

A tool to promote patient and informal carer involvement for shared wound care

Shared wound care encompasses approaches and interventions that enable patients to participate in care planning and delivery, rather than just being a passive recipient of services provided. A key step in facilitating greater shared care is identifying the individuals (patients and informal carers) who would be good candidates to be involved in shared wound care. An international survey was conducted to help identify the characteristics that may indicate an individual's suitability to participate in shared wound care. The results of which informed the development of a guide that clinicians can use to direct discussion to better understand patient and informal carer suitability for shared wound care and identify the approaches and interventions that may be suited to the patient and informal carer's needs.

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Shared care is an established practice in many parts of the globe for the treatment of chronic conditions such as diabetes (University of Southern California, 2021) incontinence (Spinks, 2010) and stoma management (Gesaro, 2013). As a result of the COVID-19 pandemic, there is now an increased opportunity for wound care practitioners to also explore adoption and wider standardisation of shared care approaches.

Shared care has the potential to maximise the health and wellness of patients and informal carers and contribute to greater satisfaction with care (McAllister et al, 2012; Wounds International, 2016). Shared care encompasses approaches and interventions that may enable patients to participate in care planning, decision making and care delivery. This approach values the patient as an active participant rather than a passive recipient of care (Wounds International, 2016).

Shared wound care extends to the engagement of the informal carer (a member of a person's social network, e.g. family, friend or guardian) who helps the individual with activities of daily living, and may assist with the patient's wound-related care. Patient involvement can not only improve wound care outcomes, but also reduce overall health costs and improve overall quality of life (Hibbard and Gilbert, 2014).

Project objective

An international expert panel from a variety of clinical disciplines, from education and research, convened online in April 2021 to develop a tool for clinicians to use with patients and informal carers to discuss shared wound care. The aim is to encourage shared wound care where appropriate. The tool is based on results from a clinician survey (phase 1) and a patient and informal carer survey (phase 2), both of which investigated perspectives and perceptions towards shared wound care.

Clinician perspectives to patient involvement in wound-related care (phase 1)

A 2020 survey of over 500 clinicians who treat chronic wounds in a community setting (e.g. nurses, wound care nurses or primary care physicians) from Australia, China, France, Germany, Spain, the UK and the USA reported that 45% of their patients with chronic wounds could benefit from greater involvement in shared wound care (Moore and Coggins, 2021). The survey also identified the key barriers to greater patient involvement, including clinician's concerns about the patient's ability to perform accurate wound care, especially for complex wounds, and whether patients would be compliant with treatment. There were also concerns among some clinicians that they could

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become redundant if patients became more involved in shared wound care.

The survey findings indicated that there was a need for a more formal approach to promote shared wound care, particularly with respect to identifying the individuals who are able to participate in shared wound care (Moore and Coggins, 2021).

Patient and informal carer perspectives to shared wound care (phase 2)

An international survey of patients and informal carers was conducted in March 2021 to identify perceptions towards engagement in wound-related care. Respondents were patients largely sampled from general population consumer panels. Some targeting was applied to recruit specifically among patients with skin/dermatological problems and carers of older people (not specifically with wounds). In total, 715 interviews were conducted in six countries: France (n=130), Germany (n=130), Spain (n=130), UK (n=130), USA (n=130) and Australia (n=65).

The phase 2 international survey results identified the four key factors required to determine a patient and informal carer's suitability to participate in shared wound care.

1. Knowledge, understanding and ability

Knowledge: Effective patient involvement is not achievable unless the patient and informal carer gains the necessary knowledge and skills and are educated about their condition (Tol et al, 2013). Education should be tailored to the patient and informal carer based on the existing level of knowledge and what they are willing to learn (Euromed Info). If they have already sought information (e.g. online), the sources used should be discussed to ensure that the information is accurate so that any misconceptions can be dispelled (Wounds International, 2016).

Understanding: The ability of patients to be active participants may be dependent on their level of health literacy and capacity to understand their health condition.

Ability: Equality, diversity and inclusion are the cornerstone of all healthcare providers and ensure fair treatment and opportunity for all. It should not be assumed that just because someone has certain characteristics that may have traditionally indicated low involvement, they should be excluded from discussions around shared care, such as advancing age, having a chronic wound or coming from a low socioeconomic background (Hibbard and Gilbert, 2014).

2. Willingness to engage in wound-related care

Not all patients and informal carers will want to be involved in wound-related care and every individual has the right to accept or refuse greater involvement in shared care. It is important for the clinician to keep an open mind about whether the patient and informal carer is willing to be involved.

3. Patient support system

A patient's support system may impact on the patient's level of involvement in their own care. Often it is the carer who conducts wound care if the patient is not able or willing (Miller and Kapp, 2015), so recognising what the carer is able to take on physically is essential to assessing suitability of shared wound care.

4. Patient-practitioner relationship

A patient's involvement in their health care is heavily reliant on the interplay between the clinician (their attitudes to patient engagement), patient (how they perceive the patient's role) and carer (their presence and behaviour). In the patient-centred model, the focus is on communication between the patient and informal carer and the clinician to support patient involvement (Wounds International, 2016)

[Figure 1].

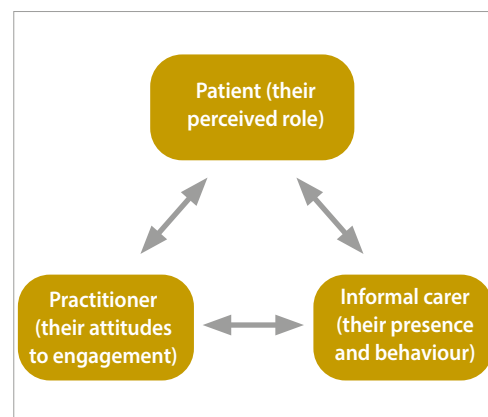


Figure 1. The patient and informal carer-practitioner relationship.

Patient involvement is not a linear process

Patient involvement in wound management is not a linear process. It is important to reassess beliefs about, and capacity to, self-manage over time to identify when health goals and care planning need re-adjustment (Kapp and Miller, 2015). Clinicians should regularly revisit the patient and informal carer's knowledge, understanding, ability and willingness to participate in care, and circumstances, e.g.

medical, financial and environmental stressors. As patient involvement is not a static construct, patients and informal carers may be more or less involved throughout their care episode (Moore and Coggins, 2021).

Potential levels of patient involvement identified in phase 2 research

Based on the factors required to determine a patient and informal carer's suitability to participate in shared wound-related care (knowledge, understanding and ability; willingness to engage in shared wound care; patient support network; and the patient-practitioner relationship), four groups were identified from the phase 2 survey data to describe to what extent a patient and informal carer could be involved in shared wound care [Figure 2]. By recognising the potential level of patient and informal carer involvement, the clinician can work alongside to set realistic wound care goals.

Key attitudes and behaviours of patients and informal carers who are 'self-sufficient' (40% of phase 2 survey cohort):

Patients and informal carers who are 'self-sufficient' may be relatively knowledgeable, able and willing to be involved in shared wound care. They may be more likely to take an active role in making lifestyle changes to improve wound healing and tend to feel the most restricted in terms of working, sleep and socialising due to the presence of a wound. They tend to have a large support network size and may be relatively less trusting of clinicians. They may benefit from regularly discussing their knowledge

and improving the patient and informal carer-practitioner partnership.

Key attitudes and behaviours of patients and informal carers who are 'reassurance seekers' (11% of phase 2 survey cohort):

Patients and informal carers who are 'reassurance seekers' may have relatively low self-perceived knowledge, ability and confidence to engage, but may have a relatively higher willingness to be involved in shared wound care. They may have a very small support network. These patients and informal carers are very trusting of clinicians and willing to consult clinicians for advice and education. They may benefit from regularly discussing fears and concerns and provide reassurance and praise when patient and informal carers are displaying necessary behaviours and actions.

Key attitudes and behaviours of patients and informal carers who are 'unaware' (42% of phase 2 survey cohort):

Patients and informal carers who are 'unaware' may have relatively low perception of their knowledge and ability to engage in care, and they may also have a relatively low willingness to engage in shared wound care. Further, they may be the most likely to be unaware that they can engage more in their shared wound care. Also, they may have a small support network. These patient and informal carers may see clinicians as 'a last resort' and may be least likely to follow advice and to make beneficial lifestyle choices. This group may benefit from regularly discussing their awareness of shared wound care.

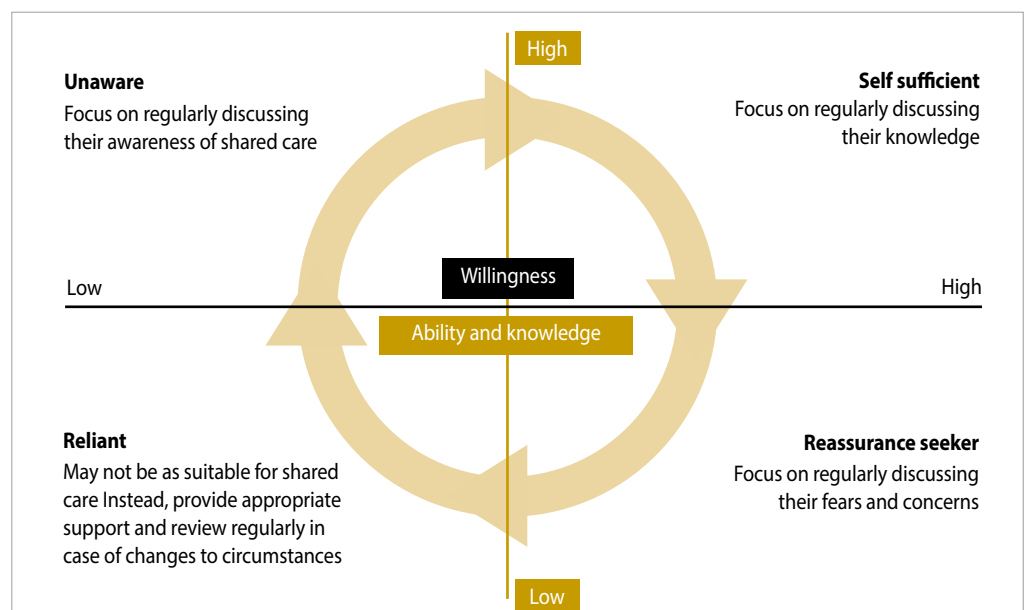


Figure 2. A patient and informal carer's potential to be involved in shared care depends on their knowledge, ability and willingness to participate in shared wound care.

Box 1. Dressing considerations for patients and carers involved in shared wound care.

The treatment and dressing selection for the patient should be based on a holistic patient and wound assessment, such as the T.I.M.E. clinical decision support tool (Moore et al, 2019). A dressing wear time of 5-7 days was indicated as potentially beneficial for patients by clinicians (Moore and Coggins, 2021) and by patients in the new research presented in this article. Patients also reported that they require dressings that control odour, are showerproof to allow bathing and are adherent to allow individuals to conduct their activities of daily living without the risk of the dressing falling off. If the dressing is to be used by patients, it should be easy-to-use and take out of the packaging especially for people with low manual dexterity, with clear instructions on which side of the dressing goes next to the wound and how to use the dressing in general.

Intuitive dressings that can clearly indicate to the patient and informal carer when there is infection or high levels of exudate would be beneficial. This may reduce the amount of unnecessary tampering with dressings and wounds and, therefore, reduce the risk of infection. For example, ALLEVYN LIFE (Smith + Nephew) incorporates a design feature that indicates when a dressing change is needed due to exudate levels. The dressing has been shown to be of benefit to both patients and clinicians in promoting wound closure and help lead to improved patient wellbeing (Rossington et al, 2013; Tiscar-González et al, 2021).

Key attitudes and behaviours of patients and informal carers who are 'reliant' (7% of phase 2 survey cohort):

Patients and carers who are 'reliant' may be unable physically and/or mentally to take an active role in improving other aspects of their health or they may have relatively low knowledge and understanding. Additionally, they may have a high level of trust and dependency on the clinician and follow advice where possible. Further, they may have a high number of clinician visits. These patients and informal carers would benefit from further assessment and education. If after further support, the patient and informal carer do not have the capacity to be more involved in care, shared wound care may not be a suitable approach at this time. Review regularly in case of changes to circumstances.

The phase 2 survey identified that most of the patients in the cohort ($n=715$; 42%) reflect the 'unaware' patient group, who scored relatively high on ability, but low on willingness, compared to other patient groups in the survey. Thus, the 'unaware' group represent the largest group of individuals who would benefit from being supported to be more involved in shared wound care.

Approaches and interventions

Once it has been established that an individual is a suitable candidate for shared wound care, the clinician, patient and informal carer can work together to determine what, when and how to be involved. Many patients are able to understand their condition and be involved in decisions about their treatment, but they are not able to take full responsibility for monitoring and managing their wound or condition (Wounds International, 2016).

A patient and informal carer's potential to participate in a certain aspect of shared wound care may change over time, so it is important to review the situation periodically. This strengthens the suggestions by Moore and Coggins (2020) that the potential for patient and/or informal carer involvement is not a static construct, but instead a continuum based on changing knowledge, understanding and ability, and willingness to engage in care [Figure 2]. It is therefore imperative that involvement, whether great or small, is encouraged and supported.

There are three main areas where the patient and informal carer can be supported to participate in shared wound care:

- **Wound-related care:** The patient and informal carer may be provided with education and

training on how to remove a dressing, clean the wound, and apply a clean dressing. They should be supplied with wound care products and information on correct application technique and wear time [Box 1].

- **Lifestyle:** The patient and informal carer may be provided with education and support to make lifestyle changes that will improve wound healing, such as appropriate nutrition, exercise as indicated, smoking cessation.
- **Supporting the patient-practitioner partnership:** For clinicians, supporting the patient-practitioner relationship means understanding their patients and developing a partnership that facilitates a transparency of information for both parties. For patients, it means being active in the management of their own health and health care, and in any decisions made about available treatment options.

Development of a tool

The international expert panel convened online to discuss the survey findings and develop a tool to help clinicians to identify patients and informal carers who may be able to be more involved in shared wound care. It was agreed that a tool should be:

- Quick to complete and usable in a range of healthcare settings (i.e., the clinic and home setting)
- Digitalised so that it can be added to healthcare records systems
- Presented in simple language that can be translated into other languages and is accessible for culturally and linguistically diverse patient groups
- Integrated into the ABCDE approach from the T.I.M.E. clinical decision support tool (CDST; Moore et al, 2019)
- Cognizant that:
 - informal carers are an integral part of the engagement process
 - involvement in shared wound care is not static and that the ability or willingness of the patient and informal carer to participate in care changes over time.

Shared wound care discussion guide

The shared wound care discussion guide developed by the panel [Figure 3] is an aid for clinicians to use with the patient and informal carer to discuss their awareness and willingness to be involved in shared wound care. The tool builds on international guidelines (Wounds International, 2016), the phase 1 clinician survey data (Moore and Coggins, 2021) and phase 2

Shared wound care discussion guide¹

Use this tool in conjunction with the ABCDE approach from the T.I.M.E. clinical decision support tool^{2,3} and follow the steps below with the patient and/or carer (also known as informal carer or caregiver)

1 Awareness: Is the patient/carer aware they can be involved in wound care?

Yes	No
<p>Talk with the patient/carer to establish:</p> <ul style="list-style-type: none"> Wound knowledge, the impact of not treating the wound and the individual's wound care needs Fears and concerns regarding shared wound care Motivation for shared wound care Willingness to participate in shared wound care 	<p>Talk with the patient/carer to clarify the meaning of shared care:</p> <ul style="list-style-type: none"> Shared care encompasses approaches and interventions that enable patients to participate in care planning over time, rather than just being a passive recipient of the services provided

2 Which of the following best describes the patient/carer in regard to shared wound care?

Self-sufficient	Reassurance seeker	Unaware	Reliant
<ul style="list-style-type: none"> Relatively knowledgeable about their wound Willing and motivated to optimise lifestyle to enhance wound healing Physically and mentally capable to participate in shared care 	<ul style="list-style-type: none"> Room for improvement in knowledge and confidence Relatively reliant on healthcare professionals (HCPs) to provide care Cautious to perform wound care Physically and mentally capable to participate in shared care 	<ul style="list-style-type: none"> Not very involved in wound care Unaware that it is possible to engage more in their care Physically and mentally capable but unwilling to participate in shared care 	<ul style="list-style-type: none"> HCPs lead in all aspects of wound care and other general health care needs Does not have the physical and mental ability or capacity to be involved in shared care

Approaches and interventions

Have regular discussion with the patient/carer regarding shared wound care, including motivational interviewing and attainable goal-setting, focusing on:

Knowledge

Fears and concerns

Awareness

Shared wound care may not be a suitable option at this time

Provide appropriate support and revisit potential for more involvement

3 Identify what the patient/carer can do as part of shared wound care

Wound care	Lifestyle change	Patient-practitioner relationship												
<p>Does the patient/carer have the potential to perform wound care, including dressing changes?</p> <table border="1"> <thead> <tr> <th>Yes</th> <th>No</th> </tr> </thead> <tbody> <tr> <td> <p>Considerations</p> <ul style="list-style-type: none"> Demonstrate and educate on how to perform treatment requirements Identify needs and provide patient/carer with educational resources (e.g. online, electronic, written) A diary for goal setting and to record dressing changes Provide patient/carer with tools: dressing change indicator; signs of infection </td> <td> <p>Considerations</p> <ul style="list-style-type: none"> HCP to conduct wound assessment and dressing change according to local protocol Periodically revisit the potential for involvement in dressing changes (e.g. if patient/carer circumstances change) </td> </tr> </tbody> </table>	Yes	No	<p>Considerations</p> <ul style="list-style-type: none"> Demonstrate and educate on how to perform treatment requirements Identify needs and provide patient/carer with educational resources (e.g. online, electronic, written) A diary for goal setting and to record dressing changes Provide patient/carer with tools: dressing change indicator; signs of infection 	<p>Considerations</p> <ul style="list-style-type: none"> HCP to conduct wound assessment and dressing change according to local protocol Periodically revisit the potential for involvement in dressing changes (e.g. if patient/carer circumstances change) 	<p>Does the patient/carer have the potential to make lifestyle changes to improve wound healing and address the underlying causes of the wound (e.g. appropriate nutrition, exercise as indicated, using compression, offloading)?</p> <table border="1"> <thead> <tr> <th>Yes</th> <th>No</th> </tr> </thead> <tbody> <tr> <td> <p>Considerations</p> <ul style="list-style-type: none"> Coach patient/carer about appropriate lifestyle changes Assess results and make changes as needed A lifestyle diary to record/track lifestyle changes </td> <td> <p>Considerations</p> <ul style="list-style-type: none"> Investigate and address reason (physical or cognitive impairment, fear, anxiety, resources) Assess whether patient/carer willingness and ability may be improved Refer to allied health professionals for review and support (e.g. dietitian or podiatrist) Periodically revisit the potential for lifestyle change (e.g. if patient/carer circumstances change) </td> </tr> </tbody> </table>	Yes	No	<p>Considerations</p> <ul style="list-style-type: none"> Coach patient/carer about appropriate lifestyle changes Assess results and make changes as needed A lifestyle diary to record/track lifestyle changes 	<p>Considerations</p> <ul style="list-style-type: none"> Investigate and address reason (physical or cognitive impairment, fear, anxiety, resources) Assess whether patient/carer willingness and ability may be improved Refer to allied health professionals for review and support (e.g. dietitian or podiatrist) Periodically revisit the potential for lifestyle change (e.g. if patient/carer circumstances change) 	<p>Does the patient/carer have the potential to share information about wound progress and inform HCPs about wound deterioration?</p> <table border="1"> <thead> <tr> <th>Yes</th> <th>No</th> </tr> </thead> <tbody> <tr> <td> <p>Considerations</p> <ul style="list-style-type: none"> Develop an open and honest patient-practitioner partnership Educate the patient/carer about how to recognise wound deterioration Educate the patient/carer to contact the HCP without delay if the wound deteriorates Provide HCP contact information according to local protocol </td> <td> <p>Considerations</p> <ul style="list-style-type: none"> Periodically revisit the potential for greater partnership (e.g. if patient/carer circumstances change) </td> </tr> </tbody> </table>	Yes	No	<p>Considerations</p> <ul style="list-style-type: none"> Develop an open and honest patient-practitioner partnership Educate the patient/carer about how to recognise wound deterioration Educate the patient/carer to contact the HCP without delay if the wound deteriorates Provide HCP contact information according to local protocol 	<p>Considerations</p> <ul style="list-style-type: none"> Periodically revisit the potential for greater partnership (e.g. if patient/carer circumstances change)
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data that have identified the need to provide educational support for clinicians in supporting patients and informal carers to participate in shared wound care. The tool aims to:

- Identify patient and informal carers who may benefit from being involved in shared wound care
- Improve patient and service delivery outcomes by increasing education among patients and carers and encouraging more continuous, consistent and collaborative care
- Directs the clinician to implement the approaches and interventions that may be most suited to the patient's needs (e.g. wound-related care, lifestyle and/or supporting the patient-practitioner relationship).

The tool should be considered to be used at the start of the shared care journey with the patient and informal carer and be revisited periodically to gauge success and satisfaction of all stakeholders of shared care. Once the shared care plan is developed, there is a need to identify any additional education, support, interventions and monitoring required for successful shared care. For example, if shared care involves the patient and informal carer conducting wound treatment, the next step is to ensure the patient and informal carer has the ability to complete self-treatment activities (such as how the patient cleans the wound and applies and removes dressings and applies compression therapy). The 'Self-Treatment of Wounds for Venous Leg Ulcers Checklist' (STOW-V Checklist) is one such tool, which has been systematically developed (Kapp and Santamaria, 2021) and tested (Kapp et al, 2021) in the community care setting and is available free of charge for use by healthcare providers.

Next steps

To evaluate the shared wound care discussion guide, the next steps will involve three essential elements:

- **Pilot use of the tool:** Pilot work will be conducted in a range of healthcare settings to ascertain the impact of the tool on practice. It is anticipated that the tool will be used globally alongside other educational tools, such as the T.I.M.E. CDST (Moore et al, 2019)
- **Support clinicians to use the tool:** An educational package (informed by pilot data) will be developed to support the implantation of the tool and promote fidelity of use

- **Changing mindsets:** There is often an assumption that health care professionals provide wound-related care paternalistically. Tools to encourage more patient involvement do not signal a reduction of care or a threat to the role of the clinician; instead, they focus on the importance of person-centred care which is supported by national and international guidance (e.g. World Health Organization, 2016).

Conclusion

Rising costs of healthcare, increasing numbers of people living with wounds and an understanding that patient wellbeing can be optimised are all drivers of greater patient engagement and involvement (Guest et al, 2015; Wounds International, 2016; World Union Wound Healing Societies, 2020).

The shared wound care discussion guide is expected to serve as a discussion guide to help clinicians identify the patient and informal carers who have the potential to have an involvement in shared wound care. By first determining the patient and informal carer's awareness and willingness to participate in shared wound care, the tool directs relevant approaches and interventions for the clinician to consider. Not all patients and informal carers will have the potential to have involvement in shared wound care, and the tool accounts for the situation where great or small involvement is possible. The topic of shared wound care should be revisited periodically with the patient and informal carer as the circumstances, willingness and ability of the patient and informal carer to participate in shared care can change. The newly developed, discussion guide aims to maximise shared wound care possibilities for patients and informal carers who would benefit from greater involvement in shared wound care. **WINT**

Declaration

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