs requiring complex nursing care. District or community nurses can be seen as pivotal in supporting the health agenda in the management of people with LTCs, providing a skill set which is complex and diverse (The Queens Nursing Institute (QNI) 2014a). They are a central part of the primary health care team, which includes hands on care for people with LTCs within their own homes, their families' homes and residential homes as well as support for families and carers. More recent work has suggested that health and social care systems in the community should focus on further engagement with local communities shifting the system from 'caring' to 'coping' (Edwards 2014). Policies across England, Wales, Scotland and Northern Ireland are focused on delivering care nearer to the patient (Department of Health, Social Services and Public Safety (DHSSPSNI) 2004, 2012, DH 2013, NHS England 2014a, Scottish Government 2012, Wales Audit Office 2014). In relation to people with LTCs, these health and social care policies have a similar aim, to increase self-care and improve management of those with more complex LTCs, prevent hospital admissions and improve quality of life for individuals. Community nurses are ideally placed to deliver this care. Accurate physical and psychosocial assessment whilst maintaining a holistic focus is one of the keys to developing a successful relationship with patients. This should be combined with close interdisciplinary teamwork and signposting of patients to the most appropriate source of information, to both promote self-care and assist individuals in making the right choices (Wilkes et al 2013, QNI 2014b, Waterworth et al 2015).

### **The challenge of long-term conditions**

Improvements in public health over the past 50 years have led to an increased ageing population, who are less susceptible to events such as serious infections that previously proved fatal, but increasingly likely to develop an LTC (Wilson et al 2005). McShane (NHS England 2014b) states that:

The NHS has a lot to celebrate: it has contributed to people surviving conditions that in the last century would have been fatal and contributed to an increasing life expectancy. That success has however created a new context for the health and care system: the emergence of non-communicable diseases or long term conditions as the dominant challenge to health and care systems.

<http://www.england.nhs.uk/house-of-care/>

The type of support required for people with a LTC can vary significantly; this is to an extent inevitable due to the wide range of conditions classed as long term (Information Services Division, NHS National Services Scotland 2008). Living with a LTC is not just about living with the impact on physical health; LTCs are associated with depression and other psychological impacts on health. In addition LTCs have a wider reaching social impact, affecting every part of an individual's life including family relationships, employment and everyday socialisation (Carrier 2015). The Quality and Outcomes Framework (QOF), the annual voluntary reward and incentive programme detailing general practice achievement results in the UK, identifies a number of LTCs and associated health indicators, as seen in Table 1 (NICE 2015). Whilst this list does not include all LTCs, the included conditions provide a broad overview of the type of conditions seen regularly in primary and community care.

- Secondary prevention of Coronary Heart Disease (CHD)
- Cardiovascular disease-primary prevention
- Heart failure
- Stroke and transient ischaemic attack (TIA)
- Hypertension
- Diabetes Mellitus
- Chronic Obstructive pulmonary disease (COPD)
- Epilepsy
- Hypothyroidism
- Cancer
- Palliative Care
- Mental Health
- Asthma
- Dementia
- Depression
- Chronic Kidney disease (CKD)
- Atrial Fibrillation
- Obesity
- Learning Disabilities
- Rheumatoid arthritis
- Smoking (in relation to specific LTCs)
- Peripheral arterial disease
- Osteoporosis: secondary prevention of fragility fractures

(NICE 2015)



More than 15 million adults in England alone are estimated to have a LTC (DH 2012). Whilst the number of people with one LTC is projected to be relatively stable over the next ten years, for those with multiple LTCs it is set to rise from 1.9 to 3 million by 2018 (NHS England 2014 a). Age is a major factor, in England 14% of adults under the age of 40 reported having an LTC, compared to 58% of those aged 60 and over, with 25% of this latter group having two or more LTCs (DH 2012). Significant variance exists across the UK as a whole with prevalence of LTCs linked to both age and socio-economic status (Carrier 2015).

### **Case management**

Many elderly patients on a traditional DN case load will have significant co-morbidities or have been diagnosed with more than one LTC, resulting in complex care needs. Providing high quality care for people with multiple LTCs and/or other co-morbidities provides a particular challenge, as there is little direct evidence identifying the most appropriate type of care, with most research trials excluding this group (Goodwin et al 2010). Waterworth et al (2014) suggest that multi-morbidity in patients with LTCs presents patients with a high treatment burden which can result in challenges for their self care and self efficacy. They

argue that highly motivated nurses with expanded capabilities, such as the ability to use empowerment strategies are required to support patients with these challenges. Using a case management approach has traditionally been considered crucial in the co-ordination of care for this group of patients. Indeed in the past fifteen years health policy in the UK related to LTCs has been strongly influenced by case management, an initiative developed in the United States (US).

The term 'case management', with its roots in social care, was developed as a method of delivering holistic individualised care, tailored to the needs of people with complex health and social care problems (Hutt et al 2004 p.6). Initially instigated in the 1950's to provide care to patients with severe mental health problems, it was expanded for use with older people with complex health and social care needs, to both contain health care costs and co-ordinate services thus reducing the need for institutional care (Drennan and Goodman 2004, Hutt et al 2004). The Kaiser Permanente triangle, on which a number of LTC Models have been based, including the DH (2005) NHS and Social Care Long Term Conditions model, is well known. It consists of a three-tier triangle approach, stratifying patients in order to match them to appropriate packages of care, as shown in Figure 1:

**Figure 1**  
**Kaiser Permanente triangle**



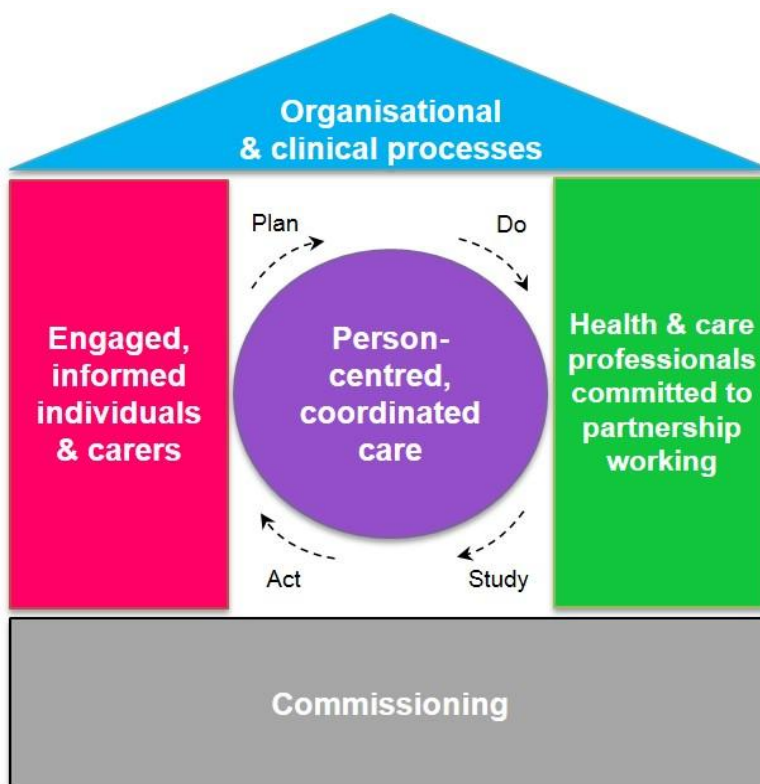
Level three, case management, has become a well established method of care delivery in the community through multi-disciplinary community based health and social care teams, for individuals who have been identified as 'at risk,' or who have complex needs related to LTCs (Goodwin et al 2013). Rather than being a single intervention, case management refers to a wider package of care (Ross et al 2011) with two main types the brokerage model, (similar to the UK social worker model), where case managers hold the budget to finance user care packages and the key worker extension model, closer to the approach historically used by district nurses in the UK, where the case manager both provides and co-ordinates services for the user (Drennan and Goodman 2004). There is, however, limited evidence regarding the most effective types of case management as highlighted in a number of King's Fund reports (Hutt et al 2004, Goodwin et al 2010, Goodwin et al 2013). Indeed Goodwin et al (2010) suggested that case management has not always been implemented in a cost effective way, or to the benefit of patients and carers and that the lack of impact of these programmes could be partly explained by the fact that those requiring care were not properly identified. The report concluded that case management has significant potential to deliver cost savings and better care for patients, but must be well designed, involve appropriately trained professionals and be embedded in a system that supports and values integrated and co-ordinated care (Goodwin et al 2010). Case management works well when at risk patients are clearly identified, and specially trained nurses, who assess the patient and carer needs and co-design an action plan, are integrated into primary care practices (Goodwin et al 2010). Community nurses are in an ideal position to provide this care and indeed the RCN (2013) argue that the poor outcomes seen from the plethora of case management initiatives designed to augment services in the community, including community matrons, are as a result of the lack of integration with mainstream district nursing services. Edwards (2014) agrees, arguing that the result of services being created for a particular purpose or client group, without a clear plan for how they relate to the wider system, has resulted in community services becoming complex and fragmented, with weak connections to primary care and hospital services.

### **House of Care**

More recently NHS England have adopted the House of Care model (Figure 2) as a framework to enhance the needs of people with LTCs. McShane (NHS England 2014 b), discussing the model, outlines how it arose out of a need to change the way the NHS deals with LTCs, moving away from the 'medical model' of illness, effective in the 19th and 20th centuries in reducing morbidity and mortality, towards a holistic, outcomes focused model

which takes into account the expertise and resources of people with LTCs. The building of this model is outlined in the King's Fund policy document '*Delivering Better Services for People with Long Term Conditions*' (Coulter et al 2013). The model focuses on the wider resources required to support people with LTCs, putting the individual at the centre, surrounded by a framework that includes the best clinical, organisational evidence and practice as the roof of the house, supported by two walls, one representing professional collaboration and the other engaged and informed individuals and their carers. District nurses, as a pivotal point of nursing in the community (RCN 2013) can be seen as a key element of the model.

**Figure 2**  
**House of Care model (Coulter et al 2013)**



### **Co-ordinated care, advocacy and empowerment**

How then can district and community nurses ensure that they provide effective and efficient care to people with complex care needs arising from LTCs? Co-ordination of care for people with complex chronic illness is considered to be a global challenge, with success highly



dependent on the way this is implemented locally (Goodwin et al 2013). Where programmes have been successful this has been significantly influenced by the context within which they operate. Goodwin et al's (2013) review of five UK based care programmes for people with complex care needs resulting from chronic conditions, describes a number of key factors essential for high quality care, delineated between six levels: personal, clinical and service, community, functional, organisational and system level. Whilst not exclusive, these elements, as outlined in table 2 can be seen as pertinent strategies for community nurses to adopt.

- maintain holistic focus on the needs of both patients and carers
- relational continuity
- build resilience among carers
- focus on promoting functional independence and well-being
- promote self-management through appropriate support packages
- be the patient's advocate
- provide care directly in the home environment.

Similarly, Wilkes et al's (2013) consensus study used a modified Delphi technique to identify descriptors of the community nurse role in the multidisciplinary team caring for clients with chronic conditions. Seventeen volunteers formed the panel of experts, the criteria for inclusion was that participants, all registered nurses, were involved in the care of clients with chronic conditions and complex health needs in the community or in education and at least 65% of their time was spent on client cases. Wilkes et al (2013) argue that whilst multi-disciplinary team (MDT) work is central to effective care, defining the role of the community nurse within this is essential. They maintain that each member of the MDT requires clear role delineations to provide effective care for people with LTCs and propose that the role of the community nurse has six main domains-advocate, supporter, coordinator, educator, team member and assessor. They suggest that the least developed of these is advocacy

and further development of this domain is needed to provide a more transparent view of how community nurses can advocate on behalf of people with LTCs.

A qualitative study conducted by Waterworth et al (2014) of nurses' experience of working with people with multiple LTCs focused on the role of patient navigation models and concluded that three key themes represent patterns of nursing work in this context; system work, relationship work and patient work. The participants (n=42) were selected from three sources, who all worked in New Zealand: a database of nurses who had completed postgraduate study in LTC management, a network of nurses working in Heart Failure roles and a national network of district nurses. Whilst the study was not solely focused on community nurses, participants in this study included community nurses due to their significant role in caring for people with LTCs, particularly at the end of life. Waterworth et al (2014) suggested that patient navigation is unique in reducing healthcare disparities and that rather than consider patients as a case to be managed, patient navigation models could be adopted which focus on critical outcomes, reducing barriers and empowering patients, working with, rather than managing the patient. A similar model outlined by Edwards (2014) is People Powered Health, a model of care suited to an ageing population with LTCs. The features of this model include mobilising communities to support patients to live well and work alongside healthcare professionals and developing a partnership of equals between people and health care professionals that is orientated to the individual's needs whilst organising care around the patient that supports self-management.

## **Conclusion**

Current UK policy provides an emphasis on self-management, with case management central to provision of care with patients with more complex needs. In addition to promoting self care for all people with LTCs, recent studies have focused on the importance of community engagement and empowering carers, families and volunteers as partners in care. For case management to be effective it should include: case finding; assessment; care planning and care co-ordination and be embedded into primary care practice, not seen as a separate service. An inter-disciplinary approach to care is essential and community nurses should work with the patient, focusing on empowerment and advocacy, rather than seeing them as a case to be managed (Waterworth et al 2014). The role of the community nurse has continued to expand, this has included the development of advanced clinical assessment and decision-making skills enabling them to assess diagnose and plan care for patients with more complex LTCs, whilst continuing to be an essential part of the MDT

supporting all individuals with LTCs. Community nurses should continue to adapt to professional and organisational challenges, including ensuring their voice is heard with regard to the location of community services and should see themselves as being ideally placed within the MDT to provide care to all patients with LTCs. Integral to this is further refinement of the community nurse role, particularly in relation to advocacy and empowerment in order to assist patients, their families, carers and the wider communities to remove the barriers that prevent them managing their own care.

Declaration of interest-None declared

#### Key points

- The burden created by the rise in prevalence of LTCs is one of the greatest challenges to face health-care systems globally in the twenty-first century
- It has been argued that the poor outcomes seen from some case management initiatives result from a lack of integration with mainstream district nursing services
- Multidisciplinary team work is central to effective care of people with LTCs, however health care professionals need to work cohesively and focus on setting agreed outcomes, rather than their own individual goals, for their clients,
- Promotion of self-care and self efficacy is an essential strategy for all people with LTCs regardless of complexity
- Community nurses should focus on empowerment and advocacy, orienting care to meet the individuals' needs

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