

# Transforming lymphoedema care in the Scottish Borders

This article describes the content of the Chronic Oedema Ambassador Programme (COAP), a 2-day training programme focussing on care and management of lymphoedema and its practical impact on a real-world tissue viability practice in the Scottish borders. Delegates on the training programme had the opportunity to learn more about lymphoedema and to share best practice, discussing challenges and successes in this area of care. Lymphoedema is an issue that affects many patients in practice; lack of effective care can lead to serious consequences and affect patient quality of life. There is a need for effective and consistent evidence-based care for lymphoedema patients.

Lymphoedema is a chronic progressive disorder of the lymphatic system, which is generally characterised by the swelling (oedema) of one or more limbs, and may include the corresponding section (quadrant) of the trunk. Swelling can also affect the head and neck, breast and genitalia. It occurs as a result of an imbalance between lymph formation and lymph absorption; fluid and its contents (e.g. subcutaneous fat, protein) accumulate in the tissue spaces due to functional inadequacy of the lymphatic system. Lymphoedema is a relatively common condition, with an estimated prevalence of up to 250 million people affected worldwide (Hill et al, 2023).

Despite its prevalence, there has generally been a lack of awareness about lymphoedema, resulting in a lack of timely, effective and cohesive treatment for affected and at-risk patients. This lack of urgency in lymphoedema care has arisen from insufficient knowledge about the condition and limited knowledge among healthcare professionals about managing lymphoedema effectively (Fletcher et al, 2024).

## Understanding the lymphatic system and how lymphoedema occurs

Recent consensus has demonstrated that there is an unmet need for awareness of the basic science behind lymphoedema, so that effective treatment can be deployed (Fletcher et al, 2024).

The overall function of the lymphatic system is to maintain the body's normal physiological environment, and elements of the lymphatic system are present in nearly every tissue in the human body (Breslin et al, 2018; Mortimer and Rockson, 2014).

The lymphatic system is an exchange and

transport network throughout the body that moves fluid, macromolecules and cells, and provides immunity from pathogens (National Institute of Health, 2023; National Cancer Institute, 2023). It is made up of lymphatic capillaries, lymph vessels, lymph nodes and a variety of cells, plexuses and organs.

## There are three main functions of the lymphatic system:

- The return of the interstitial fluid that has leaked into the interstitial tissue space
- Scanning this fluid for any potential pathogens
- Absorbing and transporting fats and fat-soluble vitamins to the venous system (NCI, 2024).

If the lymphatic system fails, this results in accumulation of fluid in the tissues, which causes swelling and inflammation, known as lymphoedema.

## The individual patient

In each individual, it is important to understand the underlying cause of lymphoedema and the progression of their condition. Factors associated with lymphoedema include:

- Heart failure
- Use of certain medications, including calcium channel blockers, alpha blockers, hydralazine or testosterone
- Chronic kidney disease
- Hypoalbuminaemia
- Chronic venous insufficiency/deep vein thrombosis
- Chronic liver disease
- Surgery or trauma
- Cancer treatment

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## Key words

- Chronic Oedema Ambassador Programme
- Evidence-based care
- Lymphoedema
- Training programme

## Declaration of interest

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- Obesity
- Inflammatory diseases (e.g. arthritis)
- Immobility or altered gait (Fletcher et al, 2023).

The symptoms of lymphoedema can significantly impact patients, both physically and psychologically, as (depending on the location) the swelling can reduce mobility and affect the individual's capacity for their usual daily activities (Fu et al, 2013). Patients may also experience pain and discomfort, and can become more susceptible to infection and cellulitis (Keast et al, 2015).

Body image and confidence can be affected, which may have an impact on the individual's mental health. On a practical level, shoes and clothing may no longer fit and, as the swelling worsens, some patients describe a feeling like 'their skin is about to burst' or complain of tightness and heaviness associated with aching pains (Fletcher et al, 2023).

### The Chronic Oedema Ambassador Programme

The Chronic Oedema Ambassador Programme from Essity (COAP) is a 2-day course designed to enhance understanding and clinical skills in managing chronic oedema, particularly in the lower extremities. Training was built around the content from the chronic oedema best practice statement which focuses on the six simple steps of assessment. The training is led by Liz Stott (Clinical Nurse Consultant, Essity), who has a bachelor's degree in Lymphoedema Management, as well as training in Casley-Smith Manual Lymphatic Drainage, and a clinical background rooted in community nursing.

Participants have a month to integrate key concepts from the first day into their practice before returning for a second day of clinical reflection, where they can discuss and analyse their experiences with a lymphoedema specialist. This programme emphasises experiential learning to help clinicians effectively apply theory in their practice.

### Why the COAP initiative is needed

Access to specialised lymphoedema services operates as a postcode lottery, typically restricted to patients with a cancer diagnosis, while those with wounds frequently fall outside the eligibility criteria (Wound Care People, 2019). As a result, primary care clinicians, community and practice nurses, and treatment room staff often find themselves managing complex cases.

However, clinicians often face significant challenges due to limited treatment options, resources, and training, making it difficult to navigate these intricate clinical presentations. Moreover, patients who have previously received inadequate treatments — such as ill-fitting

garments — may be incorrectly categorised as non-adherent to treatment plans.

Equipping and empowering nurses to confidently assess, develop, and implement appropriate care strategies has been shown to enhance patient engagement and comprehension of treatment rationale and execution. Importantly, this educational approach improves overall patient outcomes.

### Day one agenda

Day one of the course was run by Clinical Nurse Consultant Liz Stott, with the morning focused on theory and the afternoon on practical application of knowledge.

The first module, 'Understanding Chronic Oedema' focused on the basic science and physiology, with the following learning objectives:

- Understanding the function of the lymphatic and vascular systems
- Defining what constitutes chronic oedema and lymphoedema
- Understanding the six 'S's of assessment and how these can support clinical practice
- Understanding management of chronic oedema and gaining confidence in managing affected patients.

The second module 'Simplifying Compression' focused on managing oedema through compression therapy. This module had the following learning objectives:

- Understanding different types of compression garments
- Explaining the four components of successful compression
- Exploring flat-knit hosiery, circular-knit hosiery and compression wrap systems.

The afternoon focused on practical education, led by compression therapy specialist Stewart Gilmour. This included:

- Measuring workshops
- JOBST® UlcerCare Kit™
- JOBST® FarrowWrap®
- JOBST® Elvarex Made to Measure®.

Finally, this was followed by a session aimed at 'Bridging Theory and Practice: Engaging in Reflective Clinical Practice'. This comprised a group discussion focused around the following questions:

- What key learning elements will you take into practice?
- What is reflective practice?

### One-month inter-session period

The programme incorporated an interval of one month between the two training sessions, so

that the learning points could be integrated into practice as part of the training process. During these inter-sessional periods, participants were encouraged to apply the core principles learned on Day one to their clinical practices by implementing targeted strategies and techniques.

During this time, participants were invited to reach out for support from either a local lymphoedema specialist or the Essity Compression Therapy Specialist whenever needed.

### Day two agenda

The morning of day two focused on clinical reflection, which included:

- Time to compose reflections and consider questions to ask the expert
- Group discussion on major themes and experiences
- Recap of 'Understanding Chronic Oedema'.

This was followed by a further clinical reflection session led by a lymphoedema specialist, Garry Cooper-Stanton, Lymphoedema Research and Innovation Specialist, in which participants were encouraged to share their reflections, discussing their insights and posing questions to the expert.

In the afternoon, there followed a compression therapy masterclass. This comprised of:

- Measuring workshops
- Using made-to-measure thigh length and tights
- Using toe caps.

Finally, attendees discussed conclusions and next steps following the training, exploring further resources and opportunities in lymphology.

### Impact of the COAP

Essity's COAP aims to educate and support clinicians who work outside specialist services by providing them with the necessary tools and training, while fostering a realistic understanding of the limitations of available resources and treatment options, to improve the quality of care and life for patients enduring this debilitating and isolating chronic condition.

Reflective practice is a key focus of the COAP, which is vital to its implementation and success. Clinical training is frequently conducted in one-day workshops, during which nurses are expected to apply their newly acquired skills. However, when these practices encounter resistance from the team or fail to yield the anticipated results, nurses often revert to their previous methodologies. This cycle undermines the potential for enduring change and diminishes the effectiveness of the educational intervention.

Liz Stott, who leads the training, has found

that the intersessional period between days one and two is 'the heart of the programme'. This offers clinicians the opportunity to trial new approaches in their own practice settings, supported by ongoing guidance.

Day two of the programme provides clinicians with a safe space to reflect on their experiences, and discuss them with peers and expert lymphoedema practitioners. It is also an opportunity for the trainers to assess their understanding and guide towards 'constructive alignment'. Clinicians are always encouraged to try again, plan their next steps, and confidently implement best practices.

Liz Stott has noted encountering clinicians who initially lacked confidence in managing complex lymphoedema cases. Many had previously been disheartened by poor outcomes or patients had been labelled as 'non-adherent' due to misunderstandings, such as ill-fitting or inappropriate garments. Through COAP, these same clinicians began to reframe their understanding, gaining not only technical skills but also a renewed sense of purpose and agency.

What was found to resonate the most was the emotional weight that community nurses carry. They are unsung heroes in managing long-term conditions in isolated, housebound patients. Equipping them with practical tools and a reflective framework not only improves patient outcomes, it also validates their role and reinforces their value within the field of lymphoedema care.

Similarly, Garry Cooper-Stanton, expert lymphoedema practitioner, saw clinicians grow in confidence and clinical reasoning. One participant, for example, moved from uncertainty to confidently distinguishing between chronic oedema and lipoeedema after a focused case discussion. These moments highlighted how the training model enables meaningful, practice-based learning.

By focusing on experiential learning and providing clinicians with a safe space to reflect and analyse their experiences, supported by expert lymphoedema practitioners, they can develop the confidence to implement best practices. This model empowers clinicians to reflect on what works, what doesn't, and, importantly, why. The COAP transforms passive learning into active problem-solving.

### Success in practice: lymphoedema care in the Scottish borders

The Scottish Borders service is led by Cheryl Lugton, a Tissue Viability Nurse of 32 years' experience, who is responsible for the operational and strategic running of the service, as well as staff education. The service covers

the acute, community, mental health and care home settings. The service covers a large rural geographical area with a notably ageing population of approximately 116,000. Key hobbies of local residents include rugby and equestrian sports.

The lack of training and knowledge within the service was evident from the number of patient referrals from clinicians struggling to correctly diagnose and manage patients experiencing chronic oedema. The need was recognised to implement training and provide evidence-based care.

No specialist lymphoedema service is available in the area, therefore sustainable change had to be made in managing patients with lymphoedema, and for this to be embedded within standard practice across the community workforce.

In 2022, in partnership with Essity, an educational upskilling programme was commenced, to empower nurses to manage lymphoedema confidently and effectively. Initially six carefully selected delegates, who were willing and keen to enhance their knowledge and skills in this area, attended the COAP training course. In 2023, this number was increased to 17 delegates.

The feedback from clinicians having taken the COAP training course was powerful, with clinicians noting their increased confidence in identifying and managing lymphoedema and applying compression therapy. In particular, increased confidence and understanding of flat-knit technology led to more appropriate garment selection, improving patient outcomes.

Levels of patient satisfaction have also been clearly visible, with patients reporting improvements to their health and quality of life, reduced pain and increased comfort. See **Box 1** for clinician and patient experiences. Significantly, the commitment to empower and upskill clinicians has led to a 74.6% reduction in the number of referrals to Tissue Viability.

### Conclusion and next steps

Essity's COAP training course has proven to be an effective way to increase clinicians' knowledge and confidence around

lymphoedema management, particularly around compression therapy selection and application. The focus on experiential and reflective learning, and the incorporation of the one-month intersessional period for the opportunity to embed learning and seek support if needed, have demonstrated ongoing changes and benefits in practice.

The example of the Scottish Borders service and the impact the COAP training has had on real-world practice show the effectiveness of the training on clinician and patient experiences. The benefits and improvements to the service continue, with the course now oversubscribed. This training model has led to sustainable change that continues to be seen in practice, with continual improvements to patient outcome. ●

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### Box 1.

#### Clinician perspectives:

- 'This has given me confidence to go out and apply compression'
- 'In the absence of a lymphoedema service, the programme has successfully bridged the gap, providing me with confidence'

#### Patient perspectives:

- 'Been really good since I had the water off my legs, with the wraps at first then the stockings; it's been really good'
- 'You feel like you can move better, the weight's come down considerably, much more comfortable and I'm able to get clothes on I couldn't get on before and footwear'
- 'I had no footwear for over 3 years as nothing fitted. It's been really positive for me. I had so much pain before and I couldn't stand, and I can stand now'