



ALL-PARTY PARLIAMENTARY GROUP ON  
**VASCULAR AND VENOUS DISEASE**

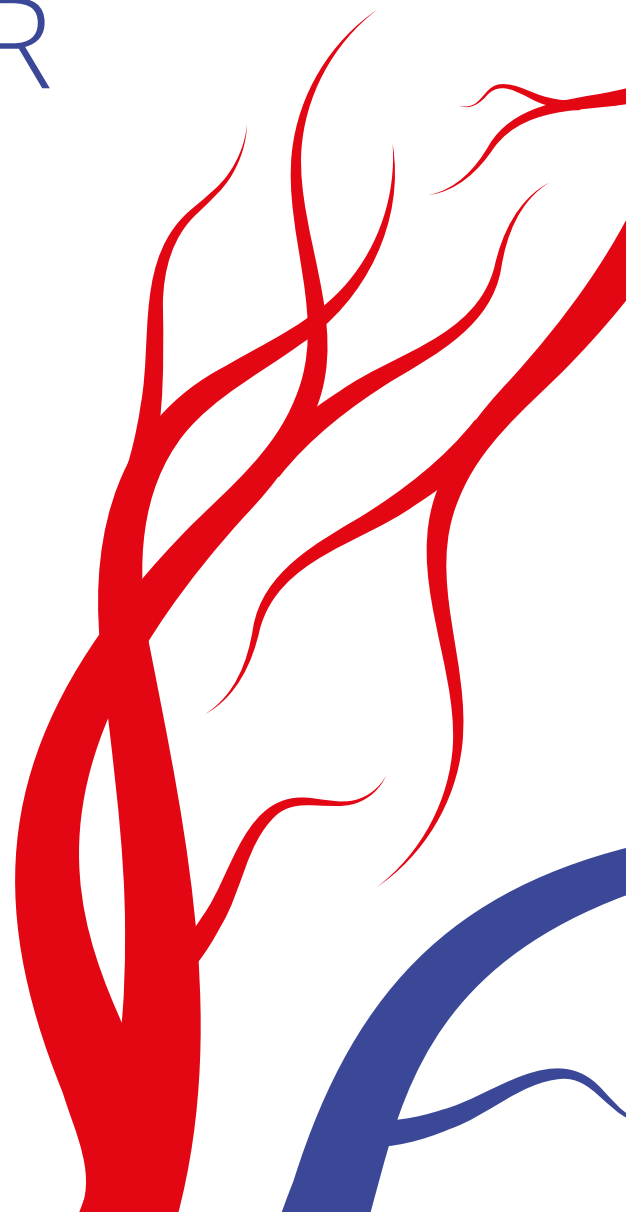
# EMPOWERING CHANGE:

## A VISION FOR SUPPORTED SELF CARE.



ALL-PARTY  
PARLIAMENTARY GROUP  
ON VASCULAR AND  
VENOUS DISEASE

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# Acknowledgements



People.Health.Care.

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Members of the Working Group of Experts:

- **Dr Una Adderley**, Director, National Wound Care Strategy Programme
- **Mr Jonathan Boyle**, Senior Editor, European Journal of Vascular and Endovascular Surgery and Past President of the Vascular Society of Great Britain and Ireland
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- **Tracy Goodwin**, Experts by Experience
- **Kristy Widdicombe-Dutch**, Experts by Experience

# Executive Summary and Recommendations

The NHS is facing significant pressures across the country. The current elective backlog is now over 7 million patients, equating to over 12% of the population in England. There is a growing workforce crisis, with current gaps in staff across all areas; and financial pressures are creating ongoing challenges.

These issues existed to some extent prior to the outbreak of COVID-19. Nevertheless, the pandemic has compounded the many years of funding and resource challenges facing the health system, brought on by a growing, ageing patient population with multiple comorbidities.

Struggles with the patient backlog, community workforce shortages and increasing pressure across the NHS on nursing resources has meant long delays in care and treatment management for lower limb wounds. This has led to increased rates of late-stage conditions and mortality.

A failure to sufficiently manage lower limb wounds in their early stages results in delayed healing, increased recurrence rates, an increased risk of cardiovascular conditions, dependency on antibiotics and hospital admissions. Further, it leads to extended delays to care and increased strain on both NHS nursing and consultant resources.

Under significant and continuous pressures, it is clear that care management for lower limb wounds must be transformed to deliver a higher quality and more sustainable service that reduces the burden on the system, improves clinical outcomes, and reduces the variation in care.

With an estimated 3.8 million patients presenting with wounds in the UK, at an annual cost to the NHS of £8.3 billion, chronic lower limb wounds are significantly contributing to that pressure.

The Self Care Forum's definition of 'self care' is "the actions that individuals take for themselves, on behalf of and with others in order to develop, protect, maintain and improve their health, wellbeing or wellness".

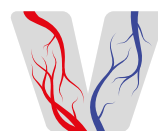
Supported self care provides an opportunity to improve patient experience and reduce their reliance on their health care providers; reduce pressures on the workforce and save money in the long-term. This is a triple win for the NHS and a significant improvement in care for patients across the country.

There have been significant steps to improve the supported self care agenda, including through the National Wound Care Strategy Programme (NWCSP), Leg Clubs, and Legs Matter, and increased use of technology and innovation to support patients to manage their own conditions with support, when necessary, from clinicians. However, these have not been adopted across the country, and as such there is variation in how supported self care is offered throughout the NHS.

The case studies used in this report paint a stark picture of unequal care, poor communication from clinicians, patients not being listened to, and their expertise in their own conditions ignored.

However, if implemented fully across the country, supported self care has the potential to deliver benefits for patients, clinicians, and the NHS. Giving patients support to care for themselves provides better outcomes and allows them to rely less on their health care providers and their schedules; clinicians are given more time to care for patients with more severe wound-care needs; and there can be financial savings through quicker healing of wounds, less need for clinical intervention, and savings for patients through needing fewer journeys to see clinicians.

It is time to empower patients to own their own care and treatment. It is time to support clinicians to have open conversations with patients about their own care and treatment. It is time to deliver a step change in lower limb wound care, making supported self care a standard practice, supported at all levels of the NHS. It is time for a change in mindset, and time to deliver supported self care for those with lower leg wounds.



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# Recommendations

The VVAPPG has made a number of recommendations:



## GOVERNMENT

- To support and champion the National Wound Care Strategy Programme's lower limb implementation proposals to become an NHS E priority from 2024 onwards.
- To include in clinical experiential education a greater focus on the provision of health care outside hospital settings where supported self care is more relevant.



## NHS ENGLAND

- To support ICSs to measure the use of local supported self care in every region of England to ensure that resource can be adequately distributed.
- To implement the NWCSP's lower limb recommendations as a fully funded NHSE priority for national uptake.
- To co-develop, produce, and deliver appropriate, evidence-led materials to support the supported self care agenda for clinicians and patients, including effective signposting to ensure it can be disseminated and found by those who need it, when they need it.
- To ensure equal access to all treatments, including compression and proven technology to support supported self care in every ICS.



## CLINICIANS

- To ensure that patients are given the option of supported self care, where appropriate, and given support throughout their journey.



## PATIENTS

- To be supported and empowered to speak openly about the care and treatment they receive, and become equal partners in, rather than simply recipients of care.

## Introduction from the Chair



The challenges being faced by the NHS are well-known – staffing shortages, financial pressures, increased demand, with many more people suffering from multiple conditions, and the elective care backlog increasing the wait times patients must endure before treatment.

Patients across the country, including in my constituency, are faced with long waits for treatment and care across a range of condition areas, including those suffering with lower limb wounds. These patients often suffer in silence.

However, supported self care can help to tackle many of these issues. Patients are often already experts in their own conditions, and with appropriate support from clinicians, many can help to manage their own lower limb wounds effectively. This helps to empower patients and support better patient outcomes, but will also bring about many benefits for the NHS itself, including saving money and freeing up clinicians' time.

I am proud that the VVAPPG has brought together a range of experts from across the Vascular Community to develop this report and its recommendations. I hope that with this information, Government and the NHS can be persuaded to act to implement a greater emphasis on supported self care across the country.

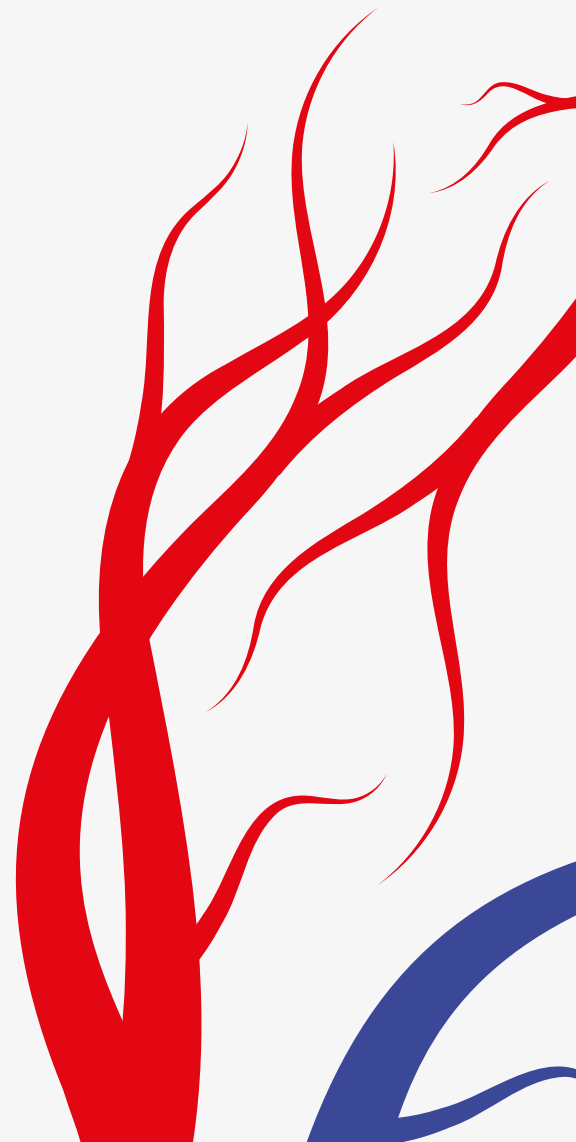
I am looking forward to engaging with stakeholders from across the Vascular Community, Parliament and Whitehall in greater detail on these recommendations in the weeks and months to come, and will continue to push for greater patient empowerment through these recommendations.

**Jim Shannon MP**

*Chair, VVAPPG*

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# Introduction

In a healthcare system facing funding and workforce challenges, and a growing demand for care, the burden of lower limb wounds is a significant strain on NHS resources. In the current system, patients are unable to access the required standard of care to appropriately address their needs, and are experiencing devastating consequences, impacting clinical outcomes and leading to a deepening dependency and strain on an already depleted health and social care system.

Struggles with the patient backlog, community workforce shortages and increasing pressure across the NHS on nursing resources has meant lengthy delays in care and treatment management for lower limb wounds. This has led to increased rates of late-stage conditions and mortality.<sup>7</sup>

Rather than having their needs and preferences understood, patients are experiencing variations in access to care and services across the country and a lack of continuity in their treatment and care management. A failure to sufficiently manage lower limb wounds in their initial stages results in delayed healing, increased recurrence rates, an increased risk of cardiovascular conditions, dependency on antibiotics and hospital admissions. Further, it leads to extended delays to care and increased strain on both NHS community nursing and consultant resources.

Care management for lower limb wounds must be transformed across the country to deliver a higher quality and more sustainable service that reduces the challenges on the system, improves clinical outcomes and reduces the variation in care, as well as meeting current and projected demand for care. While the NHS has invested in a new model of care, 'personalised care', and there has been noticeable collaboration between the National Wound Care Strategy Programme (NWCSP), NHS England, NHS Improvement and the Queen's Nursing Institute to identify and recommend increased opportunities for supported self care, this is yet to become the standard way of managing lower limb wounds<sup>8</sup>



## Benefits

The NWCSP, commissioned by NHS England, estimates that improving lower limb wound care offers large financial and workforce productivity benefits for the NHS, and a reduction in equipment and clinical time spent on wound care, thereby increasing staff capacity, improving clinical outcomes, and healing rates.<sup>9</sup>

To ensure ongoing improvements in results and equality in the delivery of care across the country, supported self care needs to be facilitated more consistently throughout NHS lower limb wound services and accompanied by increased awareness and education to ensure sufficient patient and clinician buy-in. This mindset change will require education and patient signposting through clear pathways, clinical and patient training, safeguarding and care monitoring, increased data collection and quality and utilising technology and innovation.



# State of Care for people with lower limb wounds in England

## State of Care

The NWCSP defines a chronic lower limb wound as a “wound below the knee that fails to heal as normal”.<sup>10</sup> These lower leg wounds commonly occur either because of problems with blood returning through the venous system, or insufficient blood reaching the lower leg due to circulation issues with arteries. Some leg ulcers can be due to a combination of both arterial and venous problems.

According to the NWCSP, chronic lower limb wounds are estimated to account for 42% of all wounds in the UK and approximately 1.5% of the UK’s adult population, equating to 730,000 patients, are affected by active leg and foot ulceration. Estimates of prevalence suggest that between 2012/2013 and 2017/2018 the annual prevalence of wounds increased by 71%.<sup>11</sup>

Chronic lower limb wounds are often extremely painful and cause significant discomfort. Patients frequently suffer from impaired mobility, increased risk of infection, anxiety, sleep disturbance, and social isolation, often resulting in a loss of independence as they increasingly depend on family and carers.<sup>12</sup>

As chronic lower limb wounds are slow healing, they account for a considerable proportion of the total wound care spend in the NHS. The Burden of Wounds study in 2015 estimated that in 2012-2013 there were 2.2 million patients with wounds in the UK, with the annual NHS cost of managing these wounds being £4.5-5.1 billion after adjusting for comorbidities.<sup>13</sup> Since that study, it has been suggested that the cost of wound care for an average ICS is estimated to have increased from £26.7 million to £50 million per year.<sup>14</sup>

In England, lower limb wound care is provided by a variety of health and care providers including general practice, podiatry, community nursing services, care homes, and secondary care in-patient and out-patient services, as well as new models of care such as Leg Clubs.<sup>15</sup> While therapy of lower limb conditions varies depending on the cause, most commonly it is based on:<sup>16</sup>

- Compression therapy for venous insufficiency
- Surgical, interventional radiological revascularisation or ablation surgery
- Offloading pressure reduction
- Pain management
- Minimising the risk of infection
- Lifestyle modifications such as nutrition, medical optimisation and quitting smoking

According to the NWCSP, mobile patients generally receive wound care from practice nurses in general practice or community or district nursing services, while the housebound receive care from community or district nursing services.<sup>17</sup> The majority of lower limb wound care is delivered within community settings and accounts for over 50% of community nursing time.<sup>18</sup> Between 2012 and 2018, Guest et al found that 81% of total NHS costs for lower limb wounds were incurred in community and that district nurse visits increased by 399% and practice nurses visits by 51%.<sup>19</sup> This is because lower limb wounds require dressing and bandage changes at least weekly, with each appointment lasting about thirty minutes each at either a GP surgery, clinic or at the patient’s home.

With nursing resources and capacity under increasing pressure within and across the NHS more broadly, people with lower limb wounds are struggling to access services staffed by clinicians with sufficient knowledge, skills, and capacity to provide appropriate and quality evidence-based care.<sup>20</sup> For patients, this results in increased waiting times for diagnosis and treatment, leading to unnecessary pain and added avoidable risk of complications and worse outcomes.

## Opportunity and scope for improvement

This expenditure of time and resources is unsustainable for an NHS system that is struggling against the backdrop of historic challenges around funding and compounded workforce shortages. Existing NHS financial resources must be utilised more efficiently to improve chronic wound care prevention and lower limb wound care delivery.

In 2020 the NWCSP published its recommendations for lower limb care which was followed in 2021 by a business case for implementation.<sup>21</sup> The business case posited that improving wound care, and in turn healing, recurrence, and amputation rates, would significantly alleviate the burden on financial and personnel resources.<sup>22</sup>

The NWCSP estimates that improving lower limb wound care through implementing the recommendations they have devised, would offer financial benefits for the NHS equivalent to a net value of £14.6 billion through a predicted 30% reduction in leg ulcer prevalence.<sup>23</sup>

The programme further predicted that improvements would deliver an estimated £7.8 billion of net cash released savings.<sup>24</sup> With a limited workforce, this release of clinical resources would increase staff capacity across the NHS and is equivalent to a 9% saving on the NHS cost of leg and foot ulcer care in England.<sup>25</sup>

Improvements in lower limb wound care can be delivered through structural, information and technological changes. While supported self care is being used in some places, this is inconsistent across clinical care settings. There remains a lack of awareness among patients, healthcare professionals and the system on the impact, benefits and roll out of these changes to deliver a new standard of care that embraces supported self care.<sup>26</sup>



**£14.6  
BILLION**

**Estimated financial  
benefits from  
implementing NWCSP  
recommendations on  
lower limb care**

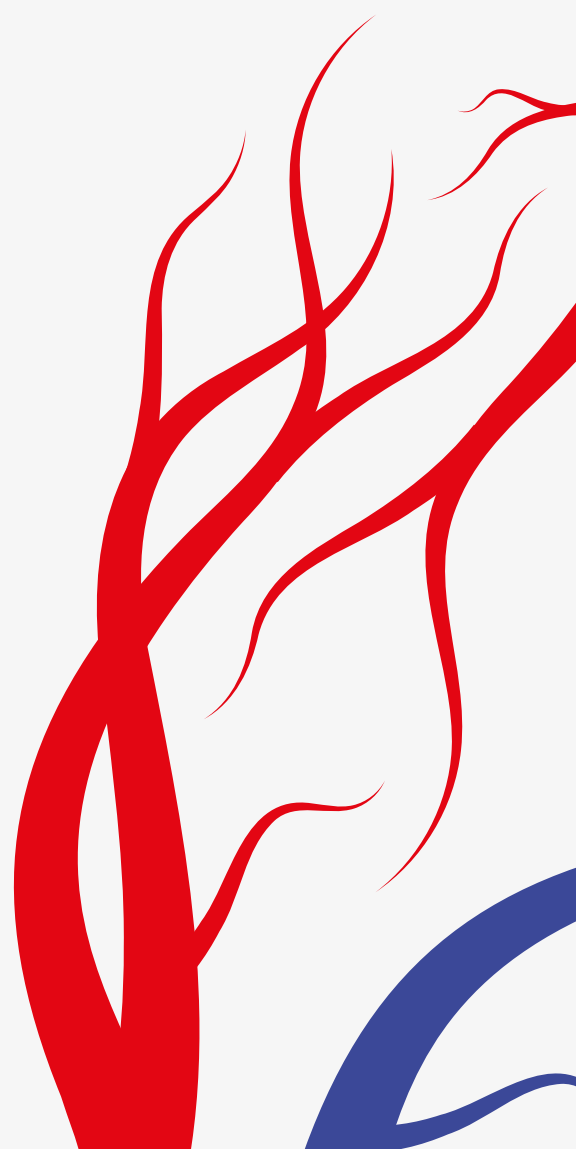


**9%  
SAVING**

**Potential savings for  
the cost of leg and foot  
ulcer care in England**

## **A Supported Self Care Programme**

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# Supported Self Care

## Introduction to supported self care

There are many and sometimes competing definitions of supported self care, with no common language used across the NHS.

Broadly, a supported self care model is when patients are encouraged to be partners in the care they receive and actively participate in their own care as experts in their own conditions.<sup>27</sup> The Self Care Forum's definition of 'self care' is "the actions that individuals take for themselves, on behalf of and with others in order to develop, protect, maintain and improve their health, wellbeing or wellness".<sup>28</sup>

To implement this model of care consistently and effectively, there must be a mindset change around the common language and terms of reference.

The key principles of supported self care are:<sup>29</sup>

- That patients are seen and heard within the context of their whole life.
- Patients feel confident in advocating for their own health and wellbeing.
- Patients are able to access clear and timely information and guidance that meets their needs and preferences.
- Patients are listened to and understood in a way that builds trust and effective relationships.
- Patients are valued as an active participant in conversations and decisions about their health and wellbeing.
- Patients have access to a range of support options including peer support and community-based resources to help build knowledge, skills and confidence to manage their health and wellbeing.
- Patients experience a coordinated approach that is transparent and empowering.

Supported self care enables patients to become active participants in their own care plans by developing their knowledge, tools and confidence, and taking on greater responsibilities in achieving better health outcomes. Consequently, patients feel seen, heard, informed, and empowered to take control of their health, strengthening the relationship between people, healthcare professionals and the system.<sup>30</sup>

People most often have the tools available to take care of themselves for common symptoms such as coughs. The same is often true for those with long term conditions where people learn to manage their condition with support from healthcare professionals. This level of supported self care should be the standard way of managing care for those who are able and when it is safe to do so.

Empowering people to take care of themselves with confidence, knowledge, and clinical support when they need, gives people greater control of their own health and encourages healthier behaviours that prevents ill health in the long-term and improves quality of life.



The actions that individuals take for themselves, on behalf of and with others in order to develop, protect, maintain and improve their health, wellbeing or wellness.

The Self Care Forum's definition of 'self care'



## Application of supported self care to lower limb health

Current care for lower limb wounds is provided through multiple healthcare providers across different clinical settings. Any transformation in the standard care model for lower limb wounds would require collaboration and consensus across multiple disciplines.

Assessing whether supported self care is appropriate for lower limb wound patients should be based on a conversation between a healthcare professional and patient on:

- If supported self care is safe and suitable for the patient
- If the person with the wound is able to make a decision about supported self care or if they have someone who is willing and able to act in their best wishes to make a decision on their behalf
- If the person with the wound is physically able to undertake the necessary care or has someone who is willing and able to carry out care on their behalf
- If the person with the wound / carer agree to undertake supported self care until the next agreed review date.<sup>31</sup>

Based on this discussion, a wound care plan would be implemented based on the type and presentation of the wound. It would involve detailed information on how to change, remove and replace dressings, apply compression, and monitor for signs of infection.<sup>32</sup>

Those patients identified as suitable for supported self care would still require regular face-to-face appointments for review of care and treatment plans and to monitor for infection and the rate of wound healing. However, this new provision of care can help reduce the frequency of visits to or from clinicians.

## Benefits to patients, healthcare professionals, the system

Adopting a more widely adopted supported self care programme across lower limb wound care would have positive implications for patients suffering with lower limb wounds, as well as for the NHS workforce and the wider health and social care system.

## Patients

For patients, the introduction to a supported self care system would move the system from a reactive and deficit service provision to a proactive anticipatory model of care. It would produce three key benefits:

- Increased adherence to treatment and heightened awareness of symptoms through empowering patients to take ownership of their care.
- Improve patient wellbeing and psychological health.
- Reduce the time and cost burden for patients in attending regular appointments.

The mainstay of effective evidence-based care for treating the majority of lower limb wounds, which are caused by venous insufficiency, is compression therapy which is applicable to many patients and can be applied outside of clinical settings.<sup>33</sup> While all types of compression therapy can be applied outside of clinical settings, hosiery and wraps are easier to apply than compression bandaging. The healing rates for hosiery are equal to those for bandaging but the quality of life is higher for those using hosiery. Research has found that a significant proportion of the venous leg ulcer population cannot cope with hosiery but the NWCSF is discovering that if patients are offered hosiery at an early stage of their condition, then a larger proportion are comfortable in hosiery, do not need bandaging and can undertake self care and heal faster.<sup>34</sup>

With compression therapy the healing rate is likely to more than double from the current estimate of 32% at 12 months to 74%. Similarly, it is expected that the recurrence rate will at least halve from 46% within 12 months to only 18%.<sup>35</sup> Increasing the proportion of patients receiving compression therapy, and encouraging patients to deliver this care themselves, releases clinical time and resources to focus on those with more developed wounds.

By increasing care that actively listens to and respects patients as experts in their own conditions, treatment becomes a joint initiative between patient and care provider, increasing adherence to treatment plans.<sup>36</sup> This helps to reduce infection and recurrence rates and improve healing rates which reduces the number of complex lower limb wounds presenting in the system.

A programme of supported self care further improves patient wellbeing and psychological health.<sup>37</sup> With patients being able to change their own dressings and compression in a timely manner, when it works best for them, they are able to reduce anxiety around malodour and leakage which often leads to social isolation.<sup>38</sup>

Giving patients more flexibility on when to change their dressings and compression means they are no longer confined to set appointments at clinics. They are able to remain in employment, without using up paid leave or sick days to attend clinics. They also have the ability to call a named nurse anytime with concerns or questions regarding their care.<sup>39</sup>

In reducing time spent at clinical appointments, patients are relieved of the cost burden associated with frequent visits. Patients are no longer required to fund travel or parking costs to attend clinic appointments, undertake additional laundry for soiled clothing as they are able to change their dressings more efficiently, or pay for childcare while they get their dressings changed. This reduction on pressure on clinic time frees up clinic space for those waiting for appointments and clinician advice and support.

### Clinical workforce

For the workforce, the transformation to a supported self care system would produce three key benefits:

- A reduction in the use of clinical time and resources.
- An improvement in workforce wellbeing.
- Progression in sustainability by reducing carbon dioxide emissions and treatment associated waste.

A supported self care programme would reduce the use of GP and nurse consultation appointments, releasing time and resources to patients with more complex conditions.<sup>40</sup>

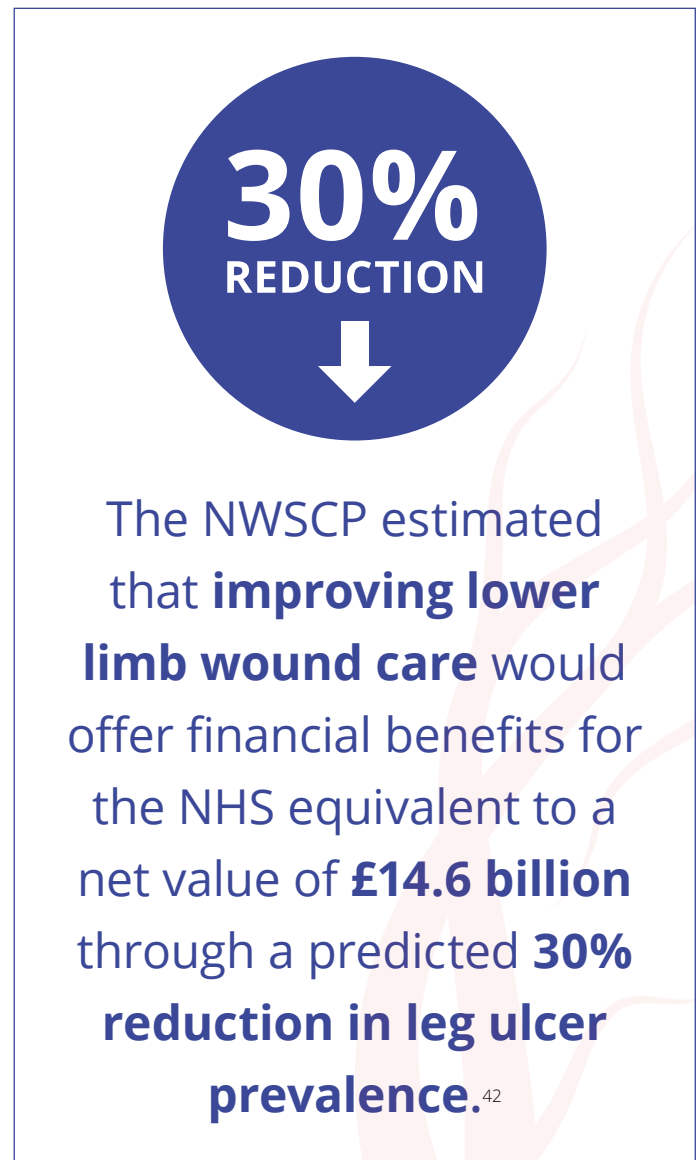
Further, in empowering patients with issues with circulation to have a heightened awareness of their symptoms and care management, patients are more likely to seek timely treatment, thereby reducing healing times and recurrence rates, reducing the burden on the NHS workforce over time.

The implementation of a supported self care programme would require additional training and upskilling of healthcare professionals to identify suitable patients, equip them with the skills to manage their care through evidence-based therapies, and to ensure these patients are supported through their treatment plan.

With additional skills and knowledge, healthcare professionals find greater levels of job satisfaction which inevitably leads to a higher quality of care.<sup>41</sup>

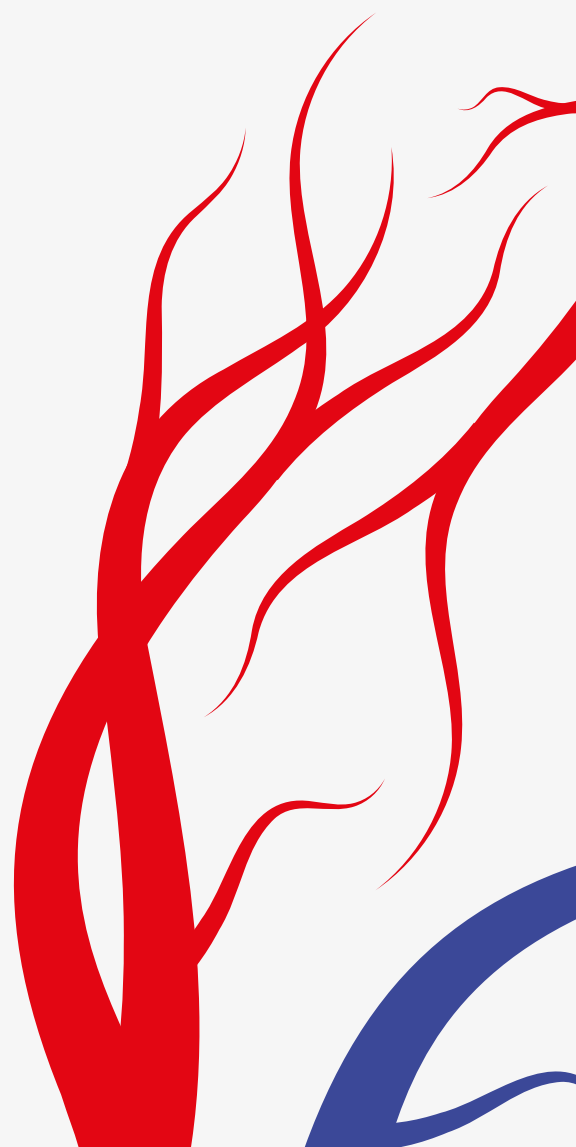
### System

For the system, the implementation of a supported self care programme would produce significant cost benefits. In reducing recurrence rates and improving healing rates, this care model would reduce the average amount spent on clinical time for wound care, compression therapy and dressings, drug prescriptions, hospital admissions and GP visits.



The infographic features a dark blue circle at the top containing the text "30% REDUCTION" in white, with a white downward-pointing arrow below it. Below the circle, the text reads: "The NWSCP estimated that **improving lower limb wound care** would offer financial benefits for the NHS equivalent to a net value of **£14.6 billion** through a predicted **30% reduction in leg ulcer prevalence.**" The background of the infographic shows a faint, stylized illustration of a human leg.

## **Delivery of Supported Self Care**



# Delivery of supported self care

The delivery and successful implementation of a supported self care model as a priority for appropriate patients will require patient education and signposting through clear pathways, clinician training, safeguarding and care monitoring and increased data collection, as well as the utilisation of digital and technological capabilities.

The Lindsay Leg Club Foundation has already taken significant steps to improve the supported self-care agenda. The foundation works to educate the public on how leg ulcers can be diagnosed, prevented and treated; ensure healthcare professionals are trained to an efficient and high standard in wound management; and ensure that care is provided equally to patients.<sup>43</sup> Providing this support nationally could provide positive outcomes for patients.

## Patient education and signposting

There are numerous examples of support kits for clinicians to signpost patients to trustworthy information. These include the PIF TICK Trusted Information Toolkit for healthcare professionals. Developed by the World Health Organisation, this toolkit identifies credibility marks as part of the solution to misinformation and identifies healthcare professionals as trusted sign posters of health information. Using the PIF Tick as a quality mark for trusted health information, the NHS website could be populated with independently assessed content for both patients and clinicians.<sup>44</sup>

The NWCSF has further published resources aimed specifically towards patients. These are being translated into the most common languages and aims to use easily accessible terms and language.<sup>45</sup>



## Clinician training

To ensure patients are equipped with the correct knowledge and skills required to manage their wound care, healthcare professionals will require additional training, throughout their careers. They will be required to respect patients as specialists in their own conditions and empower patients to take ownership of understanding and implementing their treatment plans. These learnings must be put into practice, and successes measured to reinforce and encourage good practice. This will require a shift in culture between patients and clinicians, which may raise its own challenges, while also bearing in mind the challenges which clinicians are already facing in a pressurised NHS.<sup>46</sup>

Further, clinicians will be required to undertake education on utilising digital platforms to monitor patients remotely.

Health and care bodies must ensure comprehensive training opportunities for healthcare professionals that are funded, given protected time for, and that follows a nationally agreed curriculum, to avoid regional variation.

## Care monitoring and safety

While the self-management of wound care has the potential to improve clinical outcomes and save capacity and resources, it requires sufficient monitoring and safeguards to be delivered safely.

These safeguards and support may include:

- Access to care when needed.
- Access to dressings and other necessary items.
- Review and monitoring of risk.
- Reporting and progress reporting.
- Dialogue and continued agreement from patients on treatment plan in a partnership way of working.
- Access to a responsive system for the escalation of support.<sup>47</sup>



## Supporting self care through innovation and technology

Understanding and facilitating access to technologies that enable supported self care will be key to success. These solutions can ensure that patients have ongoing access to the best treatments, support through remote access to clinicians, and support to help manage their own condition.

There are clear opportunities to support implementation, examples include digital education tools used by healthcare professionals to assess a patient's ability to participate in supported self care, digital remote monitoring solutions, including wound management digital solutions, and wound and compression equipment tailored to deliver supported self care. Implementation of these technologies must ensure a comprehensive understanding of the value delivered across the whole patient pathway – in alignment with the Government's Medical Technology Strategy.<sup>48</sup>



## Data collection and reporting

There is a necessity to improve the data landscape of lower limb wounds. The 2016 Carter review reported that most NHS Trusts had not captured basic information on the number of patients presenting with wounds, wound types, treatment plans or, most critically, wound healing rates.<sup>49</sup> Further, there is no reliable prospective data for chronic lower limb wounds, aside from diabetic foot ulcers. To improve systems and processes, and thereby reduce costs, it is necessary to measure real and meaningful clinical outcomes through quality data collection and reporting in primary, community, and secondary care, including patients who self care.

Improved data quality and collection is also required to ensure the effective implementation of a standard supported self care programme across lower limb wound services.

With an increase in quality data, services can be more effectively evaluated against cost and successful outcomes to ensure more efficient use of health and social care resources through value-based decision making by commissioners and health planners to help deliver broader efficiencies and savings in the future.



**Good data can inform value-based decision among commissioners and health planners and help deliver broader efficiencies and savings in the future.**

## **Vision: The Future of Supported Self Care**

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## Vision: The future of supported self care

Decision-makers must take the opportunity to tackle the growing burden of wound care, improve the quality of life for people with lower limb wound care and secure better value from existing healthcare resources, by supporting the delivery of a standard supported self-care programme for lower limb wound care.

Healthcare professionals must engage more confidently with patients about managing their own care, once trust, consistency of approach and clarity of boundaries is established between the clinician and patient.<sup>50</sup>

For many patients, a conversation about supported self care would offer them a welcome alternative, and the freedom to shape and take greater ownership of their own care and treatment.

These people must be enabled to do so by clinical support and guidance. This includes the use of digital technologies.

Supported self care will not be appropriate for all patients, for a range of reasons, including age, vulnerability, and complexity of the health issue. However, for those who are suited to supported self care, the range of technological and medical support available, alongside the ability – now more than ever – for clinicians to support remotely, means that there are opportunities to transform the treatment and care of 1,000s of patients across the country.

This transformation will require the support from patient and clinicians, as well as senior stakeholders within the NHS, Government and Parliament. It is clear that there is a pathway to support patients, to save limbs and to save lives.

The VVAPPG will utilise this report to engage with patients, clinicians, NHS representatives, the Department of Health and Social Care, and Parliamentarians, to build further support for this vital area of work and deliver for patients right across the country.

## Testimonials

This is not an official publication of the House of Commons or the House of Lords. It has not been approved by either House of its committees. All-Party Parliamentary Groups are informal groups of Members of both Houses with a common interest in particular issues. The views expressed are those of the group.



# Testimonials

## Tracy Goodwin

Tracy Goodwin is a business-owner, mother and wife, and has suffered with chronic leg ulceration for almost all of her adult life.

Tracy suffered from Deep Vein Thrombosis (DVT) when she was pregnant with her first child. The condition re-occurred after her son was born, causing her throbbing and aching in her left leg, requiring daily pain relief, and leaving her with silvery, paper-thin skin on her left ankle.

She was not told of the potential dangers that this would cause and was not given any advice or guidance on leg compression.

Several years later, a simple knock to the ankle caused an ulcer, which has caused Tracy untold trauma since.

*It was just a tiny cut to my inner ankle that refused to heal and for several weeks, I tried to carry on as normal. After a few more weeks, I was sent to the hospital to have it dressed. I hadn't even heard of leg ulcers and had no concept of the affect that such a small wound could have on a person's life. The ulcer healed after 12 weeks which at the time seemed like a lifetime – you can only imagine now what I would pay for a 12 week healing time!*

Despite several years of pain, the ulcer did not return until she knocked the same ankle, causing a large ulcer which led to her being hospitalised.

*Leg ulcers are misunderstood in many ways, it seems madness to most people that a small wound cannot heal. I probably could have broken and healed every bone in my body in the time I have had this stubborn little ulcer. I do not have any pre-existing medical conditions, I wasn't overweight when this all started and I have never used drugs – I've not even smoked a cigarette! **I have just been unlucky.***

### Challenges

Living with a chronic wound has affected my life in every single way.

*First and foremost, it has affected my confidence. Many people wear nice clothes or shoes to treat themselves or to feel good about themselves. I cannot do that. For many years, the only shoes I could wear were flat backless mules. In fact, in the beginning, I distinctly remember wearing flip flops (which were the only shoes I could fit over the four layer bandage) in all weathers - even in the snow.*

*I haven't been able to wear heels or strappy shoes for over 15 years. I cannot wear shorts, skirts or dresses without my leg and my highly unattractive compression stockings being on show. It makes me feel old and ugly.*

*It has also made a big difference to my social life, I haven't been able to drink alcohol since being on warfarin, so along with not being able to wear 'dressy' clothes or shoes and not being able to stand for long, I have stopped going on nights out.*

*I feel very underdressed in an evening social situation. I have had to turn down a number of invitations to weddings, christenings and other such occasions because of this.*

*My foot and toes have actually changed shape because of the ulcer. I have spent so many years walking on the side of my foot that the ligaments have shortened, and I find it hard to straighten my foot.*

Tracy's self care journey has been one of luck, rather than design.

*I have been lucky enough to have been looked after by Leanne Atkin and her team at Pinderfields Hospital in Wakefield. I first met Leanne in 2003 when I was first diagnosed with a leg ulcer and I have been under her care ever since. I have 100% trust in Leanne and I know that she does everything she can for me.*

Long before supported self care was introduced for patients with chronic leg ulcers, Leanne was structuring Tracy's care around her needs.

*I have a great relationship with Leanne and this has made a massive difference to my ability to cope with this condition. Leanne knows that I am busy and rather than me having to go to appointments that have been decided by the hospital, she is flexible and fits round me.*

As well as having difficulties getting to and from hospital due to an inability to drive and the challenges of using public transport, coupled with having to care for two young children, Tracy's self-care was created out of necessity, with ongoing care and support from her clinician, Leanne.

*I do my own dressings at home. If I am ever concerned about the look of the ulcer, I email Leanne to ask for advice. She will then either arrange to see me in clinic (at a time that suits us both) or she will suggest a different dressing or treatment to try.*

***I hate to think how much harder this would be if I didn't have a trusted professional like her looking out for me.***

However, her journey has not been a smooth one. As well as seeing clinicians who do not understand the impact of the ulcer, Tracy has seen many unempathetic and uncaring clinicians, and instances where she has been ignored or talked down to regarding her own treatment.

“

I think it is important to understand that people are treated according to their own needs, so that the impact of a chronic wound on a patient's life is minimised.

”

## Message to others

For Tracy, she would like to see patients, who have a better understanding of their own condition and the impact, be able to better manage their care.

There has been a lot of work done to support patients, particularly from Legs Clubs®.<sup>51</sup> People are being signposted now where they weren't before, and being empowered to ask further questions about their conditions, treatment and ongoing care; but there needs to be a change of mindset from patients and clinicians around supporting self care.

For some people, this will mean being able to manage their own conditions at home, saving time, travel and money not attending needless appointments at hospitals, taking up clinicians' and the patient's time.

However, this change in practice will require effective communication from patients and clinicians across the system, and a change in attitude about how treatment is administered and supported in practice, as well as respect for patients as the experts on their condition, treatment and experiences.

*I know I am lucky to have wonderful family and friends that love and care for me and of course I am grateful that I haven't got any awful diseases that are life threatening. However, having a chronic wound affects my life in so many ways.*

***I know I am in the minority having a chronic leg ulcer at my age. I think it is important to understand that people are treated according to their own needs, so that the impact of a chronic wound on a patient's life is minimised.***



## Kristy Widdicombe-Dutch

### A Patient's Perspective: "It's all in the telling and re-telling"

Stories of disease can go untold and unheard. Stories of distress cannot always be told in a way that is palatable for, or understood by, clinicians. Clinicians are not always, as Professor Peter Mortimer points out, 'adequately taught about the lymphatic system and lymphoedema'.<sup>52</sup> The language used by patients can and does make the difference between a referral to a specialist or a delay in treatment that has repercussions and consequences that result in further physical or indeed psychological harm. Many patients don't even know who or how to ask for help. It can be hard to navigate what has become, in my lived experience, an inaccessible NHS with confusing points of access. We know the NHS is under huge pressure with staff shortages<sup>53</sup> and limited funding and access to treatment does vary depending on where you live.

Owning my story as a human with chronic conditions impacting my lower limbs is important as I have not always felt empowered; I have not always felt as if I have agency or even a valuable perspective in my own care. I have received the following diagnoses all within the last 2 years: secondary lymphoedema, eczema (venous and pompholyx), issues in both knees related to patella hypermobility, subluxation and trochlear dysplasia, patellofemoral crepitus, and other labels I find hard to understand and, at times, reconcile. Many of these conditions have, however, been longstanding. Oedema certainly developed in childhood as I remember my mother describing me to her friend as "having legs like large loaves of bread" even though I was a generally considered to be a slight child.

My story is messy and when asked by a vascular surgeon in an initial consultation to, from memory, recount the dates and locations of many previous interventions and surgeries, that included radio frequency ablation and varicose vein stripping, language failed me, and I broke down under the pressure. Although questions are essential in helping the clinician to build a picture and plot a diagnosis and course of treatment, questioning without compassion can devalue and invalidate experience, particularly when certain questions are left out. This surgeon didn't look up from his clipboard and was surprised when I asked to leave the room. I could not return.

At a subsequent appointment with a different surgeon at the same hospital I was told that as I no longer had varicose veins so "there was nothing [he] could do". I felt exasperated at the end of a long road after first experiencing issues with what I now know to be my lymphatic system in my 20s. Now in my 40s, presenting to GPs and other specialists over the last 20+ years I've been told, among other things, that I was "too young" to be presenting with such conditions or that I was "just being vain" in drawing attention to my legs, even though I was more concerned about the impact on my daily life than appearance.

Compression is the main form of treatment prescribed for lymphoedema and it's important to treat early to reduce the risk of developing ulcers and other complications. Even though I was presenting with chronic oedema before and after surgery, I was not advised to wear compression hosiery on an ongoing basis, something that I now know is crucially important to manage my condition. I believe that it is this oversight that led to the exacerbation of my symptoms and, eventually, being diagnosed with chronic venous insufficiency and, later, secondary lymphoedema. I was gaslit by clinicians who minimised my experience and failed to recognise my symptoms and the pain and distress that venous disease created over many years. Countless times at my GP practice unsuccessful attempts were made to carry out a Doppler test but, as a reading could not be produced, compression hosiery could not be prescribed and, yet again, I found myself without the right course of treatment. As a member of the Legs Matter Coalition<sup>54</sup>, I'm painfully aware that other patients don't even have access to compression on prescription due to where they live and the demoralising "postcode lottery".

So, how did I get the much sought-after diagnosis? Is there a light at the end of the tunnel? I carried out research and learnt that I could take back control. I spent hours online trawling through medical papers and researching symptoms. It was during this process that I came across Legs Matter, a coalition working to increase awareness, understanding and action on lower leg and foot conditions among the public and healthcare professionals. I found information on lymphoedema on their website, and everything seemed to fit. I then searched to see if there

was a lymphoedema service in my area and I was very relieved to see that there was. I wrote an eConsult form to my GP practice writing that I felt my symptoms indicated that I had lymphoedema and requested that I be referred. Without further consultation I was referred and am now, finally, under the treatment of a specialist unit. My treatment journey continues but it has taken a lot of perseverance to arrive at this point and I'm hoping lessons can be learnt in the retelling of my story.

Let me conclude by reflecting on what supported self-care means to me and what a programme might look like? Health literacy is key: once I gained access to the right information, I could make better decisions about my own health. Knowledge is power and the terminology I learnt enabled me to create my own route into the system; carrying out research helped me to finally get the treatment I needed and it's empowering when you feel better able to ask for the care that you deserve. However, I already had a level of digital literacy and skills that enabled me to access the right types of information. Working in a university I had access to medical journals and papers that aren't freely available online. Not everyone in my community has the same level of digital or health literacy and this, as to be expected, creates further inequalities.<sup>55</sup>

A supported self-care programme would need to equip patients with the skills they need to navigate the wealth of information available, it would help patients to develop confidence to speak up if they don't feel supported or treated with compassion. Patients as well as clinicians need to see what good care looks like. Such a programme would also need to build communities, helping patients to feel less isolated<sup>56</sup> and perhaps share self-care tips. I would also like to see more crowdsourcing and use of imagery to identify the possible causes of symptoms on black and brown, as well as white, skin.

To be truly supported, patients like me need to feel in safe hands and more clinicians should be taught about the lymphatic system and lymphoedema, or the importance of early intervention in wound care. There are so many clinicians with different roles, and it can be hard to understand the difference between professional territories even if many work as part of a multidisciplinary team. For example, before joining Legs Matter as a patient partner, I had never heard of a tissue viability nurse, a key role in the provision of advice on complex wound management. It's important that job titles are standardised across the NHS and that patients understand how these highly trained individuals can help.



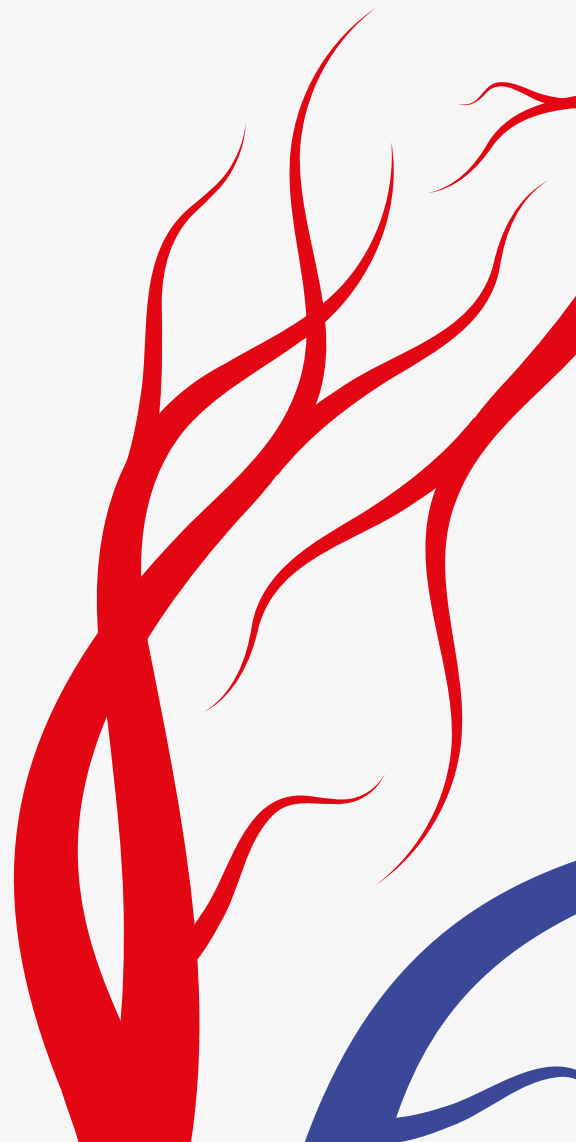
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Health literacy is key: once I gained access to the right information, I could make better decisions about my own health.

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## Recommendations



# Recommendations

Through this report the VVAPPG is calling for:



## GOVERNMENT

- To support and champion the National Wound Care Strategy Programme's lower limb implementation proposals to become an NHS E priority from 2024 onwards.
- To include in clinical experiential education a greater focus on the provision of health care outside hospital settings where supported self care is more relevant.



## NHS ENGLAND

- To support ICSs to measure the use of local supported self care in every region of England to ensure that resource can be adequately distributed.
- To implement the NWCSP's lower limb recommendations as a fully funded NHSE priority for national uptake.
- To co-develop, produce, and deliver appropriate, evidence-led materials to support the supported self care agenda for clinicians and patients, including effective signposting to ensure it can be disseminated and found by those who need it, when they need it.
- To ensure equal access to all treatments, including compression and proven technology to support supported self care in every ICS.



## CLINICIANS

- To ensure that patients are given the option of supported self care, where appropriate, and given support through their journey.



## PATIENTS

- To be supported and empowered to speak openly about the care and treatment they receive, and become equal partners in, rather than simply recipients of care.

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## About the VVAPPG

The All-Party Parliamentary Group on Vascular and Venous Disease was first formed in 2011 as a forum for MPs, Peers, clinicians, patients and industry representatives to discuss vascular and venous disease and related issues.

The group has four main purposes:

1. To raise awareness of vascular and venous disease and to encourage actions to promote a greater priority of their prevention and treatment;
2. To encourage research into the causes of vascular and venous disease;
3. To advance excellence and innovation in vascular and venous disease;
4. To inform parliamentarians of the work of medical professionals, and how they can be helped to provide better services to patients.

*Healthcomms Consulting provides the Secretariat to the APPG.*



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