

WORLD UNION
OF
WOUND HEALING SOCIETIES



The Lindsay
LegClub
Foundation

Patient-centred care and advocacy: a call to action

Why do we consistently fail to support our patients when it comes to advocating for them? Is wound management any different from other therapy areas?

'Many of us have already been advocates for people we are close to,' says Ellie Lindsay OBE, Founder and Life President of the Lindsay Leg Club Foundation and Chair of the World Union of Wound Healing Society's (WUWHS) panel on patient advocacy.

'In doing this we may have had to challenge the system that is meant to help and care for us. We are also highly likely to be bedridden ourselves at some point, and we will want those who are close to us to advocate for us too.'

The WUWHS panel on patient advocacy has just produced a white paper on patient advocacy in the wound care arena, the start of a series of projects intended to provide support and education on patient advocacy, not just for clinicians and health-care organisations, but also for patients and their carers.

The aim of the panel is to promote a patient-centred approach for wound care at an international level. The panel consists of experts from both within and outside wound care, who have a professional commitment to understanding, charting and promoting the patient experience. There was also a large contribution from a lay person, someone who had undergone an extremely unpleasant experience relating to their own wound management.

The white paper is available to download on the Lindsay Leg Club Foundation website (www.legclub.org).

It provides an extensive summary of issues relating to patient advocacy in wound care, from several standpoints.

Introduced by Ellie Lindsay and Roland Renyi, the white paper begins by discussing the factors that make wound care a 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 the patient's individual treatment journey.

Patricia Wilkie OBE (UK) and Dr Fran Valle (Assistant Professor, US) explore patient-centred care in the wider sense. Wilkie proposes ways that the treatment team can provide holistic care that is individualised to the patient's treatment needs, while Valle discusses the application of this concept to wound management, and presents recent work by the American Association of Advanced Wound Practitioners (AAWP), proposing a patient 'bill of rights'.

Wendy White (Australia) examines the role of the clinician as patient advocate, and suggests various strategies that would allow them to listen more clearly to the patient and form a more meaningful connection. Professor Vincent Maida (Canada) looks at the wider responsibilities of the clinician when treating patients with wounds, with a special emphasis on the importance of correct diagnosis.

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patient-centred wound care research are discussed by Professor Helen Edwards (Australia), while Dr David Foster (UK) considers how policy can be advanced on both national and international levels.

Throughout the document, illustrations and perspectives are provided from several different countries. The authors also propose questions that we all need to resolve within our field, such as:

- What is the real difference between wound care and wound management?
- How do we define 'advocacy'?
- How can we ensure that the patient is included as a partner in the care team?
- Is the term 'patient' the most appropriate way of describing people with wounds?

The aim of the panel is to use these discussions to support the development of a clear path for patient advocacy to be followed in the complex and multifactorial world of wound care.

'As a group of international experts in the field of wound management, it's vital that we harness the thoughts and perceptions which can contribute to a robust international advocacy protocol' says Ellie Lindsay. 'This would allow individuals to gain confidence to contribute as stakeholders in a wound management pathway from the outset, promoting a sense of ownership and involvement.'

'Our health is vitally important to us, but sometimes maintaining it is a struggle' says Dr David

Foster, one of the authors and Chair of the Lindsay Leg Club Foundation. 'For example, I recognise this struggle in the members who attend Leg Clubs for the treatment of their leg ulcers or to maintain their healed legs in a healthy condition. Crucially for me, the Clubs have members not patients; this helps position people away from the often passive role of patients and into one which empowers them to make informed decisions about care and treatment for themselves.'

For more information and latest news on the development of an international consensus on patient advocacy wound care, go to: www.legclub.org.



Interaction of The Lindsey Leg Club members