

OPTIMISING WELLBEING IN PEOPLE LIVING WITH A WOUND



an expert working group review

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FOREWORD

In February 2011 a group of wound care health professionals and researchers met in Cape Town, South Africa to establish a framework that would help to ensure that clinicians are able to maximise patient wellbeing when delivering effective wound care. The meeting was not concerned simply with the quality of the treatment of individual wounds, but rather the human cost of living with a wound and the role of clinicians, industry and organisations in addressing patient wellbeing¹.

This was followed up by a consensus meeting in May 2011 in Brussels, Belgium, which was attended by key experts from Europe, the USA and Australia, providing a diverse range of experience and backgrounds, including medical, nursing, allied health professions and industry researchers. Following the consensus meeting, a draft document was produced, which underwent extensive review by the expert working group. Additional international experts were also consulted to reflect practice across different geographies. It culminated in consensus on all statements as indicated by sign off from each member of the expert working group.

In October 2011, a workshop was held with two service user groups at the University of Leeds in the UK. The aim of the workshop was to gain insight into the impact of living with a wound on patients, their carers and family members. Members of the Pressure Ulcer Research Service User Network (PURSUN UK) and the Bradford Wound Care Group discussed their personal experiences and went on to contribute to the text review process. Their quotes are used to illustrate points throughout this document.

This document aims to:

- increase stakeholders' understanding of the impact of living with a wound on the wellbeing of individuals and their carers
- improve clinicians' ability to share decisions about treatment with individuals and their carers to help improve concordance and reduce complications
- emphasise importance of good listening skills and highlight ways to enter into a dialogue about wellbeing
- increase stakeholders' ability to implement strategies for cost-effective wound management that optimises wellbeing and involves all key stakeholders.

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Optimising wellbeing in people living with a wound

Although health care has increasingly become patient-centred, clinicians, healthcare organisations and industry all have important roles in ensuring that care is delivered effectively and takes account of the complex needs of individuals living with a wound¹.

WHY IS WELLBEING IMPORTANT?

The impact of living with a wound is complex and multifactorial. Clinicians, industry and healthcare organisations often focus on wound healing as a key outcome measure. Clinicians measure and record data about the wound, such as the reduction in size and depth, and appearance of the wound bed; healthcare organisations may request prevalence and incidence figures for different patient populations and wound types; and industry researchers often focus on the properties of an individual dressing, such as its antimicrobial efficacy or fluid handling properties.

While these are all important elements, many people living with a wound may focus on different priorities such as reducing the pain or odour, covering up unsightly strikethrough or concerns about wearing bulky dressings that prevent them from wearing items of clothing or shoes, or performing daily activities.



People 'at risk' of or those living with a wound face major changes in their everyday lives and need to integrate a number of treatment-related procedures that may be difficult to adopt long term and conflict with existing lifestyles, priorities and behaviours

“
The morning routine takes two hours every day before breakfast. It's hard work ”

While the physical aspects of a wound can be measured with various tools, the concept of 'wellbeing' is more difficult to capture. In those living with a wound, wellbeing may be adversely affected by chronicity (ie where the wound is slow to heal or recurs)², while people with a healed ulcer may also have a poorer quality of life compared with the general population³. The later may be related to high recurrence rates and/or the need for lifelong treatment measures (eg compression therapy)³.

It is recognised that psychosocial factors, such as anxiety and depression are associated with delayed healing of wounds⁴⁻⁶, while poor symptom management can cause patients to become non-concordant with therapy⁷⁻⁹. There is now strong evidence which shows that where individual patients are actively involved in their care, outcomes improve¹⁰. This requires empowering people to take charge of their own health and to have a greater choice and control over the services they use. In addition, easy access to care and referral to clinicians with up-to-date knowledge, skills and resources is vital for early diagnosis, prompt initiation of appropriate treatment and avoidance of complications².



Improving health and wellbeing is increasingly thought to be linked to economic and social benefits¹¹

A definition of wellbeing in relation to wound management was agreed by the consensus group (Box 1).

BOX 1 Wellbeing in relation to wound management

Wellbeing is a dynamic matrix of factors, including physical, social, psychological and spiritual. The concept of wellbeing is inherently individual, will vary over time, is influenced by culture and context, and is independent of wound type, duration or care setting. Within wound healing, optimising an individual's wellbeing will be the result of collaboration and interactions between clinicians, patients, their families and carers, the healthcare system and industry. The ultimate goals are to optimise wellbeing, improve or heal the wound, alleviate/manage symptoms and ensure all parties are fully engaged in this process.

Factors affecting wellbeing

DOMAINS OF WELLBEING

Health refers to the general condition of a person, usually meaning to be free from illness, injury or pain. The World Health Organization first defined health in 1948 as 'a state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity'¹². This definition continues to influence policy and is typically linked to three inter-related domains of wellbeing:

- **Physical wellbeing:** the ability to function independently in activities such as bathing, dressing, eating, and moving around
- **Mental wellbeing:** this implies that cognitive faculties are intact and that the patient is free from fear, anxiety, stress, depression, or other negative emotions
- **Social wellbeing:** the ability to participate in and engage with family, society, friends, and workers¹.

In addition, the consensus group agreed to a fourth domain to broaden the definition of wellbeing:

- **Spiritual/cultural wellbeing:** an ability to experience and integrate meaning and purpose in life through connections with one's self and others. This is an integral part of mental, emotional and physical health and may be associated with a specific religion, cultural beliefs or personal values.

“
As soon as the skin becomes red or broken it can be very frightening. Life stops”

Physical wellbeing

The physical parameters involved in a wound include direct factors such as its size, depth, location and duration². Other physical parameters that are indirectly linked to the state of the wound include odour, pain/irritation and leakage caused by excessive or mismanaged levels of exudate². These factors can lead to:

- **Reduced mobility**, eg inability to climb stairs, walk or use public transport
- **Avoidance of social contact**, eg due to poor exudate control¹³
- **Poor nutrition**, eg worsening obesity due to immobility or lack of appetite due to depression
- **Sleep disturbance and fatigue**, eg due to pain at night².

Data from international focus groups have consistently identified pain as one of the symptoms that people with chronic wounds find particularly distressing¹⁴⁻¹⁶. Odour and excessive exudate associated with leakage can also act as a constant physical reminder of the wound and can lead to feelings of disgust, self-loathing and low self-esteem¹⁷.

Although healing is the primary objective in the care of the majority of people with wounds, for malignant or non-healing wounds, healing may not be as important as managing the physical symptoms. In such cases, it may be appropriate to consider the overall wellbeing of the individual as an equally important outcome as wound healing.

In addition, people who have a chronic wound often have other conditions that affect their ability to function independently, which may lead to greater dependence on others, unplanned admission to hospital and/or the need to adapt their living arrangements to self-manage their condition at home.



It is important that clinicians look for existing capabilities and work with patients to help support them in their everyday activities

“
It is very easy to get depressed and isolated”

Psychological wellbeing

Living with a chronic wound is often associated with increased anxiety and poor quality of life^{5,7,18} (see Box 2). Cole-King and Harding⁴ found a significant correlation between anxiety and depression and delayed healing in patients with a venous leg ulcer. Further research has shown that depression may precede the wound or be a reaction to the wound (eg due to pain and odour) and delayed healing^{17,19}. Depression may also be a precursor to self-neglect, disturbed sleep and poor nutrition, which can impact negatively on wound healing⁴.

BOX 2 Associated psychological issues of living with a wound

- Anxiety/depression
- Fear (eg of further trauma/infection)
- Altered or poor body image and low self-esteem
- Feeling unclean
- Anger/frustration - 'why me'?
- Stigma (eg reaction of others)
- Embarrassment
- Loneliness and social isolation
- Guilt (eg difficulty with being concordant with therapy)

“ It (the wound) can take over your life. From not understanding it as a young man, to not being able to swim or socialise. You can't wear shorts in the summer. It's lots of little things like not being able to see friends, go swimming or run around the garden with the grandchildren ”

The psychological impact of living with a wound may be particularly difficult for the individual to discuss. People who live with a wound over a long period of time can lose confidence and hope, seeking to protect themselves by developing social defenses, retreating from contact with others²⁰ or hiding the true extent of their problems²¹. Some may be in denial of the problems associated with living with a wound²², while others may express anger about the wound itself — 'why me' — and about the therapies they are prescribed¹³.

People often become frustrated that their wound will never heal²³ and is 'forever healing'²⁴, or be extremely fearful of their wound deteriorating. Breakdown of the skin can lead to feelings of guilt and frustration, especially if the person has done everything right — making them feel even more powerless, leading to greater dependence on clinicians and others²⁵. Friends and family can provide great comfort and strength by helping the person to maintain a positive outlook and supporting them in their daily activities.

Social wellbeing

People living with a wound can spend many hours in bed or sitting with little to do. This may lead to social isolation and depression with fewer opportunities for social interaction through recreation or work¹⁵. Many people may need to balance their social world with the need to cope with potentially embarrassing aspects of living with a wound such as odour and strikethrough as well as the physical factors such as pain and reduced mobility, or psychological issues such as depression. In addition, individuals who are unable to work due to their wound, often feel a loss of role within the family and find it difficult to cope financially²⁶.

Living with a chronic wound can be extremely disruptive and many individuals find it difficult to organise their daily routines around their wound care. This may lead to a feeling of being unable to live their lives as they wish²⁵ and to 'a struggle for control and independence'²⁷. It is important for clinicians to encourage self confidence and support patients with chronic wounds to self-manage at home. This can be an extremely positive experience for individuals, although it can place a large emotional and financial burden on carers and family members and their needs should be considered when making decisions about care²⁸.

People's ability to manage their wound will vary and some may not feel a sense of ownership of their condition and will be less vigilant in preventing recurrences²⁴. Some people may be more dependent on others (eg live in a nursing home or are confined to bed) and may welcome the involvement of the healthcare team, feeling that there is a strong link between the advice of the clinician and their wellbeing²⁵.

Spiritual/cultural wellbeing

There is a lack of information on the way in which spiritual and cultural issues influence wound management choices and practices. How individuals perceive their wound and expectations around healing may be related their level of health knowledge, literary skills and belief system. The influence of such beliefs, which may have been handed down through different generations, may be in direct conflict with clinicians' advice and lead to a failure to adopt appropriate treatments²².

Clinicians need to recognise and endeavour to understand peoples' beliefs, religious sensitivities and cultural backgrounds and involve patients in decisions rather than imposing them. This may include avoiding clinic appointments during religious festivals, seeking patients' permission to incorporate treatments that have been manufactured using animal products²⁹ and helping people to overcome the belief that certain treatments are ineffective²². Similarly, clinicians should recognise that people have a right to refuse treatments or want to use alternative therapies.

LOOKING BEYOND THE FOUR DOMAINS OF WELLBEING

To further understand how people live with a wound and how this affects their everyday lives, 7bn, a UK-based agency set out to gain an insight into human behaviour (including patients and clinicians as well as industry and healthcare services) around wound management.

There were 13 participants from London, UK and Georgia, USA, who had a variety of diabetic, vascular and undiagnosed chronic ulcers. The team used an ethnographic approach to understand the everyday lives of those living with a wound. This involved a pair of researchers spending four hours with each participant in his/her home. The topics covered included everyday wound management routines and focused on factors that influence quality of life, such as hobbies or social engagements, the impact of chronic wound care, clinical practices, family life, the local community and support networks. This information was recorded using observational techniques, film and photography.

As well as the in-home work, the team visited two Georgia (USA) nursing homes and held group sessions with 12 clinicians to explore their attitudes to concordance and wellbeing.

Examples of how a chronic wound affected the daily lives of people captured by this research, included:

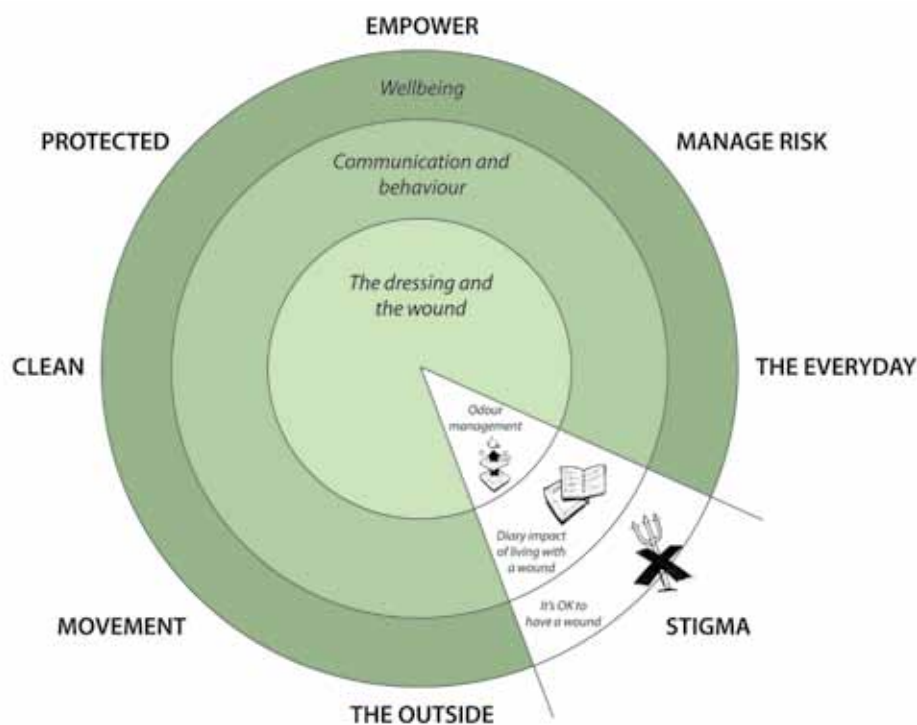
- A retired gentleman in his sixties, who 'lived for his cricket', complained of being unable to continue his hobby as a cricket umpire due to worsening of his ulcers after long periods of standing (eg umpiring for six hours).
- A woman with a chronic ulcer was prevented from playing badminton due to difficulty in finding a dressing to manage the high levels of exudate. This led to weight gain, a reduction in her ability to meet with her friends and increased depression.
- A paraplegic male developed a pressure ulcer due to friction and increased moisture (sweat) following a recent house move. This caused extreme frustration, embarrassment and feelings of being dirty.
- A woman with a venous ulcer used the internet to learn more about her condition and has become the local expert in dressing changes.
- A young male with a chronic vascular condition was unable to visit the local shops without extreme embarrassment due to the odour from his wound. This had prevented him from attending university and restricted his social activities.

From this research a set of eight principles were identified that encapsulated all elements of the patients' wound management experience:

- **Empowerment:** a person's need to take control of the physical, psychological and emotional elements of wound care
- **Management of risk:** a person's use of certain behaviours surrounding his/her wound management (eg the weighing up of certain activities and the level of risk attached to them)
- **The everyday:** the 24/7 impact of wound management on the patient's everyday living
- **Stigma:** how the responses of other people can affect those living with a wound
- **The outside:** the appearance of dressings and products
- **Movement:** how a person's activities 'fit' with the wound dressings used
- **Cleanliness:** the person's requirement for cleanliness may conflict with the need to keep dressings in place for up to seven days.
- **Protection:** the role of dressings and wound management products to protect the body from physical damage and infection.

These eight principles were then applied to a three-ring model for wellbeing in relation to wound care (Figure 1).

FIGURE 1 An innovation model that aims to provide solutions to common wound management issues using the eight principles identified as being important to people living with a wound (courtesy of 7bn: <http://www.7bn.co.uk>)



Service user/carer involvement

This work is supported by service users and carers involved in developing this document. For many of these individuals, there was a feeling of a constant invasion of privacy and a fear of the wound recurring, becoming infected or of 'being knocked'. Spending time with family or friends, going for a drive or walk and keeping busy through hobbies (such as gardening, listening to music or reading) were all deemed important in providing a sense of wellbeing and guarding against feelings of isolation and depression.

Many talked of the need to have control over their lives, even if this involved doing simple things like tidying the house or taking photographs of their wounds to keep up to date with their progress. Having access to the right equipment and products that fitted with their lifestyle was also important in helping patients to manage their wounds at home, while limited access to appropriate hospital care and equipment (eg pressure redistribution mattresses) was often a frustration.

Developing a shared approach

All of the research and opinion gathered for this document demonstrates the wide-ranging needs of people living with a wound and emphasises the need for a shared approach to optimise wellbeing. Such an approach will require clinicians, healthcare organisations and industry to:

- Work with individuals living with a wound to identify and address their concerns
- Engender concordance through empowerment and choice
- Implement an effective treatment plan through shared decision-making with individuals living with a wound.



What people want is control over their own situation. Self-management and shared decision making are key outcomes of empowerment³⁰

Assessing and measuring quality of life and wellbeing

BOX 3 Using TELER for clinical notetaking

TELER is a system of clinical data collection that incorporates HRQoL domains and has been adapted to measure patients' experiences of the impact of wounds and wound-related issues. It has two main elements — clinical note-making and clinical measurement. This allows the clinician to assess the pattern of change, or lack of, in an individual patient's condition as well as specific parameters of a dressing (eg dressing performance and symptom management) to define optimal care⁴³.

“ It is important to find out what people like doing when they are well and to see if this can still be done or find ways of helping the person to achieve this ”

TOOLS TO MEASURE HEALTH-RELATED QUALITY OF LIFE

Health-related quality of life (HRQoL) measures are used in health care to inform clinical decision-making and policy-making decisions. HRQoL incorporates physical and functional status, emotional status, and social functioning, and may be assessed using generic or disease or condition-specific instruments:

- **Generic HRQoL tools** such as the Nottingham Health Profile, EuroQoL-5 and Short Form-36³¹.
- **Condition-specific HRQoL tools** such as Charing Cross Venous Leg Ulcer Questionnaire³¹, the Cardiff Wound Impact Schedule³² and The Freiburg Life Quality Assessment, which has been validated for all types of acute and chronic wounds, including hard-to-heal wounds³³. Condition-specific tools may be supplemented by tools to evaluate any wound care interventions and benefits to patients (eg PBI-w³⁴ and the Treatment Evaluation of Le Roux's (TELER®) method (Box 3).

In addition, there are simple tools to capture patient experiences, including the Measure Yourself Medical Outcome Profile (MYMOP)³⁵, which can be self-administered; the Schedule for the Evaluation of Individual Quality of Life – Direct Weighting (SEIQoL-DDW)³⁶; and the Patient Generated Index (PGI)³⁷.

Clinicians can also make use of everyday instruments to assess the patient's pain experience (eg Visual Analogue Scale; short form McGill Pain Questionnaire³⁸), as well as the level of anxiety and depression (eg Hospital and Anxiety Depression Scale³⁹).

Much of the research has focused on patients with chronic venous leg ulcers^{23,40,41} and the importance of pain management. However, recent work has also highlighted the impact of living with a diabetic foot ulcer⁴² and pressure ulcer²⁷ on quality of life and wellbeing.

While HRQoL instruments provide quantitative information, they are designed to look at deficits in functioning and may not capture what people think and feel about living with a wound⁴¹. Wellbeing is subjective, fluctuates over time, and is typically difficult to measure. Focus, therefore, needs to be placed on self-reporting and observational methods to enable processes that support individuals living with a wound to help them achieve their potential and increase their overall satisfaction with life.

ASSESSMENT OF WELLBEING

It is important for clinicians to view the patient 'as a person' and to focus on their individual experiences — the goal is to have as complete an insight as possible into the person's medical condition, quality of life and how his/her wound impacts on all aspects of everyday living.



Questions about wellbeing should not replace a full assessment of the patient's medical condition or the use of diagnostic tests and these remain paramount

Building a therapeutic relationship

The consensus group discussed fostering an atmosphere of competency, caring, commitment and compassion when engaging with patients and how clinicians need to build a relationship that is equitable and based on trust. To achieve this, clinicians should:

- **Be fully focused** on the person during each interaction
- **Avoid distractions** eg switch off mobile phone
- **Ask questions** to understand the person's current wound experience better
- **Avoid interrupting** in the first 60 seconds of the consultation, or directing the person's comments

- **Consider how the person may react** to what is being asked
- **Observe** the person and **listen** attentively
- **Record any observations** for example, that he or she seems anxious; or that he or she was limping slightly when entering the room
- **Provide a time frame** for any interview or discussion — ‘This will only take a couple of minutes’
- **Be aware of cultural differences** and be sensitive to spiritual needs of patients
- **Build up information over several visits** — continuity of care is important to distinguish any wellbeing information from the initial discussion, which will include diagnosis and past medical history, and then follow this up
- **Avoid professional defensiveness/labeling**, for example, if the person says she is nervous because has had bad experiences with clinicians in the past, it is important not to take this personally or begin to view them as ‘difficult’. So-called difficult patients are regularly blamed for non-healing, but this can be a reflection of the way they are being viewed by clinicians rather than their actual wound status.



Interpersonal skills are important, particularly in chronic conditions where it is important for the clinician to develop and maintain a relationship with that person. This includes being honest about the severity of the wound and limitations of their knowledge as this helps to build trust

Ensuring empowerment and choice

Clinicians need to listen to individuals to gain their confidence and trust, and explain to them what they are doing and with empathy⁴⁴. Improved communication should lead to a partnership in which the person feels empowered to discuss any treatment options or concerns, while the clinician can offer information to help them judge the benefits of those choices⁴⁴.

A recent report has shown that informed choice about one's care is highly valued by individuals, especially among the elderly⁴⁵. In addition, the quality of the relationship between the patient and the healthcare professional can impact positively on treatment outcomes, by improving their ability to self-manage and level of concordance⁴⁶⁻⁴⁸.



Knowing what is available, being able to say what they want, being listened to and taking part in decisions about their care are the things that really matter to patients

Timing of assessments for wellbeing

As well as setting aside specific time during patient visits to ask questions, it is also possible for any member of the multidisciplinary team to assess wellbeing while performing routine clinical tasks, either during home visits or clinic appointments.

Taking observations such as blood pressure is the perfect time to check a person's muscle tone and mobility. Also, while performing the basic tenets of nursing care, such as washing or bathing patients, nurses can check personal hygiene levels and weight loss, as well as skin changes, perfusion etc. This can also provide an opportunity for informal conversations, which may help reveal how the person is feeling.

When assessing patients, it is important to create a non-stressful environment in which they feel safe and comfortable and this may vary for different people. For example, some patients may prefer to have an initial consultation in a separate room or office, making interruptions unlikely and giving them permission to talk about themselves frankly, while others may prefer a more social environment in which concerns are shared.



In considering which questions to ask, it is important to keep it simple

Developing tools for wellbeing

A person's perspective on his/her illness and care can help clinicians understand individual experiences of living with difficult and frequently painful wounds. Nurses in particular can play a critical role in listening to individuals and using the information provided to optimise care⁴⁹.

There is a need to develop simple tools to enable individuals to discuss their wellbeing in relation to their wound and any particular concerns they may have. Tools should be dynamic to allow people to recalibrate their views in accordance to their shifting priorities as they progress along the treatment journey.



Tools to elicit information on wellbeing need to be practical, easy to use and able to be adapted for any clinical setting or patient interaction

Trigger questions to assess wellbeing

How clinicians elicit this information will be dependent on where the individual is seen. For example, it may be easier to pick up clues from the person's home environment, while for those who are followed up in the clinic, a simple questionnaire on a card, to be completed in the waiting room, can provide a useful prompt for conversation, helping to draw out more reserved individuals, and allowing them time to organise their responses before they see the clinician. Box 4 below offers sample questions that may be used to initiate discussion on wellbeing.

BOX 4 Example trigger questions for wellbeing

1. Has your wound improved or got worse? Please describe. If new, how did it happen?
2. Has your wound stopped you from doing things in the last week? If so, what?
3. What causes you the most disturbance/distress and when does this occur?
4. Do you have anyone to help you cope with your wound?
5. What would help to ease/improve your daily experience of living with a wound?



When questioning patients this should be done in an open rather than prescriptive manner and clinicians need to 'connect' with patients, rather than simply fill in a checklist

Understanding how a person's wound changes over time

Information will be time dependent and change over time. It is therefore important to adapt the questions to understand how the person's life is affected at the different times of the day (Figure 2).

FIGURE 2 How does your wound affect you at different times of the day?⁵¹

A review of daily routines can be monitored on a regular basis to check progress and can be supported by validated tools to monitor specific problems such as pain^{38,50}. Any changes can provide important feedback that can be used to implement appropriate strategies to manage symptoms more effectively or persuade individuals of positive trends.

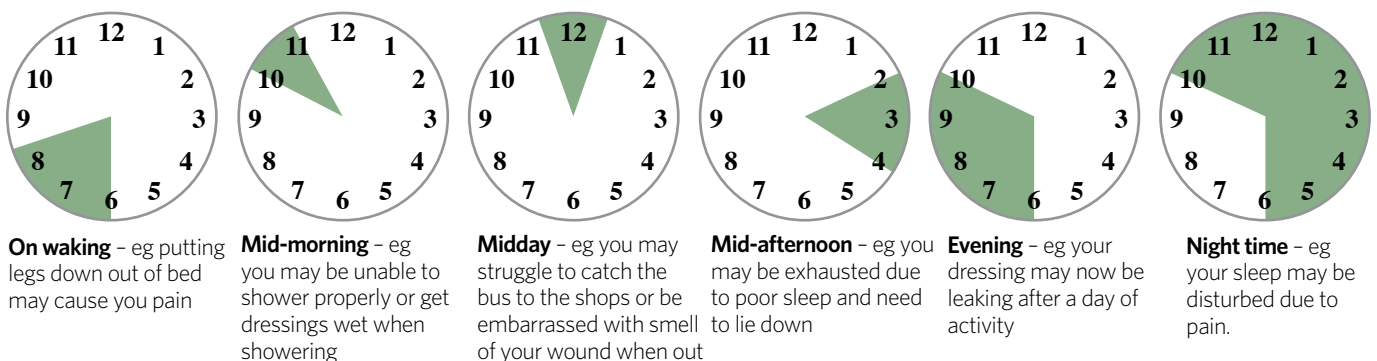


FIGURE 3 An example of a patient diary showing one day only. The entry should take no more than five minutes to complete, although patients may wish to take longer to express their thoughts and feelings completely and prefer a more unstructured, narrative or 'stream of consciousness' approach. The use of photographs is also important in tracking progress and can help to initiate discussion at the next visit. For further information on patient diaries, go to the Scottish Health Council: <http://tinyurl.com/799gydy>

DAY 1 What has been the best thing that has happened to you today?

How would you describe how your wound has impacted on your day?

What has been the worst thing that has happened to you today?

Please take a photo of your dressing (or get someone else to take one if it is not accessible to you)

Has your dressing been changed today? Yes / No

If dressing has been changed:

How long did it take?

Did someone change it for you?

Day 1

Day 1

Day 1 photograph of dressing.
- researcher will collect the photograph and attach here.

If your dressing was changed today how did you feel during the process?

How do you feel after the process?

Day 1

Day 1

For a more personalised, detailed account over time, **patient diaries** can be used to communicate qualitative information about a person's experiences of living with a wound. These self-reported accounts may be particularly useful for those who are in contact with several services or staff (Figure 3).



Different people will feel comfortable with different forms of communication. It may be useful to have a range of tools available to help with this

“ It is very easy to be labelled as non-concordant if you disagree with the clinician. Advice needs to be practical and balanced — it is difficult to sit in a chair all day with legs raised ”

Ongoing assessment

Information about wellbeing should be documented in a clear way and used for follow up. Questions will need to become more individualised over time with a focus on specific concerns that affect wellbeing. For example, this may allow the clinician to monitor the patient's sleeping patterns, the level of pain and ability to use aids for everyday living. Ongoing discussion will provide important clues about when things change and help to inform the management plan to ensure it reflects the current situation and patient concerns.

Many people living with a chronic wound may interact with many different healthcare professionals over a prolonged period of time (eg nurses, surgeons, physiotherapists, psychologists and nutritionists). This may mean that some individuals and their carers will need to provide the same information many times, which may be distressing or become a source of frustration. It is important that any assessment is documented and, where possible, shared between the multidisciplinary team to ensure continuity of care and avoiding unnecessary changes to the treatment regimen by different members of staff.

BARRIERS TO ASSESSMENT

There may be a number of obstacles to obtaining this important information, such as the ability of individuals to access services, rushed clinic times or lack of privacy as well as the lack of a common documentation system for all professionals involved in the care of people with a chronic wound.

Similarly, many individuals avoid discussing their wellbeing for fear of 'bothering' clinicians, or worry that clinicians may judge them. In addition, clinicians should consider the ability of people to convey information both verbally and in writing. It is therefore important for clinicians to engage with family members and carers, who play a key role in the day-to-day management of the person living with a wound, especially for those who are not able to communicate, such as the frail elderly or cognitively impaired.

However, clinicians' day-to-day exposure to physical and emotional distress can lead to reduced sensitivity or 'blunting', causing them to underestimate an individual's experience of pain, for example. They may feel impotent and become overwhelmed or anxious when dealing with the expectations of their patients and family members²². This may mean that patients' goals differ from what the clinician believes is best for that person. This can lead to detachment, impeding the clinician's ability to correctly assess and promote behaviour change.



There may be a 'gulf' between what individuals say they want and what clinicians believe should be provided⁵².

Case Report: from 'ill-health' to wellbeing

The following case report, based on the experiences of one of the members of the expert working group, highlights the importance of accurate assessment and how an incorrect diagnosis or failure to diagnose a non-healing wound can impact on a patient's wellbeing

This 72-year-old man lives on an island in western Sweden. Over the past 12 years he had developed bilateral, circumferential wounds, which completely covered both lower limbs and caused him unbearable pain. The wounds had to be dressed more or less continuously by his wife as well as once a day by a community nurse. There was no confirmed diagnosis, although it was assumed that the wounds were venous leg ulcers. The man had lost approximately 15kg of weight during the 12-year period and was wheelchair-bound. Overall, he had very poor wellbeing and his circumstances also influenced his wife's quality of life as she had to be constantly available to change dressings.

When a wound specialist nurse, who was also a stomatherapist (stomal therapist/ET nurse), visited him when the community nurse was on holiday, his first reaction was that the wounds were not venous leg ulcers. He noticed the man's anorectic appearance, as well as his pained expression, and decided to admit him to the department of colorectal surgery at the region's university hospital. Following assessment the man was diagnosed with ulcerative colitis. The patient was provided with medication and intensive nutrition therapy and has now gained weight. He is also able to stand without needing the wheelchair. The wounds were finally diagnosed as pyoderma gangrenosum and appropriate treatment was commenced, which led to healing within eight weeks, dramatically improving the wellbeing of the patient and his wife.

Optimising wellbeing for effective wound management

To ensure that wellbeing is the principal focus of care, there is a need to develop strategies that make the delivery of healthcare more efficient and time responsive to the needs of people living with a wound. Good outcomes depend as much on good self-management as good medical care. Empowerment and education are key in delivering effective wound management, with an emphasis on patient-centred care⁴⁸.



Establishing patients' preferences for information and participation in their care is the first step in creating a successful partnership, which can lead to improved satisfaction with care and better outcomes

Education about why a wound has developed and how certain treatment decisions are made can help to address individual worries and manage expectations. This can be further supported by patient information leaflets and educational resources. In general terms, individuals are far more likely to be concordant with a treatment if they understand it and will usually accept strategies that are broadly consistent with their own background and beliefs⁵³.

People should be offered services that are safe, easy to access and responsive to individual needs. This may include the provision of drop-in centres or flexible clinic times. Some people derive support and encouragement from sharing their experiences with a group of people with similar wound problems. Social models of care such as the Lindsay Leg Club[®] (see Box 5) have been shown to improve the health and wellbeing of clients who have chronic leg ulcers⁵⁴. By removing the stigma attached to living with a wound, such clubs can improve concordance, reduce anxiety and depression and have a positive impact on healing and recurrence rates⁵⁵.

The cost of treating non-healing chronic wounds is high. Important variables include length of time to healing, frequency of dressing changes and nursing time as well as the organisation of care (ie acute or community-based)⁵⁶. For patients at increased risk of delayed healing, early identification and a structured approach to management using appropriate treatment strategies (eg advanced therapies) has been shown to reduce healing time, improve quality of life and reduce the overall costs of care⁵⁶. In addition, continuous training of staff aimed at improving their knowledge and skills was also found to be important⁵⁶. However, further research is needed to fully understand the benefits of this approach using well-designed health economic studies.

DEVELOPING A FIVE-POINT PLAN

Stakeholders must work together to improve wellbeing in a cost-effective and efficient way. There is a need for clinicians to develop a therapeutic partnership with patients and their carers in which decisions are shared, for healthcare organisations to support initiatives for wellbeing that respond to patient preferences, and for industry to develop products that optimise efficacy, cosmesis and quality of life.

BOX 5 The Lindsay Leg Club[®]: a model of social care

The Lindsay Leg Club[®] Foundation was set up in the UK for patients with lower limb problems to come together for care and support. These clubs offer high quality clinical care, which may be delivered in non-traditional settings such as community halls or local churches. Each Leg Club belongs to its members who attend for advice and treatment and to meet and socialise with other members. Within the UK and Australia over 1,000 people receive advice or treatment each week within Leg Clubs. The key elements of a successful Leg Club are the complete integration of social interaction and healthcare provision, resulting in collective treatment where members with leg ulcers are treated together, and the role of volunteers, who raise funds and manage their local club. Appointments are not prescriptive and patients/members can 'drop in' for social support and/or to receive care. This organisation has also been able to lobby for improved services for patients with lower limb problems and provides expert information gleaned from their members' collective experience of having a wound. For further information visit: www.legclub.org

IMPLEMENTING A FIVE-POINT PLAN FOR THE KEY STAKEHOLDERS:

This aims to provide a framework for the four key stakeholders to ensure that wellbeing is optimised when delivering effective wound management

CLINICIANS

The clinician is pivotal in optimising the wellbeing of people living with a wound, acting as the conduit between the patient, healthcare organisation and industry. Family members and cares should also be involved in this process. Clinicians should aim to:

1. Ask about wellbeing using a holistic approach and remember the patient is a 'person'
2. Prioritise wellbeing in the assessment, treatment and management of a patient's wound
3. Involve patients in their care by offering a genuine choice in treatment options and providing appropriate education and support. They should respect the right of patients to refuse treatment
4. Use patient feedback to plan/adapt services
5. Ensure collaboration with their colleagues: know when to refer and to whom

PATIENTS

People living with a chronic wound should receive the same focus of care as other individuals with chronic conditions, such as diabetes or heart disease. Patients are the one constant in the treatment journey, whereas those who provide care may change. Patients should:

1. Expect to be asked about wellbeing and to prioritise concerns
2. Recognise their right to discuss their wellbeing and voice expectations and worries about treatment
3. Take an active role in decisions made about their treatment and commit to a sustained participation in the management of their wound
4. Where reasonable, expect to be offered treatment choices and flexibility in care delivery
5. Reflect on the way their care is delivered and provide suggestions for how services may be adapted

ORGANISATIONS

Individual healthcare organisations can support clinicians in providing a good working environment for staff and appropriate services for their clients. Organisations also have an important role in education and research and in providing materials for patients that can be adapted for ethnically diverse populations. Organisations should aim to:

1. Ensure the wellbeing of their staff so that they can care for the wellbeing of others⁴⁴
2. Accept wellbeing as one of the primary drivers of knowledge-based, cost-effective wound care and commit to ongoing research
3. Make available services that support patient wellbeing in the delivery of effective wound management. These should be relevant to the needs of individual patient groups and be non-discriminatory
4. Support strategies that improve communication between clinicians and patients (including the use of modern technology, eg telemedicine, social networking and Apps)
5. Monitor complaints and improve services accordingly.

INDUSTRY

Industry can also play an active role in supporting clinicians, patients and organisations by prioritising and accepting wellbeing as one of the primary drivers of product innovation and design. Industry should aim to:

1. Develop innovative products that are in line with patient lifestyles and prioritise wellbeing in the delivery of cost-effective wound management
2. Provide relevant and robust communication systems in collaboration with clinicians and patients
3. Highlight importance of wellbeing and develop research agenda around wellbeing and wound management based on clinical and patient experiences
4. Respond to feedback from clinicians and patients about the products they offer
5. Maintain an ethical approach to production, marketing and product sales.

REFERENCES

- Gray D, Boyd J, Carville K. Effective wound management and wellbeing for clinicians, organisations and industry. *Wounds International* 2011. Available at: <http://www.woundsinternational.com/practice-development/effective-wound-management-and-wellbeing-for-clinicians-organisations-and-industry>
- European Wound Management Association. Position Document. *Hard to heal wounds: a holistic approach*. MEP Ltd, London 2008.
- Palfreyman S. Assessing the impact of venous ulceration on quality of life. *Nurs Times* 2008;104(41):34-7.
- Cole-King A, Harding KG. Psychological factors and delayed healing in chronic wounds. *Psychosom Med* 2001;63(2):216-20.
- Persoon A, Heinen MM, Vleuten CJM, et al. Leg ulcers: a review of their impact on daily life. *J Clin Nurs* 2004;13: 3,341-52.
- Vedhara K, Miles JN, Wetherell JM. Coping style and depression influence the healing of diabetic foot ulcers: observational and mechanistic evidence. *Diabetologia* 2010;53(8):1590-8.
- Solowiej K, Mason V, Upton D Review of the relationship between stress and wound healing: part 1. *J Wound Care* 2009; 8(9):357-66.
- Solowiej K, Mason V, Upton D. Psychological stress and pain in wound care, part 2: a review of pain and stress assessment tools. *J Wound Care* 2010;19(3):110-5.
- Solowiej K, Mason V, Upton D. Psychological stress and pain in wound care, part 3: management. *J Wound Care* 2010;19(4):153-5.
- Department of Health. The White Paper 'Equity and Excellence: Liberating the NHS', 2011.
- Department of Health. Our Health and Wellbeing Today. Crown Publications 15150, 2010.
- World Health Organization. Constitution of WHO. WHO Basic Documents, Geneva, 1948.
- Herber OR, Schnepf W, Rieger MA. A systematic review on the impact of leg ulceration on patients' quality of life. *Health and Quality of Life Outcomes* 2007; 5:44 doi: 10.1186/1477-7525-5-44.
- Price PE, Fagervik-Morton H, Mudge, EJ, et al. Dressing related pain in patients with chronic wounds: an international perspective. *Int Wound J* 2008;5(2):159-171.
- Fagervik-Morton H, Price P. Chronic ulcers and everyday living: Patients' perspective in the UK. *Wounds* 2009;21(12):318-23.
- Mudge E, Spanou C, Price P. A focus group study into patients' perception of chronic wound pain. *Wounds UK* 2008; 4(2): 21-28.
- Jones JE, Robinson J, Barr W, Carlisle C. Impact of exudate and odour from chronic venous leg ulceration. *Nurs Stand* 2008;16-22;22(45):53-4, 56, 58.
- Walburn J, Vedhara K, Hankins M, et al. Psychological stress and wound healing in humans: a systematic review and meta analysis. *J Psychosom Res* 2009;67(3):253-71.
- Vileikyte L. Stress and wound healing. *Clin Dermatol* 2007; 25(1):49-55.
- Lindahl E, Norberg A, Söderberg A. The meaning of caring for people with malodorous exuding ulcers. *J Adv Nurs* 2008; 62(2): 163-71
- Flanagan M, Vogensen H, Haase L. Case series investigating the experience of pain in patients with chronic venous leg ulcers treated with a foam dressing releasing ibuprofen. *World Wide Wounds* 2006. Available at:<http://tiny.cc/p8i76>.
- Moffatt CJ. Perspectives on concordance in leg ulcer management. *J Wound Care* 2004;13(6):243-8.
- Hareendran A, Bradbury A, Budd J, et al. Measuring the impact of venous leg ulcers on quality of life. *J Wound Care* 2005;14(2):53-7.
- Chase S, Melloni M, Savage A. A forever healing: the lived experience of venous ulcer disease. *J Vasc Nurs* 1997; 15: 73.
- Lindahl E, Norberg A, Söderberg A. The meaning of living with malodorous exuding ulcers. *J Clin Nurs* 2007;16(3a):68-75.
- Franks P, Moffatt C, Doherty D, et al. Longer-term changes in quality of life in chronic leg ulceration. *Wound Repair Regen* 2006;14:536-41.
- Gorecki C, Brown J, Nelson EA, et al. Impact of pressure ulcers on quality of life in older patients: JAGS 2009. doi: 10.1111/j.1532-5415.2009.02307.
- Nabuurs-Franssen MH, Huijberts MS, et al. Health-related quality of life of diabetic foot ulcer patients and their caregivers. *Diabetologia* 2005;48(9):1906-10. Epub 2005 Jul 2.
- Enoch S, Shaaban H, Dunn KW. Informed consent should be obtained from patients to use products (skin substitutes) and dressings containing biological material. *J Med Ethics* 2005;31:2-6.
- Aujoulat I, d'Hoore W, Deccache A. Patient empowerment in theory and practice: polysemy or cacaphony? *Patient Educ Couns* 2006; doi 10.1016/j.pec.2006.09.008.
- Gonzalez-Consuegra RV, Verdu J. Quality of life in people with venous leg ulcers: an integrative review. *J Adv Nurs* 2011; 67(5): 926-44.
- Price P, Harding K. Cardiff Wound Impact Schedule: the development of a condition-specific questionnaire to assess health-related quality of life in patients with chronic wounds of the lower limb. *Int Wound J* 2004; 1(1):10-7.
- Augustin M, Herberger K, Rustenbach S, et al. Quality of life evaluation in wounds: validation of the Freiburg Life Quality Assessment-wound module, a disease-specific instrument. *Int Wound J* 2010;7:493-501.
- Augustin M, Blome C, Zschocke I, et al. Benefit evaluation in the therapy of chronic wounds from the patients' perspective - development and validation of a new method. *Wound Rep Regen* 2011; doi 10.1111/j.1524-475X.2011.00751.x
- Paterson C. Measuring outcomes in primary care: a patient generated measure, MYMOP, compared with the SF-36 health survey. *BMJ* 1996;312(7037):1016-20.
- Hickey AM, Bury G, O'Boyle CA, et al. A new short form individual quality of life measure (SEIQoL-DW): application in a cohort of individuals with HIV/AIDS. *BMJ* 1996;313(7048):29-33.
- Camilleri-Brennan J, Ruta DA, Steele RJ. Patient generated index: new instrument for measuring quality of life in patients with rectal cancer. *World J Surg* 2002;26(11); 354-9.
- Melzack R. The short-form McGill Pain Questionnaire. *Pain* 1987;30(2): 191-7.
- Zigmond AS, Snaith RPT. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;67(6):361-70.
- Green J, Jester R. Health-related quality of life and chronic venous leg ulceration: part 1. *Wound Care* 2009; S12-17.
- Green J, Jester R. Health-related quality of life and chronic venous leg ulceration: part 2. *Wound Care* 2010; S4-S1.
- Gorecki C, Lamping DL, Brown JM et al. Development of a conceptual framework of health-related quality of life in pressure ulcers: A patient-focused approach. *Int J Nurs Stud* 2010;47:1525-34.
- Grocott P. Developing a tool for researching fungating wounds. *World Wide Wounds* 2001 (Jul). Available at <http://tiny.cc/zoqpb1>.
- Douglas K. When caring stops, staffing doesn't really matter. *Health Economics* 2010;28(6):415-19.
- Kings Fund. Patient choice: how patients choose and how providers respond 2010. http://www.kingsfund.org.uk/current_projects/patient_choice
- Edwards H, Courtney M, Finlayson K, et al. Chronic venous leg ulcers: effect of a community nursing intervention on pain and healing. *Nurs Stand* 2005;19(52):47-54.
- Price PE. Education, psychology and 'compliance'. *Diabetes Metab Res Rev* 2008;24:S101-5.
- Jordan JL, Ellis SJ, Chambers R. Defining shared decision making and concordance: are they one and the same? *Postgrad Med J* 2002; 78 (921):383-4.
- Hawkins J, Lindsay E. We listen but do we hear? The importance of patient stories. *Br J Community Nurs* 2006;11(9):S6-14.
- WUWHS Principles of best practice: Minimising pain at wound dressing-related procedures. A consensus document. London: MEP Ltd, 2004.
- Roden A, Young T. In: Kingsley A, Padmore J (Eds). Painstaking care, everyday issues in wound management. Wound Care Society, UK 2006
- Coulter A. Do patients want choice and does it work? *BMJ* 2010; 341: doi: 10.1136/bmj.c4989
- Enright S. The Psychology of preventive health. *BMJ* 1996;313:1090.
- Edwards H, Courtney M, Finlayson K, et al. Improved quality of life and healing for clients with chronic leg ulcers: a randomised controlled trial of a community intervention. *J Clin Nurs* 2009;18:541-49.
- Lindsay E. The Lindsay Leg Club model: a model for evidence-based leg ulcer management. *Br J Community Nurs* 2004. 9(6 Suppl): S15-S20.
- Tennvall GR, Hjelmgren J, Oien R. The cost of treating hard-to-heal venous leg ulcers: results from a Swedish survey. *World Wide Wounds* 2006 (Nov). Available from <http://tinyurl.com/cqyh6a8>

