Self-care for chronic oedema

Many government and healthcare strategies now advocate supporting self-care in the management of long-term conditions (LTCs). This approach has been driven by the increasing number of poly-morbid, obese and elderly people in the UK, which is putting an immense strain on already stretched health and social care resources. The emphasis on promoting self-care throughout the illness trajectory has been a pivotal aspect of nursing care for more than 50 years and this approach in the management of chronic oedema has always been a key aspect of treatment plans by specialists in this field. Practitioners need to be skilled in assessing the self-care needs of patients and to be ready to adopt this approach and provide appropriate support. This article gives an overview of self-care for people with chronic oedema and focuses on how nurses can encourage and support patients to do this. A case study demonstrates the importance of thorough and accurate assessment to encourage self-care and health behaviour change.

KEYWORDS:
- Long-term conditions
- Chronic oedema
- Lymphoedema
- Self-care
- Health behaviour change

During the past ten years, UK health policy has strongly advocated the promotion of self-care as a means of improving health, particularly for patients with long-term conditions (LTC) (Scottish Government, 2010; Department of Health [DH], 2010). The increasing number of people living with chronic comorbidity in the UK is challenging to those delivering health and social care.

About 23% of the population in England and 40% in Scotland currently lives with one LTC but prevalence increases with age and, as it is predicted that the number of those aged over 85 will increase by 144% by the year 2031, the number of those suffering from three or more coexisting LTCs will sharply increase (Scottish Government, 2015; King’s Fund, 2018). Conditions are categorised as being long term if they persist for a year or more, however many are lifelong and incurable, and account for 60% of all deaths and 80% of GP visits in Scotland (Scottish Government, 2015).

There are clear links between LTCs, deprivation, lifestyle influences and broader determinants of health. People living with LTCs are likely to be more disadvantaged across a range of social measures, including employment, educational opportunities, home ownership and income (Scottish Government, 2009). Additionally, people with LTCs are twice as likely to be admitted to hospital and will spend disproportionately longer in hospital, accounting for more than 60% of total hospital bed days (Scottish Government, 2009). The total human, social and economic cost of LTCs is staggering.

The emphasis on promoting self-care throughout the illness trajectory has been a pivotal aspect of nursing care for more than 50 years. The theory of self-care purports that people should be self-reliant and responsible for their health and care, and self-care and dependent care (i.e. when patients require input from others, such as carers, nurses, specialists) are behaviours that are learned within a socio-cultural context (Orem, 1971). Orem (1971) hypothesised that patients want to care for themselves and by doing so they are likely to recover more quickly and in a more holistic way.

Self-care comprises everything that people do to maintain health, prevent illness, adhere to treatment and manage the impact of chronic illness and disability. It involves the patient becoming experts of their own illness/condition (DH, 2017). Self-care is a dynamic and empowered method of LTC management and relies on several key factors. The patient must be willing, health literate, i.e. aware of the wider factors affecting their lives, and central to the decision-making and delivery process. The practitioner’s role is to provide information and support throughout the patient’s journey. There must also be suitable resources to accommodate this approach (Long Term Conditions Alliance Scotland [LTCAS], 2008). While a self-management approach to LTCs can reduce the impact on NHS resources, it is not a cost-free alternative.

Practice point

Reflect on how lifestyle issues of obesity and prolonged dependency/sedentary lifestyle may impact on your patients — their illness and recovery.
Many people actively self-care for chronic conditions with the assistance of a collaborative approach from carers, family, volunteers and healthcare professionals (Thomas-Hawkins and Zazworsky, 2005; Scottish Government, 2010). Government strategies focus on full user involvement to stimulate a culture that empowers self-management and decision-making supported by access to community-led health care. This ethos of putting patients at the heart of all their health and social care needs with the aim of having ‘no decision about me without me’, requires the provision of more choices and easy access to the information needed for patients to be in charge of making decisions about their care (DH, 2010), e.g. providing verbal, paper and digital sources of information.

**BARRIERS TO SELF-MANAGEMENT**

By recognising patients as experts in their own condition and by providing support to develop understanding and confidence, self-care leads to improved health outcomes, improved patient experience, reductions in unplanned hospital admissions and improved adherence to treatment and medication (Challis et al, 2010). However, some patients are physically or mentally unable to self-manage their conditions. Some patients say that the unpredictability of the illness leaves them emotionally and psychologically drained and they do not have the strength required for the day-to-day management, and they do not have enough time with healthcare professionals to discuss issues (Mayor, 2006). Delays in communication between hospital and GPs and prolonged waiting times for intra-hospital appointments, add to the frustration patients feel, and a lack of understanding by practitioners of the effects of the condition hinders the positive working relationship required to foster self-care (Mayor, 2006). Other factors significantly associated with reduced levels of self-care include higher levels of morbidity, greater financial constraints, compounding effects of the condition, depression and lower income (Bayliss et al, 2007).

**CHRONIC OEDEMA**

Oedema is considered to be chronic if it has been present for three months or more. Many types of chronic oedema, such as lymphoedema, are incurable and are likely to be present throughout life. Some forms of chronic oedema may be resolved if the contributory factors, such as obesity, prolonged limb dependency and a sedentary lifestyle, are removed, but patients in the super obese category (body mass index [BMI] >50) (www.clinicalkey.com/service/content/pdf/watermarked/1-s2.0-S1550728911007179.pdf?locale=en_US) are unlikely to reverse the presence of chronic oedema despite significant weight loss (Greene et al, 2015).

Prevalence rates of 3.93 per 1,000 have been cited in the literature, but in reality these figures are thought to be much higher (Moffatt et al, 2016). In people aged over 65, the prevalence increases sharply, with the greatest prevalence occurring in people aged over 85. The increase in life expectancy coupled with the rise in the number of people who have multiple comorbidities (LTCs) will lead to a greater rise in prevalence of chronic oedema.

Chronic oedema can affect all aspects of patients’ physical, psychological and social well-being. Reduced mobility, difficulty with clothing and footwear, altered body image, social isolation, reduced self-esteem and depression are some of the effects of having swollen limbs (Moffatt et al, 2003; Mason et al, 2008; Creedon, 2011). However, self-care can be supported at all levels of chronic oedema management (Table 1). Patients in all of these categories will require varying degrees of input from practitioners depending on level of empowerment, physical and mental ability, and willingness to take ownership of their care.

The provision of chronic oedema management and self-care support should be provided by suitably qualified practitioners (community nurses, lymphoedema practitioners, other specialised nurses) and preceded by a thorough and comprehensive assessment of the patient’s symptoms, needs and preferences. Any contraindications to the application of compression should be investigated and any barriers to self-care explored. The assessment should produce a holistic patient-centred care plan which is fundamental to the self-care approach.

**CORE ASPECTS OF CARE**

There are three core aspects of chronic oedema management — skin care, exercise and compression therapy. Patients who have lymphoedema will have lymphatic drainage included in their treatment regimen — referred to as the

### Table 1: Categories of chronic oedema management

<table>
<thead>
<tr>
<th>Category</th>
<th>Management strategies</th>
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<tr>
<td>Preventive</td>
<td>Information and advice on how to help prevent the onset of oedema and where to seek help if swelling occurs for those at risk of developing swelling, i.e. those with obesity, chronic venous disease, prolonged dependency or immobility. Preventative measures include skin care to prevent cellulitis, maintaining a healthy BMI, undertaking adequate levels of exercise and avoiding lifestyle factors, such as being overweight or having a sedentary lifestyle that negatively influence chronic oedema</td>
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<tr>
<td>Maintenance</td>
<td>Mild-to-moderate symptoms that can be managed with self-care. Support and review by healthcare professionals should be available based on the patient’s needs</td>
</tr>
<tr>
<td>Intensive</td>
<td>Complex chronic oedema (e.g. severe swelling, poor limb shape, extensive skin changes) will require more intensive input from healthcare professionals until symptoms reduce and the patient is able to undertake self-care in the maintenance category. Some aspects of management can be carried out by the patient throughout the intensive phase, e.g. exercise, weight management, avoiding compounding lifestyle factors such as prolonged dependency of the limb(s). Other factors contribute to the complexity of chronic oedema management, such as obesity, non-compliance, chronic wounds and recurrent cellulitis, and they pose significant challenges regarding outcomes and progression to the maintenance phase</td>
</tr>
</tbody>
</table>
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four cornerstones of care (British Lymphology Society, 2002).

**Skin care**
Promoting and maintaining skin integrity is a vital part of management to help prevent or reduce skin changes, cellulitis and ulceration. Patients can be encouraged to participate in skin care by washing, drying and moisturising the skin, preventing cuts and breaks, observing for any changes, and seeking advice or input from healthcare professionals if they experience any problems.

**Exercise**
Muscular activity is essential for the process of venous and lymphatic return from the limbs. Normal day-to-day activities of walking, breathing and carrying out activities of daily living contribute to the natural venous and lymphatic flow. However, patients with more sedentary lifestyles will require more planned and tailored exercise to counteract any inactivity. This may be passive if required for those with reduced mobility and strength/dexterity/respiratory/fatigue issues, and can involve flexion and dorsiflexion of the ankles, which can be carried out by carers.

**Lymphatic drainage**
Lymphatic massage techniques are either taught to patients or carried out on patients with lymphoedema depending on the severity of the swelling. Those in the maintenance phase will be taught a simplified version (SLD) to carry out on themselves, while more comprehensive manual lymphatic drainage (MLD) can be performed by lymphoedema specialists as part of the intensive period of management of swelling. The aim is to massage the fluid from congested zones of the body to normally functioning nodal areas.

**Compression therapy**
Compression therapy can be delivered in a variety of ways depending on severity of symptoms and patients’ needs. A wide range of compression hosiery is available and it is important to choose the most appropriate garment that will support self-care. The style and class of compression will be dictated by the severity of swelling, patient choice, and dexterity. Donning aids are available for patients and/or carers if there are difficulties with application.

Compression bandaging is indicated if there is the potential to reduce the volume of oedema, enhance limb shape or improve changes in skin integrity, which will subsequently allow hosiery to be fitted. Pneumatic compression pumps can be used in the clinical setting or at home as an adjunct to other forms of compression therapy. There are also garments with adjustable velcro straps that can be used to provide compression, such as juxtafit® (medi UK) and JOBST® FarrowWrap® (BSN medical), which are useful for patients who have difficulty donning hosiery or when variable compression is required.

**Lifestyle issues**
Obesity and a sedentary lifestyle contribute to the development of swelling and impede successful management. Sleeping in a chair instead of going to bed is also problematic, although there may be sound reasons for being unable to go to bed, such as poor mobility, sleep apnoea and lack of carer input. However, if these factors are not addressed, it will be difficult to implement interventions to reduce oedema.

Self-care is more than carrying out tasks to manage chronic conditions. If patients are to manage chronic oedema effectively, they need to be aware of how to assess and identify important changes in their condition, such as the onset of cellulitis, increased swelling, or poor fitting garments. They should also know what steps to take should any of these occur, be it calling the GP or contacting a lymphoedema practitioner.

The ability to participate in self-management of chronic oedema may be impeded by other physical symptoms (Todd et al, 2010; Williams, 2010). Some patients are unable to reach their feet due to restricted mobility or obesity, which affects their ability to carry out skin care or

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**Figure 1.**
Behaviour change stages.
apply hosiery. Self-care may also be limited if there is reduced dexterity and strength in the hands due to arthritis, fatigue, pain, or breathlessness.

There is a small percentage of patients who are unwilling to carry out self-care or address compounding factors, such as weight or prolonged dependency, especially sleeping in a chair. By using a health behaviour change model, the patient’s readiness to change can be assessed, which will allow the appropriate support to be provided. The trans-theoretical model of change (Prochaska et al., 2002) categorises patients in one of five stages (Figure 1). Patients in the pre-contemplation stage would not be aware or would be in denial that their lifestyle contributes to their condition, and asking them to make changes will be met with resistance. This may lead to a lack of confidence in the practitioner, whereas those in the preparation stage are beginning to put steps in place to make the change. Being able to identify which stage the patient is in will allow support to be tailored, which will help foster a better relationship between patient and practitioner.

Fostering Self-Care in Patients with Chronic Oedema

Self-care is not a new concept in chronic oedema. Specialists in the 1980s and 1990s advocated a rehabilitative, patient-centred approach with the aim of working from an initial high dependency/low independence relationship to low dependency/high independence after a range of clinical, informative and supportive interventions. The transition to self-management should be carefully planned and the decisions should be patient-led at all times (LTCAS, 2008). The process should entail the following components.

Information

Nurses must have knowledge of the presenting symptoms and the effect that these may have on the patient. They must also be able to assess the patient’s readiness to adopt self-care and/or make appropriate health behaviour changes. Taking time to understand the patient’s family dynamics and the way they are affected by their condition will demonstrate empathy which, in turn, enhances the nurse/patient relationship (Mayor, 2006). This will also prove useful when assessing the support systems in place that will enable self-management (Piller, 2012). The nurse must also provide the patient with a range of information resources — verbal, written and digital — on causes, factors that help and hinder improvement, and when they will need to seek help.

Instruction

The patient and those involved in supporting self-care must be given instructions on how to carry out care, such as skin care, how to apply and remove compression hosiery, tailored exercises and SLD if appropriate. Providing written literature to back up any verbal information and instructions will make it easier for the patient to remember the procedures.

Support

Self-care is not a permanent state. The balance of dependency and independence will fluctuate depending on patients’ circumstances. More nursing input may be required if ulceration develops and more carer input may be needed during periods of ill-health or if the patient suffers from treatment fatigue, i.e. is overwhelmed by treatment/self-care and psychologically unable to cope.

CASE STUDY

The patient was a 59-year-old man who was referred to the lymphoedema service for management of bilateral lower leg swelling with superficial ulceration. He was being treated by community nurses but compression could not be applied because of training issues (while community nurses are trained to deliver conventional venous ulcer compression bandaging, they frequently cite being not trained to do ‘lymphoedema bandaging’). He was morbidly obese and was sleeping in a chair at night which was preventing improvement in skin integrity, and he was viewed as being non-compliant and awkward. When asked about sleeping in bed, he said he could not manage the stairs, the bed was too uncomfortable, and he preferred to be able to watch TV when he could not sleep. He did not see why he should be forced to go to bed. This response indicated that he was in the pre-contemplative stage of behaviour change and he was in denial of the problem.

A treatment package of compression bandaging with wound care was planned, and he was given a gentle explanation of the impact of sleeping in a chair. This resulted in some hostility, so other social aspects were assessed. After some sensitively framed questions, he explained that his wife had died suddenly in the bedroom two years before. Further exploration revealed he was still grieving deeply for his wife and could not bear sleeping in the bedroom without her. A referral for grief counselling was discussed and options for having a bed installed in the living room investigated. This led to him being able to sleep in bed at night, which reduced his leg dependency which was exacerbating the swelling. Compression bandaging reduced the swelling and healed the ulceration. Custom-made compression hosiery was fitted and he was able to get shoes to fit which allowed him to go out. He joined a slimming club and began to lose weight. He is currently attending a group for grief counselling and self-managing his weight reduction and leg swelling with support from the lymphoedema team.

This case study demonstrates how important it is to avoid judging patients’ reactions and to try and understand the reasons why they are not complying with health advice. This also allows a fully tailored treatment and self-care package to be developed and it is more likely that the patient will comply with health behaviour change.
and requires more psychological support (Piller, 2012). Patients should never feel that ‘they are being left to it’. Knowing that there is a named contact in times of need will be reassuring and it may be pertinent to plan some intermittent contact initially until the patient feels confident.

Resources
Self-management is not a cost-free alternative (LTCAS, 2008); if the previous aspects of self-management are not fully resourced, the patients will lack confidence in themselves (Mayor, 2006) and perhaps lose faith in healthcare professionals and the NHS.

CONCLUSION

Chronic oedema is a long-term condition that can have a major effect on patients’ lives. In an attempt to improve health and wellbeing, the government advocates self-care strategies for patients with LTCs, which are tailored to their needs and wishes.

The self-care approach empowers patients and acknowledges their expertise in their illness and ability to manage. This can lead to improved health outcomes and improved concordance with treatments. Self-management in chronic oedema is not a new concept; the rehabilitative model of care embraces the tenets of empowered, patient-centred, self-management supported by empathetic and knowledgeable healthcare professionals. However, successful delivery of this approach can only be achieved by knowledgeable and sensitive practitioners who are caring for willing and health literate patients — and have access to adequate resources. JCN

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