

Advocacy in wound management: myth or reality?



ELLIE LINDSAY OBE
President and Founder of the
Lindsay Leg Foundation

Leg ulcer management presents several challenges to the global health economy. Leg ulceration has been referred to as “the hidden epidemic”. This phrase has a double meaning, as many older people with this condition are hidden away, isolated, depressed and attempting unsuccessfully to self-care. The experience of a non-healing wound is often secondary to its effect on quality of life. One major challenge in ageing societies is how to create meaningful pathways for late life living with a wound and simultaneously participating in and contributing to society. For many, once they reach later life, the ability to represent themselves disappears.

ADVOCACY

Advocacy is important, especially for those not empowered and/or confident in coming forward. Many may not know what standards, options or treatments can be expected in wound management. It is particularly difficult for older patients, who tend not to question what is being offered or ask about alternatives, as many accept that “doctor/nurse knows best”. These attitudes may change when a less deferential generation grows older, but the current situation remains challenging and a multifaceted approach is required. Many older individuals are vulnerable and may be unable to represent themselves adequately, so external support may be beneficial, if not essential.

Advocacy can be described as facilitating the individual in the acquisition of knowledge and authority, enabling and permitting him or her to participate in and make decisions about his or her care. The role of an advocate for a loved one is to represent his or her cause and rights, assert those rights if the need arises, and to help the individual navigate the environment and get the best care.

People suffering from chronic wounds have the potential to drive resource allocation for wound healing treatment, care and research. Currently, however, there is little effective advocacy at the national level, despite the high wound incidence, associated healthcare resources and costs.

THE PATIENT ADVOCACY WHITE PAPER

The Lindsay Leg Club Foundation and World Union of Wound Healing Societies (WUWHS) panel on patient advocacy aims to promote a patient-centred approach for wound care at an international level. It consists of experts from within and outside wound care with a commitment to understanding, charting and promoting the patient experience. The panel has recently produced a White Paper on patient advocacy. This marks the start of a series of projects intended to provide support and education on patient advocacy, not just for clinicians and healthcare organisations, but also for patients and their carers. Richard Lane, OBE, past president of Diabetes UK, said: “I know the problems that patients have encountered and the often unsatisfactory treatment and attention they have received. I hope this document will have the impact and the desired effect that it deserves.”

Changing clinical practice is a major challenge and it is unacceptable to simply produce a new clinical guideline or care pathway and expect change to happen. To address this, the White Paper, introduced by myself and Roland Renyi, also from the Lindsay Leg Club Foundation, begins by discussing the factors that make wound care a particularly complex area for patient advocacy. The fact that chronic wounds are usually a sign of wider systemic disease adds to the complexity of the process, and challenges the priorities of treatment. The multidisciplinary nature of wound care compounds this problem further, often making it hard to identify the correct specialist to manage a patient’s individual treatment journey.

FUTURE AIMS

During 2018–20, the Foundation and WUWHS scientific committee aims to strengthen patient advocacy to improve outcomes focussed on quality of life and establish an international framework that could expand to other areas in future. They also aspire to create an international patient charter based on a “Bill of Rights” to show individuals and their families what they can and should expect throughout the wound care process.

WUK

WUWHS patient advocacy White Paper

- Promotes a patient-centred approach to wound care
- Summarises issues relating to patient advocacy in wound care from several standpoints

Lindsay Leg Club Foundation and World Union of Wound Healing Societies (2017)
Patient-Centred Care – a Call to Action for Wound Management

Available at: https://is.gd/WUWHS_patient_advocacy