

Enough is enough: parliamentary reception report



JULIE SMITH, Lindsay Leg Club Foundation Trustee

The message behind the parliamentary reception ‘*Shining a light on a hidden problem*’, independently organised by Ellie Lindsay, OBE and hosted by Derek Thomas MP (Conservative MP for St Ives) was clear from the outset. Enough is Enough: this has got to stop! As speakers took their turn at the podium in the Houses of Parliament on 26 April 2023, this sentiment, underpinned by a clear Manifesto, was reinforced with statistics, research and, most importantly, patient stories. The Manifesto calls for parity of care across the UK for people with lower limb and ulcer-related conditions. You can read and sign it here: <https://www.legclub.org/manifesto>.

The guest list of healthcare professionals, members of parliament, The House of Lords, Leg Club Industry Partners (LCIP), Foundation trustees and journalists was carefully curated by Ellie Lindsay OBE FQNI (Life President). Roland Renyi, external project consultant, opened the reception by urging the gathered guests to advocate for consistent care provision. Their healthcare networks branch out far and wide, presenting the opportunity to spread the message ‘Enough is enough’ to those who can really make a difference.

Mr Renyi handed over to the host, Derek Thomas MP. Mr Thomas was clear; the work spearheaded by Ellie Lindsay, is doing to get this high

up the political agenda is essential. Shining a light on the hidden epidemic is the only way to promote real and meaningful change. As an MP, Mr Thomas is acutely aware of both the personal and the economic impact of the problem. And so, he should be. Annual NHS costs associated with wound management and comorbidities are £5.3bn. As the country gets to grips with a cost-of-living crisis, any opportunities to protect both patients and NHS resources cannot be ignored. The manifesto for the lower limb addresses this directly — if the suggested steps are taken, the benefits to patients, healthcare professionals, the NHS and the UK economy are inevitable.

Professor Keith Harding CBE was next to take to the podium. As the first consultant in wound healing in the UK, he needed very little introduction. His emphasis was on the value of data to influence future care provision. Wound care needs to be much higher on the agenda when it comes to research and development. The more we know, the better we can prepare for and even prevent some of the most challenging wounds.

Professor Harding went on to point out that we are collectively responsible for facing the problem head on and working out how to fix it. If we can get to the point where the right patient is seen by the right healthcare professional at the right time,



Derek Thomas MP, host of the parliamentary reception ‘*Shining a light on a hidden problem*’

and this happens across the UK, care provision will be improved beyond recognition. There are incredible pockets of work taking place already, he acknowledged, but this Manifesto should encourage individuals to join forces. This is how we will achieve meaningful change.

Professor Alun Davies and Mr Lukla Biasi, both vascular consultant surgeons, spoke about the clinical impact of lower limb problems. The statistics were frightening. Professor Davies explained that venous disease is a huge problem with around 4% of the NHS budget being used for this patient group with a 30–40% recurrence rate and in many patients, 12 years of care needed (and for some, much longer than this). Mr Biasi spoke passionately about the huge discrepancies in care across the UK — a key tenet of the Manifesto. One area that is of particular concern is the recommended treatment timeline; the Vascular Society of Great Britain and Ireland recommend that all patients with chronic ischaemia be treated within 2 weeks of diagnosis (or 5 days if they have been admitted to hospital). On average, this is happening in around half of all cases. The balance tips in areas where there are higher numbers of this patient group, with some only achieving this timeline for around 1 in 5 patients.

Mike Steel, Marketing Manager at Smith & Nephew and LCIP was next. He pointed out that while there are over 15000 Leg Club members, 3.8m people are currently living with a wound. Mike praised the LCIP for working with a shared purpose to achieve positive change. He acknowledged that there is massive potential to save money but in doing this, we must not lose sight of the detail; using resources efficiently and effectively and keeping care patient centred are key to addressing this crisis.

Trudie Clark, who brings a wealth of experience in tissue viability nursing, stressed the importance of community care. Wound care takes time — proper assessments, patient education, treatment and dressing changes cannot be rushed. If they are, the outcomes are likely to be poor. Ms Clark pointed out that patients are faced with a postcode lottery; many nurses are not trained in wound care diagnosis, and the medical colleagues who are often do not have the time or inclination to do so. Not everyone has access to a Leg Club, and Mrs Clark urged MPs to look into this in their constituencies.

Jacqui Fletcher OBE, Senior Nurse Adviser at STOP the Pressure and Clinical Editor of *Wounds*

UK, spoke about the importance of consistency in care. There is no process to follow patients through the system and so the data on and approach to treatment is lacking. She expressed her concerns around the public perception of lower limb problems — for many it is seen as a part of getting older — the consequence of this for many is late diagnosis, when the wound is much harder to treat.

Dr Galazka, a social scientist at Cardiff Business School has done extensive research into the patient experience of having a wound. She quoted patients who felt excluded and anxious. Many of them were housebound and their experiences are difficult but necessary to hear. One described their wound as ‘the horror show’ while another said:

‘It’s a big burden. You can’t go places. You don’t know when (the dressing) will fall off. When it gets wet, it just comes away.’

Dr Galazka praised the psychosocial Leg Clubs, explaining that members find it reassuring that other people are going through the same thing as them.

Following Dr Galazka’s presentation on the patient experience, Karen Davey stepped up to talk about her own. Mrs Davey experienced an infected wound following breast cancer surgery. While her initial surgical care was, in her words ‘amazing’, she was surprised to receive no follow-up community wound care. As an industry professional, she was well informed when it came to wounds and dressings and so was able to self-care. While this was a relief to her, it worried her that others, without her expertise would not be able to cope quite so well. Her closing words were aimed at the MPs in the room:

‘When living with a potential wound in the future, what postcode do you want to live in? What can you do on leaving here today that will really make a difference?’

The event was a resounding success and buzz around the need for change was electric. To date, it’s important for people to sign the manifesto.

After the event, Ellie Lindsay said:

‘Raising awareness of the impact of this hidden epidemic has been my driving passion for many years and I was so pleased that together we

were able to ensure MPs and members of The House of Lords understood the message and with loyal support from the Leg Club Industry Partners who showcased the professional collective best of the wound care industry that

I have the privilege to work alongside as a third sector organisation.

Don't forget to read and sign the Manifesto, which you can find on the Leg Club website: <https://www.legclub.org/manifesto>

WUK

ENOUGH IS ENOUGH!

A manifesto for the lower limb

Lower limb and leg ulcer related conditions are a major health problem and cause significant suffering. These conditions are often neglected in the primary care setting, with inadequate resources available to manage them.

IT IS A HIDDEN EPIDEMIC

Last year the NHS managed an estimated **2.2 million** patients with a wound, equivalent to **4.5%** of the adult population and the annual cost to the NHS attributable to wound management and associated comorbidities was estimated at **£5.3 billion**. Community nurse visits were the primary cost driver and accounted for **78%** of the cost of patient management.

We also know that **420,000** of the **730,000** leg ulcers treated by the NHS in the UK each year were classified as 'unspecified' (Guest et al, 2015). Without being able to understand the underlying cause, decisions cannot be made on the best course of treatment for patients. This in turn means the NHS is not providing optimal care.

Enough is enough - there is no reason for inconsistent treatment, or treatment where the concerns and priorities of our patients are not being addressed, and the time has come for us to act.

WE ARE CALLING FOR A FEW SIMPLE AND ACHIEVABLE STEPS:

- 1** **To establish an NHS lower limb and leg ulcer related conditions strategy:** This should include an evidence-based approach to assessment, diagnosis, treatment and monitoring of lower limb and leg ulcer related conditions.
- 2** **To create a lower limb and leg ulcer related conditions task force:** The task force should be made up of experts from a range of disciplines, including clinical practice, public health, nursing, research, and industry. It should be responsible for developing and implementing a national strategy for leg ulcer and lower limb conditions.
- 3** **To establish a lower limb and leg ulcer related conditions registry:** A registry should be established to collect data on lower limb and leg ulcer related conditions, including epidemiology, diagnosis, treatment, patient outcomes and cost-effectiveness.

4 **To work smarter in the community and with telemedicine:** Community nurses should be given extra resources and training to provide quality care for lower limb and leg ulcer related conditions in the community. Telemedicine should also be used to help with rapid diagnosis and treatment, as well as to provide long-term monitoring of patients.

5 **To increase public awareness and education:** Public awareness campaigns should be launched by the NHS to raise awareness of lower limb and leg ulcer related conditions and encourage early diagnosis and treatment. Education should also be provided to health professionals to increase their knowledge and understanding of the condition.

6 **To increase research and innovation:** More research is needed to understand the causes of lower limb and leg ulcer related conditions and to develop new treatments, technologies, and approaches to managing these conditions.

DISPARITY IN LOWER LIMB CARE - THE LIVED EXPERIENCE

"As a family member or carer, it's extremely distressing to witness someone, who, before the onset of the leg ulcers, was independent, sociable and active, suddenly deteriorate into someone who is frail and no longer safe to live alone."

"The reality is that you are faced with a number of different health care professionals from GPs and the Ill service, to community and district nurses, working independently of one another and not picking up on a rapidly deteriorating condition."

SUB-OPTIMAL TREATMENT HAS GOT TO STOP. WITH YOUR HELP IT CAN.

If you would like to support us and join hundreds of others who feel the same way, **please add your name to our petition.**

