

# Patient-Centred Care – A Call to Action for Wound Management

**FOREWORD BY ELLIE LINDSAY OBE,  
LIFE PRESIDENT OF THE LINDSAY LEG CLUB FOUNDATION AND  
CHAIR OF THE WUWHS INTERNATIONAL PANEL ON PATIENT ADVOCACY**

**Quite recently, in a surgical ward in the UK, my husband, who was very unwell at the time, said to me, “will you please be my patient advocate?” I was shocked to be asked this and wanted to know why. “Nobody is listening to me” he said; “I have lain on a bedframe for three nights as the mattress was not working, while the nurses kept saying that the bed mattress was working, but they are wrong.” Soon afterwards my husband ended up with a grade 2 pressure ulcer, on top of the serious illness that he was being treated for.**

One of the core objects of the charity I represent, the Lindsay Leg Club Foundation, is public education on leg health. Wound management is a major demand on health care resources which will continue to escalate with the increasing age and comorbidity profile of the patients that we care for. Prevention needs to be our priority, along with care of existing wounds, but patients also have rights and expectations that need to be taken into account. For example, they should not have to accept developing grade 2 pressure area damage as a result of not being listened to, making them reluctant to return to hospital to continue their vital treatment.

Many of us have already been advocates for people we are close to. 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. How confident are we that the structures and policies for patient advocacy and empowerment will exist when this time comes?

The aim of this document is to explore the concept and status of patient advocacy with regard to wound care. But it is also more than that. The Task Force panel that put this document together was instigated at the request of the World Union of Wound Healing Societies, whose objective is to promote a patient-centred approach for wound care at an international level. The panel consists of experts, both within and outside wound care, who have devoted a considerable part of their careers to trying to understand, chart and promote the patient experience. We hope that this document will begin a structured process of patient empowerment within wound care that will change policy at the highest level.

## INTRODUCTION – WHY ARE WE FAILING? THE OBSTACLES FACING PATIENTS IN WOUND CARE

**Roland Renyi, Chair of the Lindsay Leg Club Foundation (2014-2017)**

The United Kingdom (UK) is an example of one of several countries developing national policies designed to improve the patient experience. At least three of the five outcome framework indicators developed by the English National Health Service (NHS) are oriented towards this goal:<sup>1</sup>

<b>Domain 1</b>	Preventing people from dying prematurely
<b>Domain 2</b>	Enhancing quality of life for people with long-term conditions
<b>Domain 3</b>	Helping people to recover from episodes of ill health or following injury
<b>Domain 4</b>	Ensuring that people have a positive experience of care
<b>Domain 5</b>	Treating and caring for people in a safe environment and protecting them from avoidable harm

In a related document, the NHS states that “involving and engaging patients and the public in decisions about their health and care improves outcomes, strengthens individual well-being and contributes towards more cohesive and healthier communities”. It goes on to say that “understanding patient experience of services can help you identify areas of waste and inefficiency and how to make services better”.<sup>2</sup>

To what extent can we say that we have achieved the right level of engagement with patients and understanding of the patient experience in wound care? Can we say that we have achieved success in wound management in the domains that we listed above?

Some might say that these are unfair questions, because wound care is a particularly challenging field. Why? First of all, chronic wounds are usually a sign of a wider systemic disease that is already being treated, and since wounds themselves are considered to be secondary to the main disease, they are often ignored or even dismissed until a serious wound condition has occurred. Second, wound care is inter-disciplinary, and several different people and services may be involved in a patient’s treatment journey, increasing the risk of communication or treatment failure at so many different points of this journey. That’s where we often let people down.

Limited allocation of time and resources, a lack of consistency in care, and a lack of planning and provision for wound care during overall treatment are all obstacles that patients face during their treatment. Patient information on wound care is also at best inconsistent and at worst non-existent. Many patients struggling with chronic wounds have told us that they don’t know what is going to happen when they have a chronic wound, or who to contact and how. If patients knew what they could expect during wound progression and treatment, if they were told and better prepared at the start of their treatment journey, then they may find the treatment process less traumatic. The table below outlines some of the personal factors that exist alongside the physical aspects of chronic wounds.

**Table 1: Factors affecting patients with wounds**

Physical	Personal
Pain	Fear/alarm
Odour	Shame
Infection	Uncertainty
Exudate	Inconvenience
Bleeding/itching	Isolation
Clothing often unsuitable	Lack of mobility
Disfigurement/cosmetic aesthetic concerns	Low self-esteem
Loss of function/productivity	Poor wellbeing

In order to address the adverse personal factors affecting patients with wounds and to promote their wellbeing, several initiatives are being proposed and followed both at national and international levels. For example, the European Wound Management Association (EWMA) has put together two highly comprehensive position papers, *Optimising wellbeing (2012)* and *Managing wounds as a team (2014)*.<sup>3,4</sup>

In this latter document, the key factors necessary for a team-based approach that will resonate with patients are:<sup>4</sup>

- A patient focus using an advocate for the patient – a wound navigator
- Referral mechanisms that are responsive
- Aggregation of assessment data to form a single plan
- Appropriate remuneration systems
- A health care system sensitive to team models.



But perhaps we are in danger of preaching to the converted. Wound care clinicians are well aware of most of these issues, but we must remember that that majority of patients with wounds are not treated by wound specialists. It is here that we need to take a comprehensive approach that moves from theory to policy.

The rest of this document will outline the areas and steps that need to be covered for this to happen. Dr Patricia Wilkie begins by exploring the concept of patient-centred care in the wider sense and Dr Fran Valle follows with the application of this concept to wound management, and what a patient 'bill of rights' could look like in this area. Wendy White looks at the role of the clinician as patient advocate, while Dr Vincent Maida looks at the wider responsibilities of the clinician. Dr Helen Edwards discusses initiatives designed to ensure the inclusion of consumers, industry and government in patient-centred wound care research, while in conclusion, Dr David Foster considers how policy can be advanced on both national and international levels. You will see that throughout the document illustrations and perspectives are provided from several different countries. This panel hopes that a clear path will be developed for patient advocacy to become a reality in the complex and multifactorial world of wound care. In addition to the clinical members of the panel, there was also a large contribution from a lay person, someone who had undergone an extremely unpleasant experience relating to their own wound management. This person was able to provide valuable insight into the patient perspective.

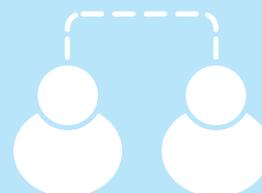
## PUTTING PATIENTS AT THE CENTRE OF WOUND CARE TREATMENT

**Dr Patricia Wilkie, OBE, President and Chairman, National Association for Patient Participation, UK**

The core concept of patient-centred care and its application to wound care is that we are looking at the whole person, not just the wound. We must remain flexible when considering the needs of the individual patient, remembering that we are all different, with different underlying problems and care needs.

Treatment needs to be individualised towards the patient and should involve a collaborative relationship between patients and professionals, in which patients are encouraged to be equal partners. A report by the Royal College of General Practitioners in London into patient-centred care in the 21st Century defines patient-centred care as:<sup>5</sup>

- A holistic 'whole' person approach to care considering the individual's needs as a whole rather than treating medical problems in isolation
- Flexible care tailoring support to an individual's personal priorities and individually defined outcomes
- A collaborative relationship between patients and professionals through which patients are encouraged to be equal partners in their own care



So what should patients expect during their treatment?

- To always be treated with dignity
- That they and their family, where possible and appropriate, will be involved in their treatment and care
- That they will be able to participate in any discussion of available treatments, options, choices and any risks
- That they and their family will always be given clear information about what is happening, with provision of appropriately-tailored information
- To be kept informed about possible length of healing time, how often dressings will be changed (this is particularly important for patients in the community) and what to expect on a clinic visit



We need to consider how medical teams can work together to provide this continuity of care. From the outset, staff should ensure that an appropriately tailored discussion with the patient (and their family) has taken place, so that the patient can be involved in their care decisions. This should cover the wound itself, the possible treatment options, the risks and the possible wound progression. Staff must get to know the patient, to assess his or her level of wound care knowledge, and identify the main concerns or fears that the patient will have. Staff should ensure that patients know which health care professionals to contact for particular problems, and who is responsible for any specific tasks.

How can teams work together to promote patient-centred wound care? We should encourage patients to ask questions. We should give information about the literature and we should remember that the patient is a vital part of the team.

Moving forward, we need to ensure that all health care professionals are educated on the importance of patient-centred care. We need to consider what we can learn from the patient, not just what we can tell them. Including patients as an equal partner in the research team as innovators, designers, co-authors and publishers of results has worked in many fields of medicine, and is already adopted in some areas of wound care. We need to ensure that patients have access to their medical and nursing notes, including laboratory/pathology results, and support in understanding what they mean. Technology could be used to improve communication between patient and staff, using a smartphone or an app for example to improve patient access to information, reducing the need for frequent clinic visits and saving patient and staff time. Social media could be used to reach out to patients, facilitating understanding.

In future, patient-centred care should allow patients and their families to have sufficient information to enable them to play an active part in their treatment, providing transparency in information-sharing with the patient and facilitating patient input. Continuity of care should be a standard process, and patients should always be treated with dignity, and acknowledged as partners in the care team. Although medical staff have the technical expertise, only the patient has to live with their condition 24 hours a day, 7 days a week, and 52 weeks of the year, and only the patient can fully appreciate the impact that this will have on their life.

## A PATIENT BILL OF RIGHTS IN WOUND MANAGEMENT

**Fran Valle, Assistant Professor Director, Post-Master's Doctor of Nursing Practice Program, University of Maryland School of Nursing, Baltimore, USA**

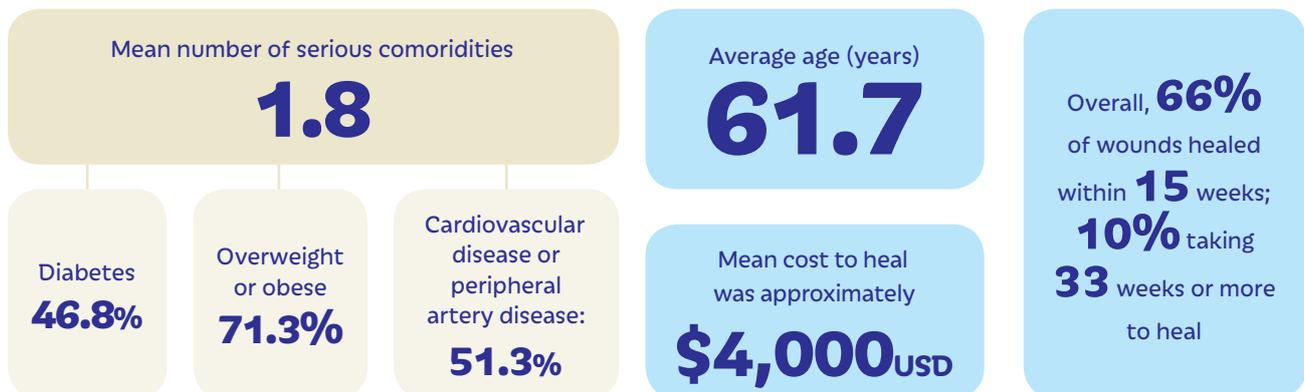
The Worldwide Wound Management Forecast to 2024 confirms what we already know — that we have a chronic wound epidemic, with 4.5 million pressure ulcers, 9.7 million venous leg ulcers and 10 million diabetic foot ulcers. Estimated growth rates show that the incidence of pressure ulcers and venous leg ulcers are increasing by 6–7% annually and diabetic foot ulcers by 9% annually.<sup>6</sup>

**Table 2: Prevalence and estimated growth of wound types**

Wound Type	Worldwide Prevalence (Thousands)	Healing Time (Days)	Compound Annual Growth Rate (2012-2020)
Surgical wounds	114,271	14	3.6%
Traumatic wounds	1,627	28	1.7%
Lacerations	20,645	14	1.2%
Burn wounds	10,221	21	1.2%
Chronic wounds	40,400	—	7.6%
Complicated skin cancer	103	28	3.1%

*MedMarket Diligence, December 2015 Report<sup>6</sup>*

### Wound patient profile:<sup>7</sup>



A comparative effectiveness review by the evidence-based practice team at the Johns Hopkins Centre found that the quality of evidence in the treatment of venous leg ulcers is quite weak.<sup>8</sup> Further to this, the team considered the future evidence base and what needs to be done to improve evidence quality, finding that patient-centred outcomes (quality of life, pain, effect of the wound on the patient and family) are poorly recorded, or really not reported at all in wound care research.

These factors have a long-term impact on patients' lives, at considerable cost to them and their family, while their wounds also create considerable expense for healthcare systems. This leads to the questions: what do we do about this? How do we help these patients?

## THE WOUND CARE PATIENT'S BILL OF RIGHTS

The US Association for the Advancement of Wound Care (AAWC)'s 'Wound Care Patient's Bill of Rights' lists a number of key rights for patients undergoing treatment.<sup>9</sup> Patients have a right to:

### Actively participate as a member of your wound care team if you are able and willing

As wound care providers we need to include the patient in all decisions, explaining the aetiologies and treatments and answering questions in layman's terms. This includes the patient's right to an interprofessional approach to wound treatments. The use of a team approach has been proven and demonstrated to be effective along the entire healthcare continuum. A joint 2014 statement by the AAWC (Wounds Australia), the EWMA and the Australian Wound Management Association (AWMA), states that: *"the patient should be at the heart of all decision-making, as working towards the universal model for the team approach to wound care begins with the needs of the patient."*<sup>10</sup>

### Have your wound assessed and monitored by trained healthcare personnel

Wound education should be incorporated into all of our healthcare professions, and certifications maintained. The wound care patient deserves the right to be treated with confidentiality and respect. Again, we need to ensure that we are focusing on the whole patient, not just 'the hole in the patient'; most patients also have more than one comorbidity. We need to ensure that the patient has appropriate access to care and resources, engaging with them to understand what resources they need, but also understanding ourselves what other resources are there to access. We must also consider the effect of the wound on the patient's life and family, evaluating their preferences and values.

### Know what wound treatment options are available to you

The healthcare provider should explain the pros and cons of treatment options in clear terms that are free of jargon. Treatment goals should be clearly stated, with an estimate provided of the amount of time needed to achieve these goals, and the expectations required to achieve them. Patients have the right to know the benefits, risks and side-effects of their wound care treatment, and to participate in the development of a treatment plan with the wound team. It is important for the patient to be part of the informed decision-making process, which in turn will help to develop trust and rapport, plus an informed patient is better-equipped to follow treatment.

### Know the benefits, risks, and side effects of your wound care treatments

A patient should be able to participate in the development of a treatment plan with the wound care team, receive timely and cost effective wound treatment, and have his or her wound appropriately treated with safe and effective products, with pain adequately controlled. A patient should also feel able to seek other opinions about his or her wound treatment plan and consult a specialist if so desired, and to be able to consult other healthcare professionals for advice about diet, exercise, therapy, or products. A patient has the right to know the benefits, risks and side-effects of proposed wound care treatment, and to participate in the development of a treatment plan with the wound team. Again, it is important for the patient to be part of the informed decision-making process.

### Receive timely and cost-effective treatment

Providers should be available to answer questions directly and to be contactable by phone if something unexpected happens at home, or just to answer questions that the patient may have forgotten to ask in person. The provider should also ensure that the patient has the necessary resources to care for the wound. Wound treatment plans may include home nursing care or a skilled nursing facility if needed.

### Have their wound treated with safe and effective products

Providers should maintain knowledge of current treatment modalities and ensure that we choose products based on what is most appropriate for the patient, not based on bias or personal gains.



### **Have their pain adequately controlled**

Older patients can be prone to certain wounds, but age should not hinder their pain treatment. Pain is not a normal part of the ageing process, and older adult patients have the same rights as all others to have their pain controlled. This may take more time in planning to ensure that the patient's safety is paramount while his or her pain is being treated. Patients with a history of drug abuse are also prone to pain and have a right to have their pain treated appropriately. This may require interprofessional treatment plans that include other providers as well as family/friends.



### **Seek other opinions about their wound treatment plan, and consult a specialist as necessary**

We all have a right to seek a second opinion. The patient has a right to seek other wound specialists for evaluation without ramifications or fear of retaliation.



### **Consult other healthcare professionals for advice about diet, exercise, therapy, or products**

These consultations should be part of the wound care provider's interdisciplinary team. If the patient has worked with specific providers in the past, every effort should be maintained to support their continued relationship with these providers. Again, this is the interprofessional part of wound care.

Beyond the wound care Bill of Rights, we should also support our patients' right to voice grievances without fear of retribution — and very specifically and importantly, to support and encourage self-advocacy. Wound care patients and their caregivers should be provided with the knowledge and tools to allow them to feel more confident in playing a central role in decisions that affect their health. This can be done through patient education, providing patients with support in understanding the choices that they need to make.

## THE CLINICIAN AS PATIENT ADVOCATE

Wendy White, Director Educator & Advanced Practice Nurse (WM)  
Wendy White WoundCare, New South Wales, Australia

### Advocacy in clinical practice...where have we come from?

Perhaps the best way to begin would be to discuss the meaning of the word 'advocate', which comes from the Latin 'advocatus' and 'advocare' – one called to aid, a pleader, or to add a voice.

The origins of modern advocacy in the health care arena began in paediatric cancer care around 60 years ago, to advocate for patients who may not be able to articulate their needs. Dr Wolf Wolfensberger proposed advocacy definitions while working in disability care, which remain widely used and accepted today.

*“Advocacy is functioning and speaking and acting and writing, with minimum conflict of interest on behalf of the interests of a person or group. And it is in order to promote, protect and defend the welfare of, and justice for either individuals or groups in a fashion which strives to be empathetic and vigorous”.*<sup>11</sup>

### 'Patient' Advocacy

There are a number of terms that we use in relation to those we care for depending on the healthcare setting (patient, client, resident, member, person/family/carer). Regardless of the term used, if we consider the patient as a 'consumer' with expectations of customer-focused care, quality service, and follow-up processes, the following are highlighted:

- Patients' 'health consumer' rights
- Patients' 'health consumer' needs
- Quality service provision, leading to quality outcomes for the 'health consumer'



The Australian Healthcare Charter for Patient Rights (2010) highlights the need for specific care requirements: safe care by competent and skilled clinicians, respect of individual characteristics, and communication which is open, timely and easily understood.<sup>12</sup> Patients should be included in all decisions and choices, their privacy should be maintained, and they should be able to comment and complain and have their concerns properly dealt with.

Figure 1: Patients' healthcare rights

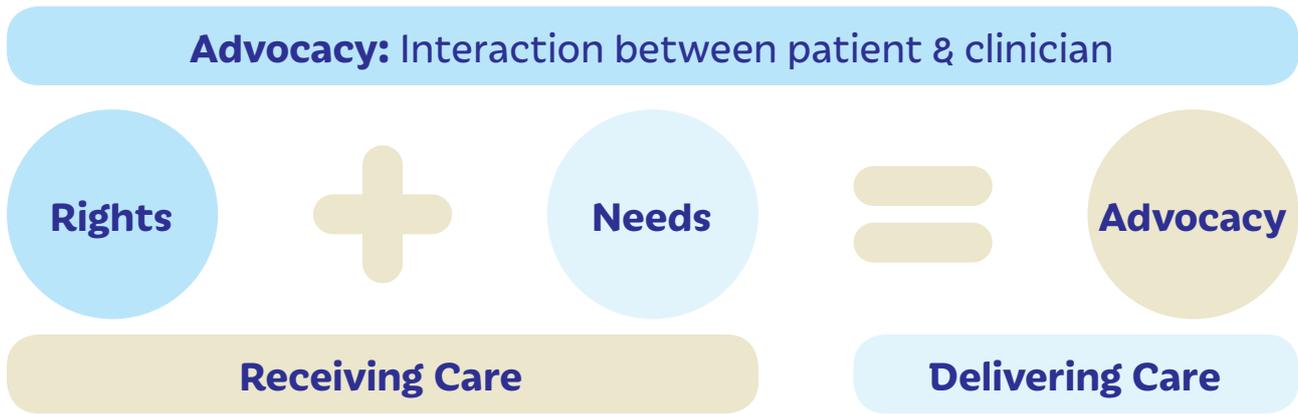
<b>Access</b>	Access services specific to healthcare need
<b>Safety</b>	Delivered professional care, skill, competence
<b>Respect</b>	Culture, beliefs, values, personal characteristics
<b>Communication</b>	Open, timely, in a way it can be understood
<b>Participation</b>	Join in making decisions & choices regarding care planning
<b>Privacy</b>	Maintained & handling information assured
<b>Comment</b>	Comment & complain, Concerns dealt with properly & promptly

Adapted from: *The Australian Healthcare Charter for Patient Rights*<sup>12</sup>

*The concept of advocacy can only work, therefore, when there is a true partnership between patient and clinician.*

Ultimately, we need to address the care that suits the patient best. People with wounds, along with their family or their carer, need advocates. These may include organisations, associations, consumer groups or governments (broader health advocacy), or the family or carer of the person, an independent consultant, the person themselves and the healthcare professional, which is where our role as patient advocates comes in. The clinician as advocate includes nurses, medical and allied health staff, as well as those undertaking research.

Figure 2:



Graphic developed by Wendy White, 2016

**What does advocacy mean in clinical practice for healthcare professions?**

Nursing encompasses the autonomous and collaborative care of individuals of all ages, families, groups and communities, sick or well and in all settings. Nursing includes the promotion of health, prevention of illness, and the care of the ill, disabled and dying people. Advocacy, promotion of a safe environment, research, participation in shaping health policy and in patient and health systems management, and education are also key nursing roles.<sup>13</sup>

A qualitative study by O'Connor and colleagues<sup>14</sup> assessed how different grades of nurses perceived and enacted being an advocate (3 focus groups, n=20). They found that being an advocate meant working as an intermediary between the patient and healthcare environment. Conflict and confrontation was reported by the study participants, which had at times impacted on them both professionally and personally.<sup>14</sup>

Heli Vaartio and colleagues<sup>15</sup> assessed via interview how advocacy was defined by patients experiencing procedural pain (n=22) and nurses (n=21). The authors reported that advocacy was seen as a professional responsibility/active involvement, while supporting patient needs and wishes.<sup>15</sup>

Patient advocacy is not merely the defence of infringements to patients' rights. It is also supporting the wellbeing of the individual: "Nothing about me without me" (Laine & Davidoff 1996).<sup>16</sup>

It is the caring professional providing personalised medicine (tailored therapeutics) that is at the core of health care, recognising the impact on life that chronic disease has, and the importance of meeting the patient's various needs (clinical, spiritual, social, psychological).<sup>17,18</sup>

Figure 3:

Graphic developed by Wendy White, 2016

**CORE BUSINESS OF HEALTH 'CARE' CARING PROFESSIONAL**



## Advocacy by clinicians for those living with wounds

Sibbald and colleagues<sup>19</sup> highlighted the importance of patient-centred wound care relating to wound bed preparation. The consensus document 'Optimising wellbeing in people living with a wound'<sup>3</sup> has helped raise the profile of the importance of the person and the biopsychosocial spiritual/cultural model; recognition of the impact that a chronic wound can have on someone's life is core to this corner of healthcare. Central to this concept in healthcare are caring professionals, who will use tailored therapeutics to assess patient needs, providing quality service and optimising outcomes, but at the same time striving for efficacy and efficiency. In the words of J.M. Bensing "without patient-centeredness, medicine can lose its human face and leave the patient alone amidst medical technology, paper guidelines and statistical figures" – something that we most definitely do not want to happen.<sup>20</sup>

The AAWC conceptual framework of quality systems for wound care summarises this by making the points that care should be respectful of the individual, should be delivered with compassion and empathy, and should be responsive to the individual's needs and rights.<sup>21</sup>

The wounded are vulnerable. They may fail to receive appropriate and timely access to good care, to trained staff, to adequate information or to a response by clinicians that respects their uniqueness as individuals. They may be excluded from choices and/or they may fall short of an equal partnership with those delivering their care. They are vulnerable because we can fail to meet their needs – physical, social, emotional or cultural. This may in turn lead to a negative sense of wellness, which can contribute to negative emotions and clinical outcomes, contributing to on-going difficulties with those around them, including healthcare providers and clinicians.

In a small study<sup>22,23</sup>, the perspective of patients living with a wound was contrasted with that of the treating nurses (n=5 patients; 4 focus groups from the nurse perspective). The patients themselves expressed that there seemed to be little insight into the complexities of living with leg ulceration. They wanted to feel that they mattered, and to have their suffering eased by a sensitive collaboration with their clinicians. From the nurse perspective, their expectations were that patients would follow their instruction, be positive and participate, and that that healing was a priority of care. If the patients endeavoured to self-manage, they were considered 'difficult' or 'uncooperative'. This study demonstrates a real mismatch between the rights and needs of patients living with delayed healing wounds compared to the perception of the clinicians.

### How can we advocate better?

This is the biggest question of all. We need to consider how we can make this concept a functional aspect of a clinician's everyday care, and make this term a lived reality for patients with wounds. As clinicians, if we believe that patients' rights and needs are important, then we need to be willing to do what it takes to incorporate a person-centred approach and be an advocate for our clients and patients. We need to take action to give our patients, not only a voice, but to listen to what they have to say, and having listened, we act – as advocacy is a functioning proposal.

Effective communication is key, which incorporates information gathering, understanding the patient perspective, building relationships and facilitating patient education. Evidence for the benefit of this strategy has been demonstrated in improved patient satisfaction, adherence, and improved outcomes. These are all essential components of good clinical practice.<sup>24,25</sup> It's a shared understanding that is important and integral, and behaviours like eye contact, smiling, gestures and even posture can be so important to the patient.<sup>24</sup>

### Strategies for implementing advocacy

A potential strategy for us as clinicians is to clear our minds for a moment before we see our next patient and put ourselves into a deliberately collaborative mode. For example, our hand hygiene during the transition from one client to another is a good time to begin to get ready to listen. The PEARLS acronym<sup>26</sup> is a useful tool for conceptualising this approach as we interact with patients; as is asking them if they have any other **I**ssues, **C**oncerns and **E**xpectations (ICE).

**Table 3: PEARLS<sup>26</sup>**

<b>Partnership</b>	in this together
<b>Empathy:</b>	expresses understanding of the person
<b>Apology:</b>	acknowledges delay or repeat test
<b>Respect:</b>	acknowledges suffering
<b>Legitimization:</b>	appreciates anger, depression or sadness
<b>Support:</b>	will not abandon

Then when we ask the questions, we need to stop, and listen. One study demonstrated that the average time taken to interrupt a patient is 18 seconds – after this, they will fail to discuss what they intended. But, if left uninterrupted they will reveal their issues, concerns, what is important to them and why they are seeking help, in around 150 seconds.<sup>26</sup>

It has been proposed that clinicians can fail to appreciate the significance of their actions, including poor communication skills, on the lives of their patients.<sup>27</sup> Day-to-day stresses experienced by the clinician can sometimes lead to them underestimating the physical and emotional distress experienced by the patient; this can lead clinicians to detach, label and blame, which impedes their ability to effectively assess and manage.<sup>28</sup> We know that ‘compassion fatigue’ really happens, and as clinicians we need to take care of ourselves, so that we can care effectively for others.<sup>29</sup>

If we fail to care, we will fail to communicate, and if we fail to communicate, we will fail to advocate. We need to acknowledge the significance of our actions on our clients. “Advocacy can open doors to participation. It can right wrongs, change the balance of power, address injustice, improve health services, and alter attitudes and values. It inevitably empowers people in their everyday lives”.<sup>30</sup>

### **Next steps for clinicians as patient advocates**

An important next step is for the universal adoption by healthcare professionals of a patient charter / bill of rights for the wounded. Clinicians must advocate for outcomes that match the unique wellness needs of each individual and promote the importance of ‘care’ and communication as core elements to advocacy. Campaigns to raise awareness of the importance of ‘care of the carer’ - for self and healthcare professionals could enable and empower compassionate and empathetic carers in wound management today and into the future.



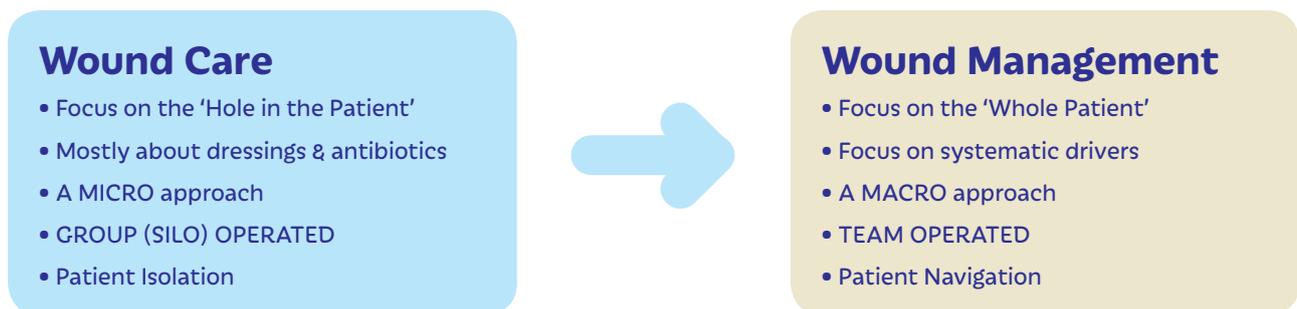
## THE WIDER RESPONSIBILITIES OF THE WOUND CARE CLINICIAN

**Vincent Maida, Associate Professor, University of Toronto; Assistant Clinical Professor, McMaster University, Hamilton; Division of Palliative Medicine, William Osler Health System, Toronto, Canada**

A paradigm shift is required from focusing on **wound care**, consisting of only looking at the 'hole in the patient' and what dressing to apply or fill the wound with, to **wound management**, which focuses on the whole patient. Wound care is mostly about dressings and antibiotics, while wound management also focuses on systemic drivers and chronic disease management. We want to move beyond a silo'd approach to wound care, to true team-working, with collaboration and communication between members, integration in support of patient interests, and advocacy for patients and better outcomes.

**Figure 4:**

### PARADIGM SHIFT



*Developed and provided by Vincent Maida, 2017*

Wounds are a huge problem, which can be considered a global epidemic. In the United States, more than 25 billion dollars are spent annually on wound care, of which 11 billion dollars are spent just on pressure ulcers. It is one of the fastest growing areas for healthcare expenditure, growing at more than 7% per year. This is driven by longer life expectancy, an ageing population, increased prevalence and incidence of diabetes, and long times for wound healing. Specifically, we are often dealing with patients with advanced and incurable illnesses. These patients don't always have a long time left to live, hence the need to set appropriate goals. Chronic wounds are also prone to develop complications, which compounds the whole situation.

There are two main areas that could be seen to perpetuate this epidemic: overdependence on using products and, not unrelated to this, on giving patients antibiotics. Expenditure on wound products and dressings has been increasing by 7% per year. There are more than 700 wound care products available to us. These products can only achieve so much, however, and the priority should be on fixing the patient's systemic issues rather than treating the wound alone. The over-dependence on prescribing antibiotics is truly concerning as in some cases they are being given randomly, with prescription guided by inaccurate culture swab techniques.

#### **A broader approach to wound management**

There is ample evidence to show that professional collaboration works, and has better outcomes for the patient society and healthcare economics. This is also furthered by interprofessional education. The old adage that teams that learn together, work better together is supported by level one evidence from the Cochrane Corporation.<sup>31, 32</sup>

In order to improve the current status quo, we need to change attitudes. Physicians tend to assume that wounds are nursing issues, and they do not really need to bother with them — yet wounds are medical issues because they are being driven by systemic illness. They are often ignored because they are very complex — while they can be malodorous, they can be hard to locate, hard to diagnose without a thorough examination of the patient and, in many cases, remain hard to obtain adequate reimbursement for their management.

Lack of wound care education is also a major problem, with medical schools frequently not devoting any time to wound care instruction. Prognostication is another important area. Wounds tell us about a person's health — that they are compromised, that there are underlying health issues. People don't die from their wounds, but with their wounds, and we should be learning more about these underlying issues.

The case studies below are intended to show some of the pitfalls and challenges in wound diagnosis and treatment from my perspective:

## Case studies

This first case is from my early days of wound care. The patient presented with this terrible looking wound and I took the product-oriented approach — ‘if it’s too dry you wet it, and if it’s too wet you dry it’, and allowed myself to be influenced by word of mouth on the best product. The wound continued to increase in size, and on the patient’s third visit she complained of having a lot of pain, so I had to re-think my strategy. I started asking her some more questions, and found that she was losing weight, with diarrhoea and abdominal pain. On biopsy, the wound turned out to be *pyoderma gangrenosum*, so I referred her to the gastroenterologist who put her on systemic therapies and the wound practically took care of itself. The learning in this case is to start by understanding the full and proper history behind the patient’s condition.

The second case highlights the dangers of over-reliance on antibiotics. A 40-year-old man came into our emergency department with a red leg, diagnosed as cellulitis. The infectious disease doctor gave him seven days of antibiotic therapy. He did not improve, and on day seven the internal medicine specialist called me for a consultation, and asked me what dressings to apply on the small wounds on his legs. I examined the patient and immediately referred him for an emergency MRI, which found a pre-tibial abscess. The case turned out to be secondary cellulitis, not primary cellulitis, and is published in *Advances in Skin and Wound*.<sup>33</sup>

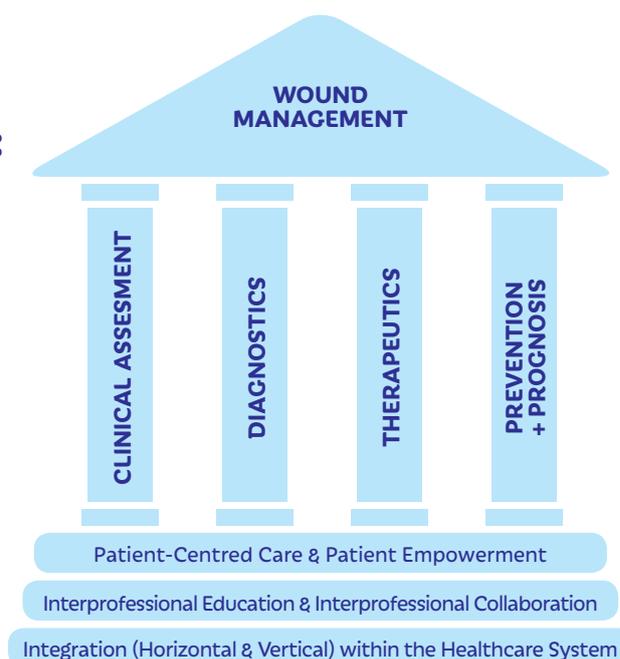
The learning from the third case is to beware of the occurrence of cellulitis, which is frequently misdiagnosed; only 33% of cases are actually cellulitis. This gentleman came in through our emergency department, and was diagnosed with cellulitis and treated with antibiotics. He was seen first by the infectious diseases doctor, then I was called to advise on wound care dressings before discharge. I observed a diabetic ulcer on the plantar surface of his foot, and erythema on top. This patient actually developed compartment syndrome which extended into his interosseous space — this was a septic foot and he had an amputation the following day.

My final case demonstrates that the key to success is getting the location right; always beware of wounds occurring in atypical locations. This patient was 95 years old and went through four different hospitals in the Toronto area for other medical reasons. The wound was not assessed by a physician, but was managed by a number of wound nurses, who applied a variety of different wound care products. The patient was referred to my clinic by her family doctor for a pressure ulcer. When I assessed her the location was wrong, none of the lesions resided over a bony prominence. I biopsied it and squamous cell cancer was diagnosed. This patient died four weeks later.

Our wound management paradigm is completely unsatisfactory. We need to make major changes to the way that we approach wounds. There is currently a tendency to look at antibiotics and wound dressings as the ultimate way of dealing with wounds, but we need to adopt a more comprehensive and MACRO approach to wounds that ensures correct treatments, based on the correct diagnosis. A new paradigm is proposed, consisting of a contextual framework for wound management which looks at different components, all of which need to be covered off comprehensively so that we can ensure the patient is being diagnosed properly.

Figure 5:

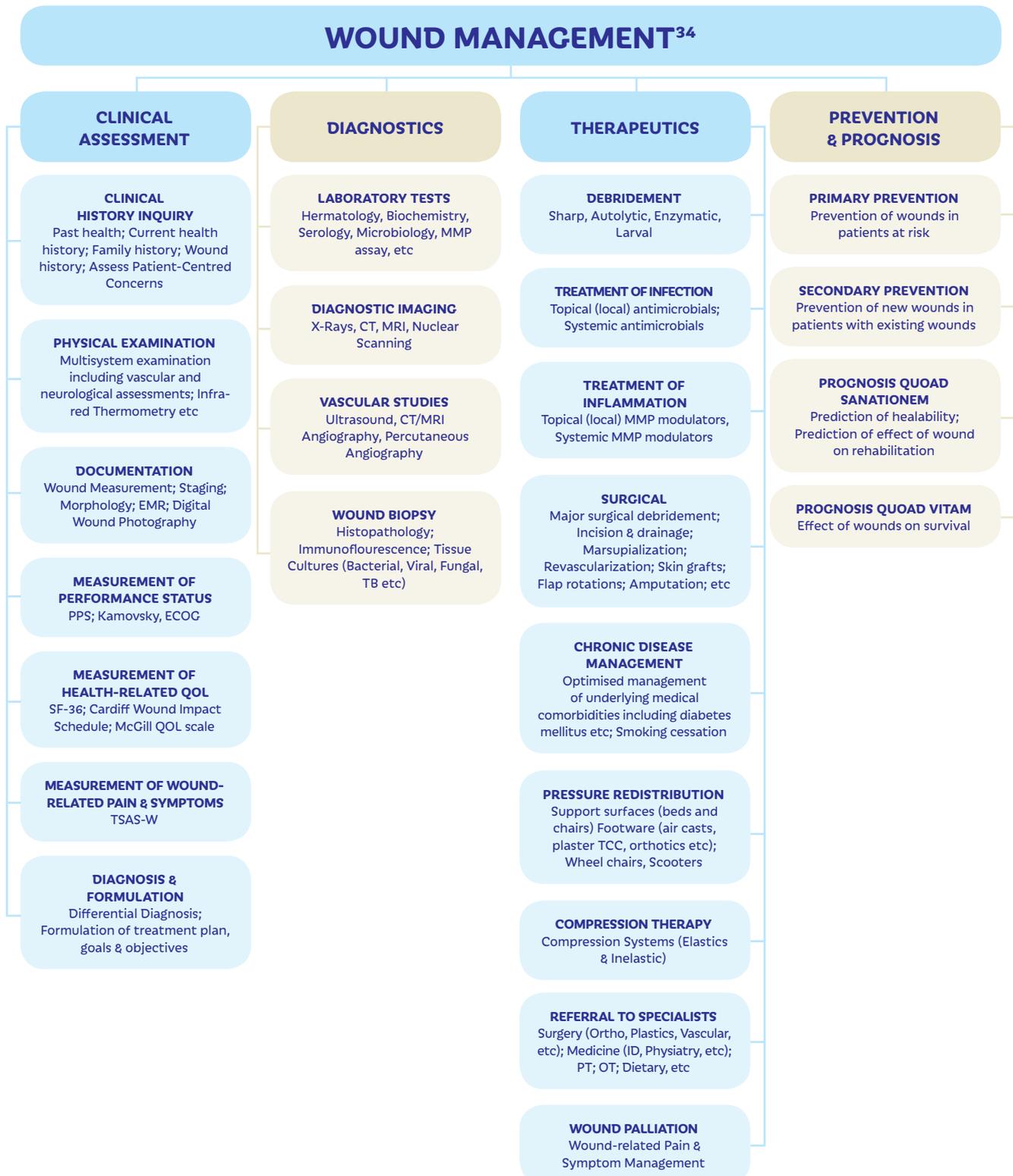
### THE 4 PILLARS OF WOUND MANAGEMENT: A CONCEPTUAL FRAMEWORK<sup>34</sup>



Developed and provided by Dr Vincent Maida, 2011

Clinical assessment should include a proper history and examination, using appropriate assessment tools. We need to gauge if the wound is a healable or non-healable wound. Diagnostics should include all assessments that might be necessary, including: blood work, X-rays, MRIs, wound biopsies, scans, etc. Therapeutics would include antibiotics and wound dressings, but they represent a small part of that pillar, which also includes debridement, offloading, specific consultations, etc. Finally, prevention and prognosis is key. We should be doing everything possible to prevent wounds in the first place, which is the ultimate form of patient advocacy. Further, secondary prevention is also vital, as patients with existing wounds are more likely to develop others. We also need to be able to review and assess the prognostic implications of wounds because our research has demonstrated that wounds are independent prognostic factors for decreased life expectancy.

Figure 6:



Developed and provided by Dr Vincent Maida, 2011

It is impossible to heal all wounds, but it is within our capabilities to ensure that they do not get worse. If we cannot heal a wound completely because a patient is terminally ill, we can at least make sure that their wound causes them the minimum of stress. Wound maintenance can therefore be a successful outcome in wound management; we should be doing everything possible in wound palliation and wound and pain symptom management. Pain is still a big problem for patients and current procedure is not always very effective, partially because the ways that wounds are being managed are still very fragmented. For example, if a patient is seeing a nurse-led wound team they are not likely to get analgesics because nurses can't prescribe opioids and adjuvants. By having a truly comprehensive wound management team with different members in terms of reference, that patient can get access to the best possible treatment plan.

#### Goals of care

- Wound Healing
- Wound Maintenance (Stabilization)
- Wound Palliation (Wound-Related Pain & Symptom Control)
- Wound Prevention (Primary & Secondary)



Wound prevention is a prime endeavour for patient advocacy. We need to change our goals of care to wound maintenance and wound palliation, while trying to prevent new wounds from occurring.

## THROUGH A GLASS DARKLY — REFOCUSING RESEARCH AND DEVELOPMENT TOWARDS THE PATIENT

**Professor Helen Edwards, Assistant Dean (International and Engagement), Faculty of Health Queensland University of Technology, Australia**

The direction and priorities of wound management research will naturally vary according to the funding organisation behind that research. The main groups involved in wound care research are listed below:

### **The clinical researcher**

Clinical researchers work directly with practising clinicians to identify research priorities directly relating to evidence gaps in practice. Work in this area is more likely to focus on different treatments and products, and alternative ways in which they might be used, with wound healing as a priority outcome. Clinical researchers will also be looking for ways to deliver education, training and care more effectively and cost-efficiently.

### **The research clinician**

In their everyday practice, the research clinician assesses patients' wounds to determine the causative and influencing factors, implementing treatment based on the best available evidence. In doing so, they need to be confident that, as the treating clinician, they have the skills and expertise to treat the wound according to current evidence. More importantly, they need to ensure that the patient is consulted and agrees with the proposed treatment plan. Recent developments in evidence-based practice have highlighted the importance of involving patients in their clinical care.

### **The academic researcher**

The aim of the academic researcher is to increase knowledge of wound and evidence based treatments and therapies; to develop research questions and to seek answers which will promote healing. They require clearly-defined research objectives and outcomes that can be accurately measured, to facilitate replication across different settings and with different patients. In addition, they aim to understand how patients and families experience the wound healing process through subjective experiences across the healing trajectory.

### **The commercial researcher**

The aim of the commercial researcher is to develop new products or devices which will appeal to consumers, health professionals, and health care services. They look for new 'break-through' technologies and diagnostics. They need to take market and economic forces into consideration, and to differentiate themselves from competitors.

### **So, what about the patient?**

Although central to research, patients are often excluded from the process and are not asked to participate in development of research protocols or determining research priorities. The priority of clinicians and patients is to achieve and maintain good health. That is critical, and should be our main aim when involving patients in research. Symptom control or management is another priority. We should consider how symptoms are measured and reported by these patients, and how their management will differ, depending on the condition and disease severity. The patient must also be given easy access to appropriate carers and treatments.

Most importantly, patients MUST be able to choose their level of involvement in the research, which we should ensure is appropriate for their wants and needs. Obviously if they are involved in a research trial, then the patient needs to fully understand all the risks and receive full disclosure. Guidance on how research involving the patient should be conducted, and on ethical standards to be met and followed, is provided by government and funding bodies. In certain areas of research, patient involvement is seen as a priority to ensure that appropriate questions are being researched and that any outcomes are acceptable to patients. This is particularly important in the area of wound management.

Research study development and implementation should also therefore include consumer representation, and encompass healed patients and their families, not just patients with active illness.

- The Champions for Skin Integrity Program is an example of consumers being involved in research:<sup>35</sup>
  - Two-year funded national programme
  - The aim: to develop, trial and evaluate a programme to facilitate evidence-based wound management and to decrease prevalence of wounds and improve skin integrity of older adults.
  - The target settings were: long-term residential aged care facilities
- Consumer involvement was central, and included:
  - Focus groups and interviews with residents and their families
  - Identification of their current practices and beliefs
  - Skin/wound care preferences
  - Preferred information delivery methods and format
  - Residents families closely involved in the strategy
  - Feedback given both ways, to residents/families on what was being done/developed, and from residents/families in how these strategies were working for them



A randomized controlled trial of the Leg Club® model of care is another example of patient involvement in research:<sup>36</sup>

- Members from a Leg Club were invited to form a steering group to guide how the Club operated
- Research staff attended the Club every week to interact and listen to ideas and feedback from Club members
- The model was successful, which led to improved healing rates and greater uptake of prevention strategies, leading to uptake in other models and other organisations. Participants provided very positive feedback

Moving forward, research priorities should be directed by consumers themselves. After all, it is the patient/consumer who experiences what it is like to live with a wound. We can learn from them when researching innovations in wound care – what their requirements are, and how they could benefit. The patient can tell us a lot more than we may be able to learn alone. It is therefore vital that we consider the patient's perspective when planning our research, and involve them from an early stage in development of research protocols and processes, enabling them to have frequent input and participation into trials and trial evaluation.

## INITIATING PATIENT ADVOCACY AT THE NATIONAL AND INTERNATIONAL LEVEL

### David Foster PhD, Chair, the Lindsay Leg Club Foundation

The objectives of the Department of Health are to protect and promote health, and to provide safe, effective and efficient care, to lead the health and care system in England to help people live better for longer, with provision of compassionate healthcare services.

The Department of Health, working for Ministers, is accountable to the public and parliament for the nation's health and care. It will ensure that the voice of the public, especially those who use health and care services, shapes all that we do to improve quality of care and help reduce inequalities. It sets direction, securing, allocating and accounting for resources, and supporting the process for legislation and parliamentary accountability; it orchestrates and brokers change working towards relationships that are important to effecting change.

#### Health assessment priorities for 2016–2017:

- Improving out-of-hospital care
- Creating the safest, highest quality healthcare services
- Maintaining and improving performance against core standards while achieving financial balance
- Improving efficiency and productivity of the health and care system
- Preventing ill health and supporting people to live healthier lives
- Supporting research, innovation and growth
- Enabling people and communities to make decisions about their own health and care
- Building and developing the workforce
- Improving services through the use of digital technology, information and transparency



There are, however, differences between what ministers claim as important, what the media claims as important, and what the public wants; these wider public priorities are not necessarily addressed consistently and systematically. Although ministers generally drive the agenda, when it comes to the NHS, the health services generally, and nursing in particular, all those involved come with pre-formed ideas. It is therefore important to help balance what ministers might think with actual evidence-based persuasive arguments.

We should consider, when we refer to people as 'patients', whether we are casting them in a passive, receptive role that doesn't necessarily enable them to act as a partner in the healthcare team. We therefore need to challenge ourselves to think beyond the term 'patient', to consider the individual. The Lindsay Leg Club Foundation, for example, has clubs with 'members', not patients. These clubs provide much more for the members than just leg care; this broader support, the company and friendship that goes with the Leg Club environment, is vital in helping to reduce the social isolation felt by many people with chronic conditions.

Policies around social care talk about voice, choice, and control. *If you have that voice, you have that choice; you can control what is happening to you, which is so important.* Advocacy is therefore a critical patient-centred activity.

Always Events, led by the Institute for Healthcare Improvement (IHI), provides a framework and toolkit to help health care providers identify, develop, and achieve reliability in person—and family-centred care delivery processes. It is currently being tested by NHS England, IHI, providers and commissioners, with staff engaging with patients and carers as partners, not just as token patients. Although in its early days, the aim of the Pioneer Trusts implementing this framework is to have 50% staff and 50% patients/carers in the room when developing their event.

This model has also been included in "Building the right support: A national plan to develop community services and close in-patient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition" (published in October 2015)<sup>37</sup> as a key way for the transforming care partnerships to demonstrate the responsiveness and accountability of services. It is really important that this national perspective is evaluated with evidence to make sure that advocacy is a key part of these processes as they develop and are implemented.

Considerable challenges remain. For example, the Code of the Nursing and Midwifery Council in the UK states professional standards that registered nurses and midwives must uphold. It has four themes (NMC).<sup>38</sup>

**The code of the Nursing and Midwifery Council in the UK is structured around the following:**

- Prioritise people
- Practise effectively
- Preserve safety
- Promote professionalism and trust



All of these are important in relation to the concept of advocacy, but the Code itself does not talk directly about advocacy. To address this, we need to strengthen international links and discussions, to form relationships. We have the WHO and the World Union Wound Healing Society to help us, and other professional associations, such as the Royal College of Nursing and the International Council of Nurses. We have a great deal to learn from the synergism between people in other countries, and from other healthcare organisations, and we need to apply these learnings to improve patient-centred care and also move towards person-centred care.

## CONCLUSION

Chronic wounds have a long-term impact on patient's lives, as well as creating considerable expense for healthcare systems. Yet patient-centred care has not historically been a research priority, and the evidence for patient-centred outcomes has been poorly recorded, or not really reported at all. Wound care is inter-disciplinary, and patients are often failed by the complexity of a system where a variety of different services may be involved in a patient's treatment journey, increasing the risk of communication or treatment failure.

Many of us have already been advocates for people we are close to, and will probably need our own advocates in the future, but we can't be confident that the structures for patient advocacy and empowerment currently exist, or will do so in the future. Action is therefore needed—not just to assess the current concept and status of patient advocacy in wound care, as this document has done, but to develop and promote an international consensus on a patient-centred approach for wound care.

So, where should this begin? The core concept of patient-centred care and its application to wound care is that we are looking at the whole person, not just the wound. We must remember to consider the care needs of the individual patient, using a collaborative approach between the various specialised treatment teams. While the Wound care patient's Bill of Rights is an excellent start, we need to progress this concept to develop a comprehensive approach, in which we consider the patient as an equal participant in their care. Patient-centred care should allow patients and their families to have sufficient information to enable them to play an active part in their treatment, providing transparency in information-sharing with the patient and facilitating their input. Continuity of care should be standard, and patients should always be treated with dignity, and acknowledged as partners in the care team. After all, the patient is the one that has to live with their condition.

Effective communication is key, not just between health care provider and patient, but within the wider multidisciplinary team. Education is also vital, ensuring that not just wound care specialists, but the wider health team are engaged with the concept of patient-centricity. As clinicians, we need to be willing to do what it takes to incorporate a person-centred approach and be an advocate for our clients and patients. We need to give our patients a voice, be prepared to listen to what they have to say, and to act on this. We need to develop guidance and procedures that make this concept a functional aspect of a clinician's everyday care, so that patients with wounds receive the support and advocacy that they need. We also need to ensure that the patient perspective is a fundamental part of our research priorities; that we learn from the patient how their needs and experiences can shape innovations in wound care, to ensure that these innovations benefit them.

Finally, language and terminology are a vital part of a patient-centred approach; do we want to continue to use the term 'patients'? Is this casting them in a passive/receptive role, which does not align with the role that we hope to give them—as active participants in the care team? Moving forward, we need to challenge ourselves as practitioners—to think beyond the term 'patient', to stop viewing our consumers as passive recipients of our advice, but to view them as individuals who have an important voice in their own care pathway.

So, what next? We need to develop/define a universally adopted charter of patient rights which can be broadly used across wound care. It should promote care and communication as being core to advocacy, while also helping us as practitioners to care for each other and for ourselves. It should incorporate specific language and concepts applicable to wound/skin care. We need to work together to promote and endorse this charter globally, to enable us to effectively advocate for outcomes that match the rights and wellness needs of the individual patient.

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