

WORLD UNION  
OF  
WOUND HEALING SOCIETIES



# OPTIMISING WOUND CARE THROUGH PATIENT ENGAGEMENT

WORLD UNION OF WOUND HEALING SOCIETIES  
CONSENSUS DOCUMENT

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# WORLD UNION OF WOUND HEALING SOCIETIES CONSENSUS DOCUMENT

**FOREWORD** 'Optimising wound care through patient engagement' is a crucial and timely topic, both in terms of wound healing (and, in some cases, symptom management), and in improving individuals' experiences of the process.

We identified the need for clear information and education, which has formed the basis for this World Union of Wound Healing Societies (WUWHS) consensus document. It was a priority to make sure that this included input from patients as well as health care professionals (HCPs), ensuring that the authentic patient voice was heard and assumptions were not made about the rights, needs, preferences, priorities and experiences of people using wound care services.

As such, this consensus document has been produced in four main stages:

- A patient focus group: held at the Welsh Wound Innovation Centre, UK, in May 2019, in which a group of individuals living with a wound, and carers, discussed their experiences and the care they have received
- An international patient survey: distributed by HCPs, to gauge individuals' views on their care and dressing experiences
- A consensus meeting of an international group of experts, held in London, UK, in July 2019, which also included teleconference/video interviews with patients for their perspective on the discussions
- An extensive review process: undertaken by the core expert working group, external reviewers and patient contributors.

This process reiterated the need for a more patient-centred mentality, HCP education and resultant action. This document aims to provide clear guidance in listening and engaging with individuals, and thus optimising the care experience for all key stakeholders, of which the patient is the most important.

**Keith Harding**  
Chair, Expert Working Group

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We would also like to thank the anonymous patient contributors and reviewers for their important input to this document.

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## WHAT DOES HAVING A WOUND MEAN TO YOU?

We asked individuals what living with a wound means to them personally, and the impact that this has on their daily lives and relationships. We also asked for the key issues that affecting them, relating to their wound or the care they have received.

'It gets me down. I just want it gone'

'I'm sick and tired of dressings'

'It takes your freedom and limits what you can do'

'You just lose your confidence'

'It stops you living your life'

'I get so fed up with it. I just feel so low'

'It's always at the back of your mind'

'Other people can't understand what living with a wound is really like. They say it's all in your head'

'You're constantly checking yourself, wondering "is that smell me?" Especially when you get that infection smell. It makes you paranoid'

'Bad experiences with care can make you feel reluctant to go back'

'It can be one step forward, two steps back'

'You have to push and push. It's hard to get the support you need'

'You need to know that you're not on your own, for someone to understand what you're going through'

'Every day is a struggle'

'You want to feel listened to and more in control'

'It makes such a difference to be treated as a human being, not just a number'

## KEY ISSUE: PATIENT EXPECTATIONS

Living with a wound is, in many ways, like living with any other chronic condition: it can have a significant effect on daily life and overall wellbeing (Moore et al, 2016). Patient feedback has indicated there can be a perception that a wound is not as 'serious' as some other chronic conditions, and so there is less empathy in the care provided. In practical terms, the NHS in the UK managed an estimated 2.2 million adults with a wound in 2012/13 (Guest et al, 2015); in the USA, this is estimated at 5.7 million people and a cost of \$20 billion (Järbrink et al, 2017). This area of care is a 'forgotten cost driver' within health care systems, which also affects product availability, limiting the care that clinicians are able to provide (Fletcher et al, 2017).

### Box 1 | Patient engagement (WHO, 2016)

Patient engagement is increasingly recognised as an integral part of health care and a critical component of safe people-centred services. People using health services are increasingly asking for more responsive, open and transparent health care systems. They expect HCPs to engage them in the decision-making process, although individual patients may vary substantially in their preferences for such involvement. Patients have their safety and wellbeing as primary drivers and thus, they can raise this as a priority in the health care they receive.

Engaged patients are better able to make informed decisions about their care options. In addition, resources may be better used if they are aligned with patients' priorities and this is critical for the sustainability of health systems worldwide.

Informed patients are more likely to feel confident to report both positive and negative experiences and have increased concordance with mutually agreed care management plans. This not only improves health outcomes, but also advances learning and improvement, while reducing adverse events.

Individuals living with wounds report not feeling supported and not feeling involved in decisions relating to their care.

**'People don't realise how difficult it is or what it involves - they just think a wound is a minor thing'**

Patient advocacy is an important element of care — it is part of the HCP's role to give the patient a voice. This means understanding and considering the patient's choices, needs and preferences, and helping to advocate for these in practice and within the health care team. This may be particularly relevant in vulnerable patients who are not able to advocate for themselves due to factors such as illness, mental capacity or social position (Nursing Times, 2017). Strengths-based nursing also represents an approach to care that involves caring for patients and families, through the HCP focusing on their inner and outer strengths — that is, on what patients and families do that can best help them deal with problems and minimise deficits (Gottlieb, 2014).

In the UK, the General Medical Council recommendations focus on protecting patients' interests: 'make the care of your patients your first concern; respect patients' dignity and privacy; listen to patients and respect their views; respect the right of patients to be fully involved in decisions about their care' (GMC, 2019).

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There is a convincing argument in favour of nurses assuming the role of patient advocate, as nurses are clinically educated, professional members of the team; they tend to spend the most time with patients and are, therefore, better equipped to assess their needs and aspirations, beyond medical needs (Schwartz, 2002). In a long-running survey, undertaken annually since 1983, nurses have still been found to be the most-trusted profession, with the vast majority of the public (96%) saying they have confidence in nurses to tell the truth (Nursing Times, 2018).

It is vital that nurses have the courage and confidence to speak up for patients where necessary, in all health care settings within the multidisciplinary team (MDT). There may be reasons that nurses feel unable to speak up, which need to be addressed within the team and wider systems (Churchman and Doherty, 2010), which may include:

- Personality
- Age
- Gender
- Fear
- Lack of confidence
- Occupational hierarchy.

Patients have the right to be involved and informed about their own care — it is important for them to be aware they have the right to ask questions and make comments. The clinician should help to encourage an environment where the patient feels safe and supported, and able to speak up.

The term 'patient engagement' is used in this context, meaning 'the facilitation and strengthening of the role of those using services as co-producers of health, and health care policy and practice' (WHO, 2016; Box 1). Therefore, the patient's involvement should be wider than the concept of 'shared decision-making'; patients should be enabled to participate in care planning over time and influence how services are shaped and delivered, rather than just being a passive recipient of the services provided to them (Moore et al, 2016).

Individualised, evidence-based care is key, as a 'one size fits all' approach does not work. It is important to tailor care to the individual: their wound, their general health and their practical circumstances. However, consistency of care is also an important element. This is important for patients' peace of mind, confidence in their clinicians, and in ensuring practice is efficient and effective. The patient should be involved in developing their own structured care plan, which is tailored to the individual. Patients' needs will vary and may be specialised; for example, patients living with chronic or recurrent wounds, or conditions such as epidermolysis bullosa (EB).

All wound management is multifactorial, therefore a genuine MDT approach is vital, ensuring that the patient receives access to appropriate referral and multidisciplinary care professionals within the wider team. The success of this approach is dependent on communication, both within the team and with the patient. All care should be documented and communicated effectively, in the way the patient can easily understand (see p9: 'Key issue: Communication').

Family and carer involvement should be considered as a part of this approach, with all stakeholders as involved and informed as possible. Self-care forms are an increasingly important part of the patient experience: this can be effective for the patient and their care, and can also empower the patient to feel more informed and involved.

However, while self-care is key, it should always be considered as part of a wider, structured

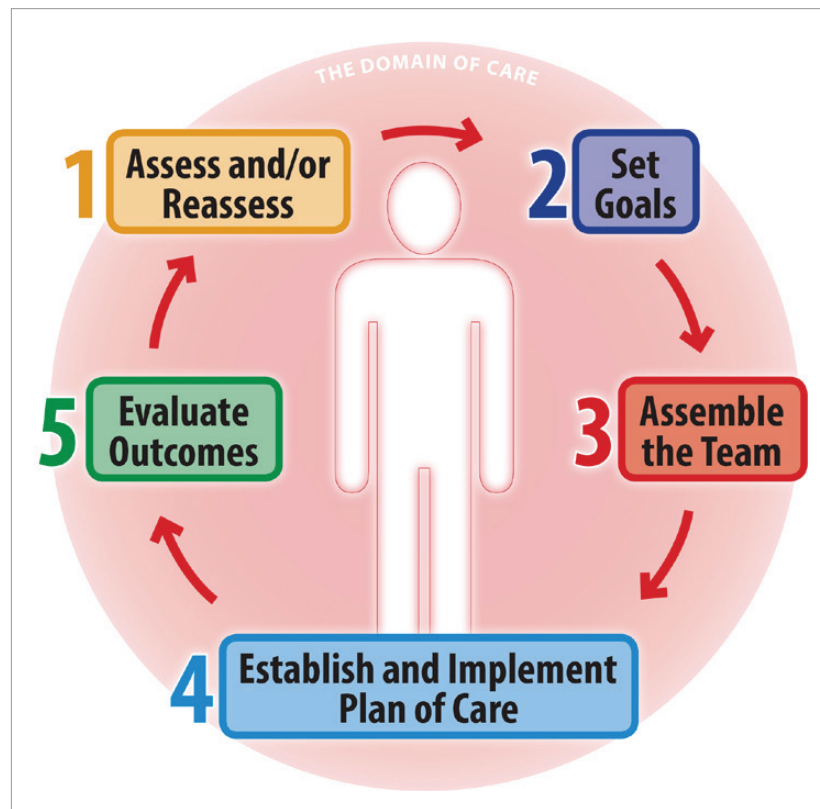
support system — it is vital that, whenever possible, self-care is conducted in collaboration with healthcare professionals to minimise the likelihood of patients ‘slipping through the net’ (see p16: ‘Key issue: Self-care’).

A logical and systematic method for developing a customised, patient-centred plan is required: for instance, the Wound Prevention and Management Cycle (WPMC; Bassett et al, 2019) begins with the initial assessment and follows through to a sustainable plan targeting self-management for the patient (Figure 1). The five steps of the WPMC are:

- Assess and/or reassess
- Set goals
- Assemble the team
- Establish and implement a plan of care
- Evaluate outcomes.

Each step is then broken down into specific recommendations to support care. If a team reaches step five and goals of care have not been met, clinicians must return to step one of the WPMC and reassess the patient, the wound and the environment to find causes or co-factors that still need to be addressed to promote wound healing. The WPMC applies to the three healing statuses of wounds: healing (causes and co-factors addressed), non-healing (causes or co-factors must be addressed before healing can occur) and non-healable (causes and co-factors cannot be addressed). The WPMC incorporates principles of wound bed preparation, with a focus on holistic person-focused care.

**Figure 1. The Wound Prevention and Management Cycle (Bassett et al, 2019)**



### The Lindsay Leg Club model

Establishing the connection between overall wellbeing and wound healing has proved effective in the psychosocial Lindsay Leg Club model for lower limb care, whereby regular structured support is provided but within an informal setting, available to all those affected by (or at risk of) leg ulcers (Lindsay Leg Club Foundation, 2016). Use of this model has demonstrated a range of benefits: leg ulcer recurrence rates in Leg Club members were found to be approximately half that of the UK national average (Clark, 2013); an Australian study found that members reported greater overall wellbeing and general health, morale and self-esteem, functional ability, ulcer healing and decreased pain (Edwards, 2009).

### The 'six Cs' of nursing

The basic 'six Cs' of nursing (RCN, 2015) stand for the professional commitment to always deliver excellent care, and can be applied to all staff delivering care, not only nurses. Each value is equal, not one is more important than the other. They focus on putting the person being cared for at the heart of the care they are given. Health and social care may change over time with new policies and governments, but the need to look after patients with dignity and compassion always remains consistent. It can be useful to bear these basic principles in mind.

#### ■ Care

Care is our core business and that of our organisations, and the care we deliver helps the individual person and improves the health of the whole community. Caring defines us and our work. People receiving care expect it to be right for them, consistently, throughout every stage of their life.

#### ■ Compassion

Compassion is how care is given through relationships based on empathy, respect and dignity — it can also be described as intelligent kindness, and is central to how people perceive their care.

#### ■ Competence

Competence means all those in caring roles must have the ability to understand an individual's health and social needs and the expertise, clinical and technical knowledge to deliver effective care and treatments based on research and evidence.

#### ■ Communication

Communication is central to successful caring relationships and effective team working. Listening is as important as what we say and do, and essential for "no decision about me without me". Communication is the key to a good workplace, with benefits for those in our care and staff alike.

#### ■ Courage

Courage enables us to do the right thing for the people we care for, to speak up when we have concerns and to have the personal strength and vision to innovate and to embrace new ways of working.

#### ■ Commitment

A commitment to our patients and populations is a cornerstone of what we do. We need to build on our commitment to improve the care and experience of our patients, to take action to make this vision and strategy a reality for all and meet the health, care and support challenges ahead.

**INDIVIDUAL EXPERIENCE**

'I worked in a nursery and I'm desperate to go back to my job. However, I'm unable to, as I'm considered a health and safety risk because I have an open wound. I could just go and work in a call centre, but I've worked with children all my life and I love it. There are other people working there who have a bad back, so they can't lift the children up, but a wound is different. My wound has got much smaller now and I want to work, but they won't have me back. It feels very unfair.'



**KEY ISSUE:**  
**COMMUNICATION**

**Listening and engaging**

A key message received from individuals is the importance of feeling as though they are being listened to, and their needs and preferences being taken into account throughout treatment. It is clear that many individuals want to be a part of the decision-making process and to have the final say in how their care is going to be delivered.

**'While the clinicians may have seen hundreds of wounds, they haven't seen my wound'**

All of the individuals in the focus group agreed that it was very important for them to feel listened to and respected. Often their own knowledge and experience of living with a wound was discounted, despite them having the best perspective on this. Patient respect and empowerment should be considered of utmost importance. However, many felt that there was a lack of support and understanding (see Table 1). They described feeling rushed at appointments, and that clinicians did not look at their wound or listen to them. There was a frustration at not being listened to and the attitude that 'the doctor knows best'.

One individual reported having their dressing changed by a receptionist and others described having to instruct clinicians themselves when they knew their dressing was not being changed correctly, for example.

**'Often it's not so much a lack of support as a lack of understanding'**

It was agreed that it can be 'purely down to luck', as some individuals reported positive experiences with their general practitioner (GP) (e.g. being able to get an appointment quickly and easily), while others reported long waiting times, errors in prescribing and referral, and lack of access. Therefore, a coordinated and standardised approach — while being tailored to the individual patient and their needs — is key. The individual needs to feel confident that they will see the correct clinician and be given the appropriate care.

All of the individuals in the focus group agreed that having local access to a wound care clinic made a huge difference, and that experiences with nurses had been largely positive. It was noted that the nurse's role as advocate can be beneficial throughout the care process (e.g. writing to the patient's GP).

**'Your wound healing can be governed by how good your nurse is'**

All agreed they prefer to feel involved in their own care, to be informed of the rationale behind it, and to be given a plan to follow. They agreed that as much information and knowledge as possible about treatments was very useful and reassuring, and would like to see more of this (e.g. leaflets, FAQs, educational resources).

It was also agreed that in some cases the individual is best placed to monitor and document their own wound and report back to the clinician, such as taking photographs of their wound to demonstrate

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progress or deterioration. All agreed that a 'wound diary' would be a useful resource that would aid communication. See p16 ('Key issue: Self-care') for more information.

Table 1   Communication/care issues reported by individuals	
<b>Time-related issues</b>	<ul style="list-style-type: none"> <li>■ Not enough time to explain/be assessed properly</li> <li>■ Feeling rushed</li> </ul>
<b>Communication issues</b>	<ul style="list-style-type: none"> <li>■ Not feeling listened to</li> <li>■ Treatment not explained properly</li> <li>■ Not asked the right questions</li> <li>■ Not given the opportunity to be involved</li> </ul>
<b>General care issues</b>	<ul style="list-style-type: none"> <li>■ Lack of support</li> <li>■ Lack of product availability</li> <li>■ Limitations in environment (e.g. space, comfort, privacy)</li> </ul>

### Delivering information

It is important that individuals are provided with information about their own care, but this needs to be at an appropriate level tailored to the individual. If information is delivered in the best way and at the appropriate rate, engagement will be more effective. There is a danger of 'overload', whereby individuals may switch off and not take in or remember important information.

Individuals should be given the chance to ask questions, and information for the individual to take away with them can be very useful. This can take different formats — for example, it may be useful for the clinician to take a video of the dressing change process so the individual can watch and learn how to do it themselves.

### Box 2 | Communicate with H.E.A.R.T

**Hear** This programme (Cleveland Clinic, 2019) aims to build a culture of compassionate communication and empowers employees to provide an exceptional patient and employee experience, at every point of interaction, by helping them to understand that their role in creating positive patient experiences is greater than the tasks associated with their job.

**Empathise**

**Apologise**

**Respond** 'Communicate with H.E.A.R.T' establishes expected service behaviours, provides a service recovery framework and demonstrates how personal accountability sustains a culture of empathy.

**Thank**

### Listening skills

It is clear that feeling listened to is a vital part of care from the patient's point of view. This is important to individual wellbeing and their overall experience, but should also be — on a practical level — a key part of the assessment and monitoring processes. The individual knows their own wound and is best placed to provide information to the clinician about their wound and its progress.

It is important to remember that living with a wound can cause many psychological and social issues. It may be a sensitive or emotional subject for the individual, and can cause feelings of isolation. Approaching the individual with empathy and understanding is key.

**Checklist | Active listening:  
what we pay attention to in  
the individual (adapted from  
Sanders, 2011)**

- Voice quality (confident, timid, strong, weak, etc)
- Facial expression (tense, afraid, relaxed, disgusted, etc)
- Breathing (deep, shallow, emotional, stressed, etc)
- Whether they are talking or silent
- Whether they have the language to describe their health and their wound, or if they need help
- The 'story' they are telling

**Box 3 | Active listening and communicating empathy (adapted from Sanders, 2011)**

Active listening means that you are paying full attention to what the other person is saying. While this may seem simple, in a busy setting or as part of a hectic schedule, it can be difficult to achieve; however, it is vital to use your time with the individual to focus on them entirely. The purpose is to make the individual feel really listened to, which may also mean that clinical clues are picked up that may otherwise be missed. We have to attend to all the signals given by the individual, which may be verbal or non-verbal.

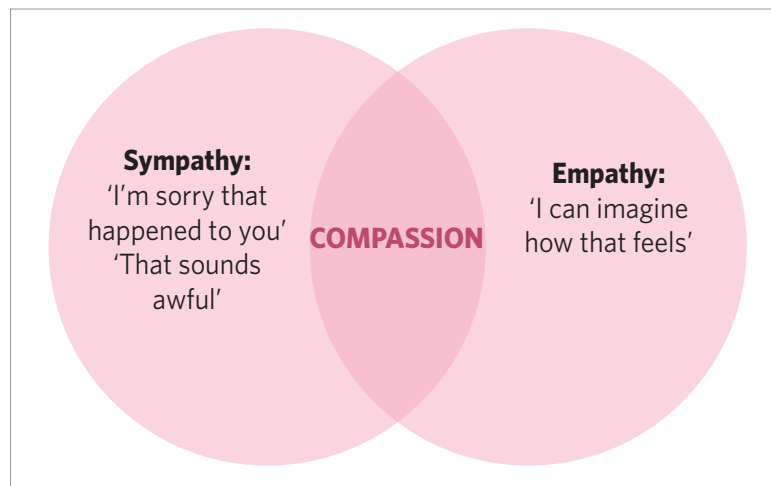
There are three stages to the skill of active listening:

- Observation
- Understanding
- Reflection.

To make sure that we really understand the meaning of what the individual is saying, we should check with them. We can do this by paraphrasing and clarifying, reflecting the content of the individual's communication back to them — by summarising what they have said to you. The purpose is to give the message: 'I am listening carefully to what you're saying and I am trying to understand. I will demonstrate this to you by letting you know that I heard what you just said. Did I get it right?'

All individuals should be treated with compassion, which can be defined as "sensitivity shown in order to understand another person's suffering, combined with a willingness to help and to promote the wellbeing of that person, in order to find a solution to their situation" (Perez-Bret et al, 2016). Crucially, compassion triggers action, whereas sympathy and empathy may not (Figure 2).

**Figure 2. Examples of responses**



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**KEY ISSUE: BREAKING DOWN BARRIERS**

Individual patient capacity will have a huge effect on their care (e.g. in terms of education about dressing options and other treatments, and the extent to which the individual is able to engage with self-care). As such, establishing the individual's capacity for understanding and education is key.

To facilitate the appropriate level, there are structured tools available. These should be undertaken at the earliest stage possible, and subsequent care and communication should be tailored accordingly. The UK GMC (2016) provides a structured mental capacity tool, which can be used to gauge the patient's level of understanding and ability to provide consent to treatment options (Box 4).

**Box 4 | Maximising capacity (adapted from GMC, 2016)**

- Discuss the options in a time and place that helps the individual to understand and remember what you say
- Ask whether having a friend or relative with them might help them to remember information, or otherwise help them make the decision
- Offer written or audio information if it will help
- Speak to the individual's relatives, friends, and others in the healthcare team, about how best to communicate with the individual.

It is important not to make assumptions about the patient's capacity or level of understanding (e.g. consideration should be given to literacy). Jargon and heavily medicalised language should be avoided as much as possible. See the Glossary (p26) for a list of suggested descriptions of commonly used terms. As well as using understandable terms, it is important to reassure individuals and set their expectations appropriately (e.g. explaining what granulation tissue is, or that presence of slough is normal).

**Ensuring care for all individuals**

Individuals will present with wounds in many different situations; for example, individuals who present with challenging behaviour, or who may have drug or alcohol problems, still have healthcare needs that must be met. Some individuals may need a different approach, which requires flexibility, empathy, support and expertise.

Additionally, challenging behaviour can make it difficult to deliver good care safely and can range from uncooperative individuals to potentially dangerous behaviour, but such action is often a sign of distress and unmet need, rather than any intent to be challenging (NHS Protect, 2013). Guidance on challenging behaviour related to clinical conditions highlights the importance of good communication, compassion and trust to prevent such behaviour, as well as practical strategies for when things go wrong.

Guidance from the UK GMC (2019) states that healthcare professionals must:

- Tell the individual (or, where appropriate, the individual's advocate, carer or family) when something has gone wrong
- Apologise to the individual (or, where appropriate, the individual's advocate, carer or family)
- Offer an appropriate remedy or support to put matters right (if possible)
- Explain fully to the individual (or, where appropriate, the individual's advocate, carer or family) the short- and long-term effects of what has happened.

Admitting fallibility where appropriate is a key aspect of building a relationship of trust. It's important to communicate the process to the individual and work collaboratively. Setting realistic goals and making honest statements, such as 'if we don't get it right this time, we will next time' or 'we can't heal the wound straight away, but we can help you to manage it' can be very helpful to ensure the individual does not become disheartened. It is worth noting that individuals will notice if clinicians lack skills and confidence, which will have an effect on their relationship if this is not addressed honestly (Anderson, 2012).

It can also be helpful to have a back-up plan in place and to communicate this to the individual. This means the individual is less likely to be lost to follow-up because they have 'given up' if the initial treatment plan was not successful, or did not meet their expectations.

It is important to remember that labelling an individual is unhelpful and often leads to barriers in accessing, understanding and accepting care (e.g. assuming that an individual is 'non-concordant'). This should mean that other strategies and communication methods are used, rather than the issue lying with the individual. There is strong evidence to illustrate that so-called 'non-concordance' is too often blamed on the individual, when in reality it is more likely to reflect the relationship between the individual and practitioner, and may be due to a lack of knowledge or experience on the practitioner's part (Moffatt, 2004). We must remember that individuals' experiences influence their subsequent behaviour, and do all we can to ensure the individual can be confident that high-quality care will be provided by the MDT at every stage.

For some individuals, care has to be a compromise and realistic goals must be set. Negotiation should always be a continuous process and finding common ground is needed, rather than retaining all control and employing a paternalistic approach. It is important to remember with some therapies e.g. compression that 'some care is better than no care'. As well as setting realistic goals, a degree of flexibility is important — not every element of treatment can be controlled, and we may need to expect some deviation from ideal plans.

Delivering care to individuals where chaotic lifestyles are an issue may be challenging. It is vital that individuals receive the care they need and that barriers to this are broken down wherever possible. It may be that a referral to an appropriate service is the way forward or liaising with key workers, social workers and mental health teams. This also applies in some groups (e.g. older individuals or particular cultural groups — where reliance on traditional medicine or beliefs may cause problems), in which case harm reduction may also be the aim.

There can be issues of unconscious bias to look out for in our own behaviour, relating to some individuals. For example, ageism can be an issue, if there is at times a perception that some health issues for older people are 'inevitable' or 'just one of those things'. Similarly there can be some prejudice about some lifestyle choices that affect the individual's health — such as smoking, drug use or weight issues. It is important to examine attitudes towards this and put any biases or judgement to one side when dealing with the individual.

**'I used to be very fit and active before my wound put a stop to everything - now I feel that I'm being judged. People make assumptions. Why should I have to explain?'**

Establishing and maintaining a relationship of trust may be particularly vital when working with challenging individuals, where individuals may have had previous bad experiences, or feel abandoned or alienated by healthcare systems. Box 5 provides tips for working with challenging individuals.

Practical issues may arise in some individuals due to communication or capacity issues, in which case it is important to communicate with the individual as far as possible and seek further support or resources where necessary. Additionally, in individuals where there may be logistical issues with care (e.g. an individual is experiencing homelessness or other socio-economic issues) it is important to provide care when and where possible around these issues.

#### **Box 5 | Tips for working with challenging individuals (adapted from Walker, 2018)**

**Let them tell their own story:** use your time with the individual to provide an opportunity to communicate their own story in their own way, which may help to reduce their distress

**Try to see the individual's perspective:** the individual's fears and anxiety, or previous bad experiences, may result in challenging behaviour that can be reduced by understanding the cause

**Find opportunities for empathy:** the most powerful skill you have as a clinician is genuine empathy, listening to the individual and understanding — for example, small gestures such as offering them a drink, or handing them a tissue if they need one, can have a helpful effect

**Ask yourself what you may be bringing to the situation:** it may be that issues arise due to workplace stresses or personal issues (for example, if the individual reminds you of a person or situation in your own life) — it is important to look at ourselves honestly

**Acknowledge the situation:** it can be helpful to speak out loud, for example saying directly 'I feel that we are getting off on the wrong foot here' and ask about the individual's needs and how you can help

**Avoid defensive posture:** remember that the individual's behaviour is not a reflection on you and you can only do your best, so try not to dwell on your own feelings and frustrations

**Set boundaries:** state that there are certain behaviours that are unacceptable and you do not have to tolerate — for example, saying 'in order to continue to talk to you, you cannot use that language, so I will step out of the room to give you time to calm down'

**Realign your body language:** if you start to get frustrated, it can help to take a deep breath and realign your thoughts; this will change your body language and may trigger a different approach

**Find extended help if necessary:** if you feel something more is needed, you can refer the individual to someone to talk to, communicating this to them so they do not feel abandoned — remember that you can't be all things to all people, and despite your best efforts, there will always be difficult individuals

**Ground yourself:** stress relief and self-care outside work are important to your own wellbeing and that of the patient, making sure that you have time to yourself where you can do other activities and are not preoccupied with work

'I have good and bad days, but mostly bad. Living with EB, I have to look at each wound every day. Dressing the wounds is the biggest challenge - it takes around 2 to 3 hours once or twice a day. I wouldn't be able to manage if I didn't have my mum to help me I don't have the confidence that anyone else would be able to deal with changing the dressings properly. I worry about dressings slipping when I'm out and about; it stops me from doing things. Leakage and odour are always a concern, and I constantly worry about infection.'

**Clinician burnout and compassion fatigue**

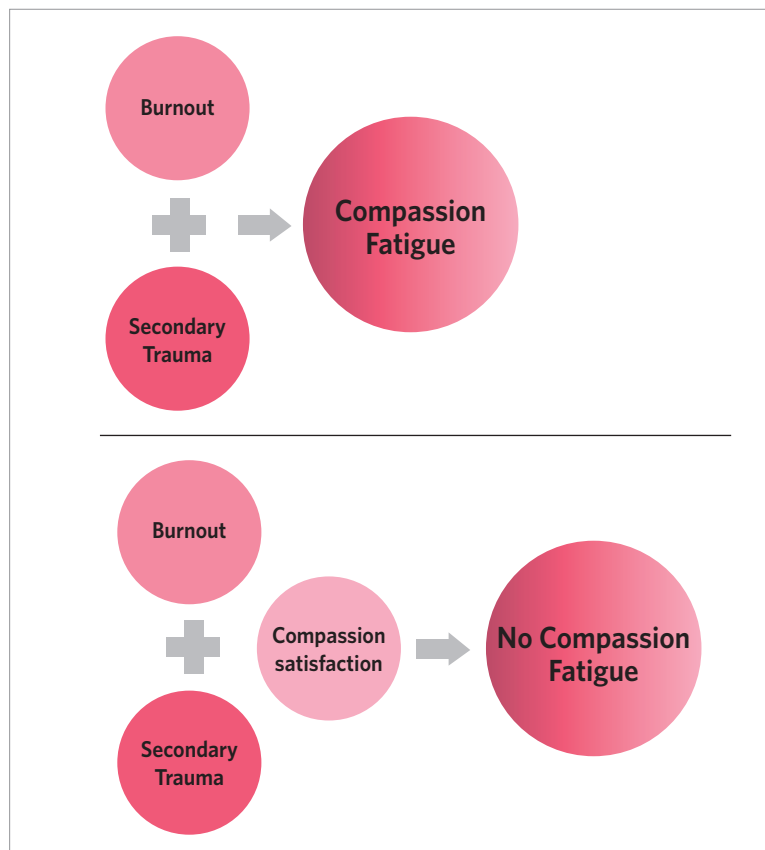
Self-care and cultivating resilience are vital for clinicians. Working in a role that involves caring for others can result in 'burnout' or 'compassion fatigue' (Figure 3). There is a difference between the two, and HCPs delivering care are at risk of both (Gallagher, 2013).

Burnout results from the stresses of the clinician's interactions with his or her environment (i.e. being worn out by work, which can affect any profession); compassion fatigue results more from the relationship between clinician and patient (i.e. a preoccupation with absorbing trauma and emotional stresses of others, which may be likely to affect HCPs).

The main symptoms and signs of burnout are emotional exhaustion, a sense of ineffectiveness, or dissatisfaction with work, all of which can result in cynicism and detachment from work (Maslach, 2001). Clinicians with burnout are more likely to make errors, and their patients are less satisfied with the quality of their care (West et al, 2006). Compassion fatigue (also called secondary or vicarious trauma) is thought to compromise clinicians in their ability to care for others because of symptoms that parallel post-traumatic stress disorder, which might result in avoidance of situations in which patient suffering is involved (Cocker and Joss, 2016).

It has been found that reflecting on experiences of dealing with emotionally draining circumstances, learning new skills, and finding meaning in working with individuals results in compassion satisfaction, allowing clinicians to be highly present and empathetic to the experience of suffering, as well as to feel energised rather than drained by it (Kearney et al, 2009).

Figure 3. Compassion fatigue: conceptual model adapted from Middleton (2015)



## CONSENSUS DOCUMENT

**KEY ISSUE:  
SELF-CARE**

In recent years, there has been an emphasis on self-care, and this is now a key part of any treatment regimen. While self-care can be valuable and should be encouraged wherever possible, it is important to note that this must be within a structured support system whenever possible.

Individuals should be given opportunities to engage with their own care. This should be commensurate with their wishes, needs and abilities, and these factors are key to developing an effective care plan.

Self-care should not be seen as a means to save time or money, and — while all self-care involves some risk of disengaging individuals — the relationship with the individual must be preserved as far as possible.

Living with a wound can be an isolating experience for many individuals. In fact, anecdotal evidence suggests that there may be many individuals living with long-term wounds who are self-caring outside of the system, and not seeking the appropriate guidance and support. Shame and stigma are strong drivers that may prevent patients from obtaining help. Therefore, self-caring without support may be more common than we realise.

If there is a mistrust in the care the individual has previously received, they may take on self-care of their own accord, and without the appropriate support, as they see it as the best option for them.

**'If we don't do it, it's not being done properly'**

In psychological terms, there is often a disparity between what people think they are doing and what they are actually doing — in practice, this applies to both patients and clinicians. Therefore, it is important to bridge this gap and make sure that reporting is accurate (both on the part of the individual and the clinician) and that goals are realistic. The individual can be engaged in gathering and reporting information, which can be important to measuring outcomes.

Research by Kapp and colleagues (2017) investigated the quality of life of individuals living with chronic wounds and found those who self-treated in a shared care model (with care also provided by doctors, nurses and allied health professionals) experienced:

- Frustration and distrust of healthcare professionals from whom they received advice and care
- A negative effect on quality of life
- Physical limitations that affected activity and compromised the management of other health conditions
- Disruption to daily lifestyle and workforce participation were disrupted when receiving professional care
- Expenses associated with wound treatment and professional care that negatively affected personal finances.

It is important to note that these findings are not dissimilar to the results of earlier research considering quality of life among those living with chronic wounds and in fact, self-treatment of wounds can have positive effects on quality of life. The study concluded that continued effort is still required to develop relationships and treatment regimens that are conducive to healing and to optimise wellbeing; additionally, health care systems should identify and address structural shortcomings of care services to create more person-centred models of wound care in the community setting (Kapp et al, 2017).



Across different geographical areas, cultural beliefs can compound the issue of patient engagement. For instance, in some areas there may be a reliance on traditional remedies and a mistrust of 'modern' medicine. In these instances, it is important to find a balance and guide individuals within the achievable parameters. A 'harm reduction' approach may be necessary. It is important to consider that not all patient and carer involvement will be helpful and education may be needed. Tailoring care according to measures such as 'patient activation' (NHS, 2020) may be helpful.

However, the focus group agreed that being involved in their own care was the best option wherever possible, preferring to be involved and feel more in control. It was agreed that, wherever possible, self-care should be promoted. One individual explained that they conducted all of their own dressing changes, not letting anybody else (even their partner) touch the wound. This was partly due to fear of infection, but also because they had the most knowledge about their own wound.

Fear of infection is a common factor, so instilling confidence in the individual regarding their own judgement can be very useful in enabling self-monitoring and knowing when to seek help (e.g. communicating and educating the individual about knowing what infection looks and feels like, and how to recognise it, then knowing where to seek help if necessary).

It is important to note that access to ongoing support is still needed. Support is vital to give individuals the confidence to self-care. For instance, it was suggested that an intermediary drop-in clinic dedicated to wounds would be useful, so that advice and support could be easily accessed whenever necessary. This would provide a good compromise between self-care and, for example, having to travel to go to a hospital.

### **Potential solutions: self-reporting and sharing information**

Encouraging the individual to keep a wound diary – either written by hand or digitally (e.g. keeping notes on a mobile phone) can be helpful. The individual knows their own wound and is best placed to monitor progress and changes, as well as any other issues. This can provide a useful starting point for conversations with the clinician, and can also be therapeutic for the patient — it can be helpful to reflect on their own progress and how this makes them feel.

Suggestions for keeping a wound diary:

- Pain levels (reporting on severity of any symptom that is a problem for them: e.g. pain, malodour, leakage, itchiness)
- Visible changes to the wound (could take pictures with a phone)
- Dressing changes
- Quality of life and any emotional/psychological issues relating to their wound
- Questions for the clinician.

## CONSENSUS DOCUMENT

**KEY ISSUE:  
EXPERIENCE WITH  
DRESSINGS**

Using the right dressing in the right way at the right time is a key part of care. Dressing selection and the process of dressing change can have a huge effect on the individual's experience and their overall quality of life (Figure 4).

**Dressing selection**

While some individuals in the focus group had found a regimen that worked well for them (e.g. one individual reported his quality of life and dressing change experience was much improved since using silicone dressings), all had experienced problems at some point in their care. Reports of this varied and related to individual need; however, the overall message was that changes in dressing selection could make a huge difference to individuals' experience and quality of life. For instance, one individual mentioned that the product they had been using was not suitable and did not stay on, however, once changed to a more comfortable product, it stayed in place, was better for their skin and easier to change.

Inconsistencies in care relating to dressing selection and usage were widely reported, particularly as individuals move through care pathways and systems. An MDT approach is ideal, but this is not always achieved in practice.

It was also noted that it is important to receive the correct dressing at the correct time — often, one dressing can work for a period of time, but then cause an adverse reaction or fail to manage increased exudate, for example. It was agreed by the focus group and clinicians that sometimes 'trial and error' and experimenting with different dressings as care continues is the only answer to this.

However, it can be challenging for the individual to have to 'relearn' their own care regimen, having become familiar with a previous dressing. Having experienced the dressings for themselves, individuals reiterated that they often know what is best for their own care, but feel they are not listened to by clinicians.

It is vital that dressing selection is a collaborative process that involves the patient as much as possible. The assessment process should be communicated to patients throughout the process. Joint decision-making should be considered a part of dressing selection.

It is important to establish the individual's priorities, with questions such as:

- What are your priorities regarding your wound and dressing?
- Are there any lifestyle issues we should bear in mind?
- Do you have any concerns?
- Do you have any questions about how the dressing will work?

It should be communicated to the individual that their needs will be considered and they have choices.

It can also be helpful to explain to the individual how dressings work (e.g. what the dressing is made of, the issues the dressing is designed to address, how it might help). It has been proven that shared decision-making promotes a more positive process and improves outcomes (Anderson, 2012; Moffatt, 2004).

The patient's and clinician's view on dressing choice may be different — for example, a dressing might look neat (which is important to the clinician) but feel uncomfortable for the individual. Competing agendas should be minimised as much as possible: the individual's agenda should be the overall agenda.

### Availability and access issues

While it is ideal to bear individual priorities in mind when selecting dressings, availability and access issues can mean that not all options are available. Due to, for example, differing approaches to dressing supply and the influence of the purchaser, clinicians may have a limited choice to offer. Furthermore, subsidised wound dressings are not a universal entitlement, and the cost when self-funding can be significant.

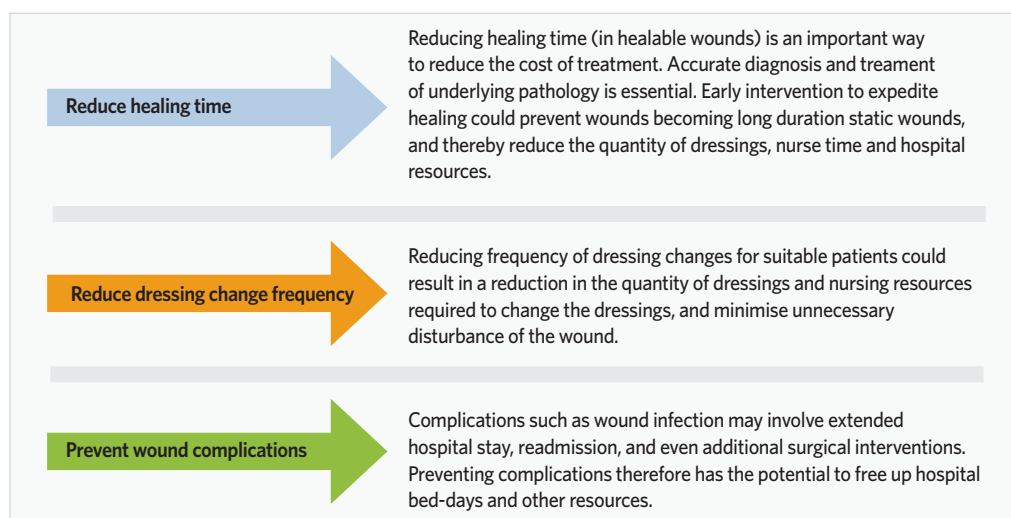
The challenge in incorporating person-centred care when dealing with procurement issues is well documented; the product evaluation process focuses on price and aiming to cut costs; however, this can result in counterintuitive decisions if consideration is not given to the total cost when an individual is being treated (Fletcher et al, 2017). However, the issues are inextricably linked as the quality of the care practitioners are able to give depends upon the products they can use and have available.

It is vital to look at the bigger picture: overall health care costs, rather than the individual prices of products and medical devices and dressings used. Excessive focus on price may in fact lead to the opposite effect on total health care costs. The CLOSE study (Bredow et al, 2015) compared the cheaper and more basic product with the more advanced dressing, and found that patients preferred the advanced dressing. This also took into account factors such as ease of dressing change and wound visibility. Crucially, it was found that when all factors were considered, the advanced dressing was more cost-effective than the more basic product. The study findings emphasised that appropriate choice of dressings will optimise healing, reduce complications, improve quality of life and reduce health care costs.

Care must be focused on individuals, which means using the right product for the right patient in the right way. This will help to avoid unnecessary problems and their associated costs further into treatment, which should reduce overall costs. In order to achieve this positive effect, communication between health care, patients, suppliers, purchasers and other stakeholders is key. In particular, clinicians need to be able to speak to procurement and management about the practical issues that are being encountered, in order to make positive changes for their patients.

Within the clinician's role as patient advocate, there is a need for clinicians to have a greater voice in dressing selection and product availability. Making the case for the appropriate products is vital and needs to be led by a focus on the individual's needs.

**Figure 4. Aims of dressing selection**



**Dressing change**

Individuals in the patient focus group reported particular problems concerning pain and anxiety around dressing change. Some individuals had had to instruct their clinician to stop and change the dressing differently in order to minimise pain (e.g. asking the clinician to soak the dressing off with warm water first). Two individuals reported dressing changes that had been so painful and traumatic, they had needed pain management with gas and air and/or morphine injection. The worst experiences around dressing change were perceived to have been due to clinician error.

Fear and anxiety around dressing change — which can be exacerbated by a previous bad experience — are a common issue. Utilising products that are proven to help reduce pain and trauma at dressing change can make dressing changes better for individuals. As well as dressing selection, technique and communication with the individual around dressing change are also key (Box 6). It is important to assess the type of pain being experienced by the individual; neuropathic pain may be a consideration (Bechert and Abraham, 2009).

Being direct in communication around dressing change can be very helpful in addressing the individual's fear and anxiety. Warning the individual of what might happen and what to expect, being honest and open is vital. Taking the time to do this can have a positive effect in all future dressing changes. It is important to communicate about the pros and cons, and possible effects, at all stages of the treatment process. Routine can be important to some individuals, so any changes should be communicated clearly, to avoid unnecessary anxiety. For instance, using a different but similar dressing may seem like a minor issue to the clinician, but may be very important to the individual.

**Box 6 | Tips for dressing usage in practice (adapted from LeBlanc et al, 2018)**

- Take time to remove dressings slowly
- Adhesive removers can be used when removing the dressing to minimise trauma
- If relevant (e.g. when dealing with skin tears) mark the dressing with an arrow to indicate the correct direction of removal and make sure this is clearly explained in the notes
- Consider using a skin barrier product to protect the surrounding skin (e.g. to prevent maceration if the wound has high exudate levels)
- In at-risk individuals, use an emollient to soften and smooth the wider skin area and prevent further damage
- Continue to monitor the wound for changes or signs of infection.

**Skin issues**

Issues regarding the surrounding skin e.g. blistering, irritation or skin tearing — were widely reported and focus group participants and clinicians agreed this was an area of concern. It is important that the individual's skin is being cared for and monitored.

Skin care and preserving skin integrity can be an important part of prevention in at-risk individuals; for instance, to prevent further skin breakdown or to prevent recurrence in leg ulcers.

Wherever possible, self-care should be encouraged for suitable individuals (LeBlanc et al, 2018). This may include emollient therapy, encouraging individuals to apply suitable moisturisers themselves, and incorporating this into their daily routines. Awareness of the individual's own skin health can be beneficial, encouraging them to monitor their own skin for any changes and be mindful of potential risks (LeBlanc et al, 2018).

### **Undisturbed wound healing (UWH)**

When considering dressing selection, it is important to consider the full dressing process in terms of the individual and their unique needs, rather than a 'one size fits all' ritualistic approach.

UWH focuses on optimising healing by minimising tissue disturbance (Brindle and Farmer, 2019). While there is evidence for the benefits of UWH, it is not commonly practised, for a number of reasons (Brindle and Farmer, 2019). It has been noted that a great deal of dressing change protocols can be dependent on routine, habit and a 'ritualistic' approach, which has been recognised as a wider issue in wound care (Berg et al, 2019). This means that, instead of dressing change being carried out when it is clinically necessary, dressings may be changed at a particular, predetermined time — not because the dressing necessarily needs to be changed, but because 'this is when we always do it'. This blanket approach means that the requirements of the individual and their wound are not taken into consideration, and it may be that the wound is unnecessarily disturbed and healing therefore impeded; in addition, there is an economic impact through increased nursing visits, and there is also an impact on the individual (Berg et al, 2019).

The individual, their wound and overall circumstances should be taken into account. The individual's history, any comorbidities and infection risk should be considered as part of a full holistic assessment. Considering the needs of the individual and their wound should play a key role in rethinking the ritualistic aspects of dressing change protocol, ensuring that the individual criteria are fully assessed in order to optimise outcomes.

The potential benefits of UWH depend on individuals and their circumstances. However, in appropriate individuals, longer wear time can result in a range of benefits, such as:

- Healing is optimised if the wound remains undisturbed (unless there is a specific reason to do so)
- Risk of contamination and potential infection is reduced
- Potential knock-on benefits, such as savings in cost and clinician time (Brindle and Farmer, 2019).

It is also important to consider the individual's circumstances, needs and personal preferences in psychosocial terms, as well as clinical factors (Brindle and Farmer, 2019). For instance, some individuals may be nervous of infection or complication, and simply prefer their wounds to be looked at more frequently — it is vital to listen to and consider the individual's concerns and preferences.

Where UWH is a potentially beneficial option, individuals may need to be educated on the rationale and the advantages of this — communication with the individual is of key importance (Blackburn et al, 2018). Similarly, cultural and personal differences may come into play, and some individuals may prefer their wound to be covered even when it is not clinically necessary. Taking into account these different requirements for individuals should be part of making an appropriate dressing selection.

When considering UWH in the context of person-centred care, it is important to remember that wound care always involves more than the dressing. For example, while UWH may be beneficial to healing, patients may like the clinician contact of more frequent wound dressing changes. If social contact and interaction is a priority and isolation is a risk, the clinician will need to bear this in mind. Equally, UWH may represent an opportunity for the patient to resume everyday activities that have the potential to improve quality of life.

It is always vital to consider the individual's priorities and concerns. This can be particularly relevant when considering wear time, as many individuals have fears about strikethrough, leakage and odour that need to be prioritised.

**'The most important thing is to feel confident about smell and leakage'**

### What makes the 'ideal' dressing?

Factors selected by individuals living with a wound:

- Healing
- Seeing progress
- Good coverage of the wound
- Dealing with moisture
- Dealing with odour
- Confidence that there will be no leakage or smell, so you can go out without feeling self-conscious
- Comfortable
- 'Wound friendly'
- Not 'cloth-like' material
- Not too much padding, as this can be bulky and feel conspicuous
- Soft on skin
- Flexible/pliable
- Secure
- Not irritating
- Not too sticky
- Not traumatic
- Waterproof
- Suited to the individual wound at that particular time
- Prefer spray products to impregnated dressings
- Goes on and comes off easily (e.g. you can fix it yourself if the dressing rolls or comes off at the edges)
- Cooling and breathable where necessary (e.g. in sweatier areas [underarm] or hot weather).

### INDIVIDUAL EXPERIENCE

**'I had surgery and the surgeon used the wrong dressing. It was stuck completely to the wound. That first dressing change was pure agony. It was bleeding. I had to have gas and air, and a morphine injection. It was a really nasty experience and those problems made it worse than it needed to be. It puts you off.'**

## CONCLUSIONS AND ACTION POINTS

This document was designed to highlight some of the issues that patients face when living with a wound. Listening to the patients and clinicians involved helped to uncover some key messages relating to patients' needs and to try and address what is important to them, as individuals and as a wider group.

Wounds are often referred to as a chronic condition; however, they are not treated as such. In other areas of chronic disease management, patients are given a comprehensive care package that they are involved in creating, to enable them to live as full a life as possible with their condition. In wound care, it is clear that this is not the case. Care may depend on routine, not on individual needs. Product choices may be minimal and again not reflect the patient's needs.

Affecting change may require a shift in clinician (and patient) mindset. 'Role modelling' in wound care influences systems and processes — so there is a need for experienced staff to act as role models, displaying compassionate behaviour and putting the patient first. Educating fellow clinicians is vital as they are often the ones carrying out care and having contact with the patient. Procurement and product availability continues to be an issue, and clinicians need to be involved in decision-making in order to be able to provide the best care to their patients.

Communication within teams can help to ensure that improvements are made where necessary. 'Huddles' have been used successfully in the acute sector to improve processes and safety, and could be used within other settings. This involves short meetings (2–3 minutes) with the express purpose of team communication and empowering all members to have their voice heard. This can be an opportunity to ask questions such as:

- Where are we now?
- What are we getting right?
- What can we improve?
- Are we treating to heal?

From a practical point of view, it is important to remember that 'cost savings' in product choices may be a false economy. It is vital to consider the individual patient and their wound: making the right choices for the patient at the right time should, in fact, result in reduced costs across the care pathway.

### Key messages

- We must look honestly at our own behaviour and how we are meeting the individual's needs before we label the individual
- While care needs to be individualised, structured systems need to be put in place so that variables do not impact on the patient
- Wounds are often labelled as a chronic condition that can impose severe limitations on the patient and need to be viewed as this by the wider team
- Self-care is vital but needs to be approached with a critical eye: what does the patient need and how involved do they want to be (and do they have the capacity to be)?
- All patients should be provided with the relevant information (in plain language) and access to the resources they need
- Ongoing communication and aftercare is important and needs to be more valued
- The therapeutic relationship between clinician and patient is key: this should be a meaningful relationship that provides support and makes the patient feel safe and understood
- Basic care and compassion should be remembered e.g. touch is important and small gestures matter
- Breaking down taboos is needed — vulnerable patients need to be engaged and reassured
- An MDT approach is key but can be difficult to achieve in practice
- A task-driven approach can mean that effective consideration and communication is lost — we must ensure this does not happen
- Lack of time can be a false barrier and should not be used as an excuse.

**We must remember that all patients are different: behind every wound is an individual.**

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**APPENDIX 1:  
PATIENT FOCUS  
GROUP DISCUSSION  
POINTS**

**1. Living with your wound**

- What does living with a wound personally mean to you?
- How does it affect your life physically?
- What impact does having a wound have on personal relationships?
- Has living with a wound had an effect on your work situation or finances?
- What are the three most important considerations for you in living with a wound?
- What have been the positive and negative aspects of living with your wound and the care you have received?
- What impact have these experiences had on your wellbeing?
- Do you feel that you were put on the correct care path straight away, or did this take some time (e.g. seeing the correct clinician, treatments that addressed all of your symptoms)?
- Do you feel you know who to turn to for clinical support if/when you need it?
- What makes it easier/more difficult for you to stick to your treatment?

**2. Dressings**

- How would you describe your experience with wound dressings?
- What have been your positive and negative experiences with dressing changes?
- How do you feel about dressings with a longer wear time?
- Would better education about this aspect encourage you to wear your dressing for longer? If not, why not?
- How do you feel about 'undisturbed healing'?
- What are the most important considerations for you in using a dressing?
- How could a dressing help you and your symptoms?
- What features would you expect in an 'ideal' dressing?

**3. The future**

- What could be improved about your care experience?
- How could dressing development improve your quality of life?
- Beyond the dressing, are there any aspects to your care that you would like to see change?
- Is there anything else that is important to you that you'd like to talk about?

## CONSENSUS DOCUMENT

**APPENDIX 2:  
GLOSSARY OF TERMS  
FOR DISCUSSION  
AND EXPLANATION**

**Chronic wound:** A wound that is not healing (or not healing as quickly as expected, or as predicted).

**Debridement:** Removing dead, infected or damaged skin from the wound, so it does not hinder the healthy skin from healing — may be done in different ways that should be clearly described to patients so that they know what to expect.

**Delayed (or stalled) wound healing:** When wound healing progresses at a slower rate than expected.

**Epidermolysis bullosa (EB):** EB is a group of rare genetic conditions that result in easy blistering of the skin and mucous membranes. Blisters are caused by minor trauma or friction and are very painful.

**Exudate:** Fluid that comes from the wound — it is important to the healing process, but may cause problems if there is too much or too little (if the wound is too wet or too dry).

**Friable tissue:** Skin that bleeds easily.

**Granulation tissue:** Healthy new skin forming that is red or pink in colour and indicates that the wound is healing.

**Infection:** When outside bacteria cause problems with the wound, such as further damage to the skin or general illness in some cases.

**Inflammation:** This causes the wound to be red, swollen, painful or hot; sometimes, but not always, a sign of infection.

**Multidisciplinary team (MDT):** The MDT is a group of health care workers who are members of different disciplines (e.g. nurses, psychiatrists), each providing specific services to the patient. An 'MDT approach' aims to co-ordinate their services and work together towards a specific set of goals.

**Necrotic tissue:** Dead skin that is often dark in colour, made up of dehydrated dead skin cells, which can get in the way of healing.

**Odour/malodour:** Bad smell associated with the wound, which may also be related to infection.

**Periwound:** The skin immediately around the wound.

**Slough:** A yellow/white layer of dead skin in the wound, which can prevent or slow down healing.

**Undisturbed wound healing:** Leaving the wound untouched, and using dressings that can be left in place for longer, as studies have shown that this helps healing.

**Wound dressing:** A dressing is a sterile pad or compress applied to a wound to promote healing and protect the wound from further harm. A dressing is designed to be in direct contact with the wound.





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