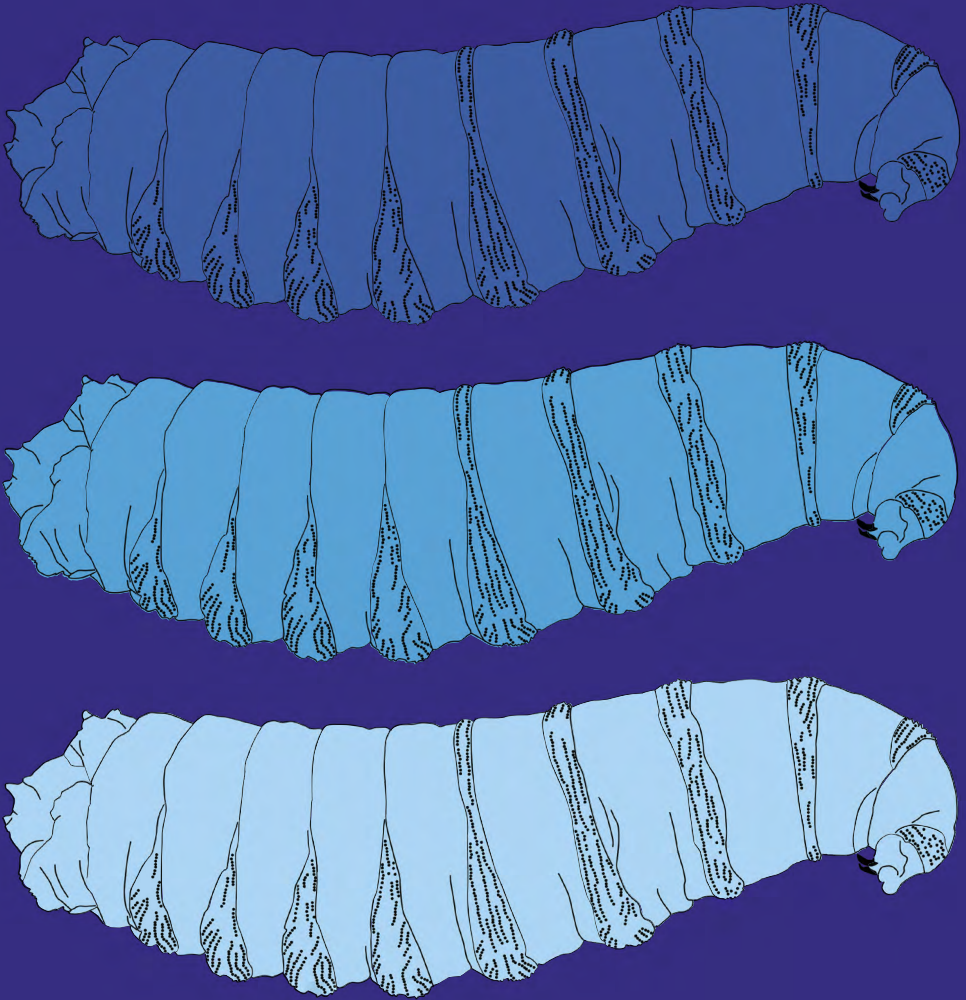


A COMPLETE GUIDE TO MAGGOT THERAPY

Clinical Practice, Therapeutic Principles,
Production, Distribution, and Ethics



EDITED BY FRANK STADLER



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Digital material and resources associated with this volume are available at <https://doi.org/10.11647/OBP.0281#resources>

ISBN Paperback: 9781800647282

ISBN Hardback: 9781800647299

ISBN Digital (PDF): 9781800647305

ISBN Digital ebook (epub): 9781800647312

ISBN Digital ebook (azw3): 9781800647329

ISBN XML: 9781800647336

ISBN HTML: 9781800647343

DOI: 10.11647/OBP.0300

Cover image: Line drawing of a green bottle blowfly (*Lucilia sericata*) maggot by Frank Stadler (2022), CC BY-NC. Cover design by Katy Saunders.

2. Living with a Chronic Wound

Rajna Ogrin and Kylie J. Elder

Any clinical intervention must be person-centered and maggot therapy is no different. Therefore, it is important to fully understand and appreciate what it means for a person to live with a non-healing wound, often for many years. Using the hypothetical but representative case of Beverly, the authors explore the impact of chronic wounds on the wellbeing of the person. Since wellbeing is a multidimensional concept, the chapter examines psychological, social, as well as spiritual and cultural wellbeing as shaped by the lived experience of a chronic wound. There are feedback loops and interactions between the symptoms and the persons' physical, psychological, social, and spiritual wellbeing.

Introduction

Living with a chronic wound can have a substantial impact on an individual's physical, psychological, social, and spiritual wellbeing. Financial cost can also burden people living with wounds and their families [1]. Maggot therapy can contribute to the better management of chronic wounds and thereby improve the wellbeing of those living with chronic wounds. Medicinal maggots stimulate healthy new granulation tissue in the wound bed [2–4] and reduce the microbiological burden in wounds through their ingestion and digestion of microbes and through the excretion and secretion of antibacterial compounds [5–8]. This supports the management of issues related to chronic wounds,

including healing time [9], need for antibiotics [9], exudate management and odour [10], and cost of treatment [11, 12]. Exudate is defined as “exuded matter; especially the material composed of serum, fibrin, and white blood cells that escapes into a superficial lesion or area of inflammation” [13]. Chapters 8 to 10 of this book give an up-to-date summary of how medicinal maggots achieve debridement, infection control, and wound healing [14–16].

A shared approach to decision making, involving people living with wounds, will encourage optimal treatment outcomes. This should include decisions on the appropriate management of wounds and consideration of the impact of treatment on individuals’ wellbeing [17]. This is particularly relevant for consideration and integration of an unusual wound care treatment such as maggot therapy in the care of people with chronic wounds. It is therefore important for stakeholders in the maggot therapy supply chain, whether they be researchers, producers, health insurers, or healthcare providers, to understand what it is like for a person to live with a chronic wound. Using the fictional, albeit entirely representative, case of Beverly who is a person on the chronic wound journey, this chapter will describe the impact of chronic wounds on physical, psychological, social, and spiritual wellbeing as well as the structural aspects of health systems that impact on how people live with chronic wounds.

Wellbeing in People Living with Chronic Wounds

Beverly. Five months ago, while working in her garden, 74-year-old Beverly scratched her lower left leg on a branch, causing her skin to break open. She has diabetes, diagnosed 10 years ago, hypertension, hypercholesterolaemia and arthritis in her left knee. Beverly is active in the community, volunteering at the local charity shop twice a week. Her family live an hour’s drive away and although she has assistance for house cleaning, she is otherwise self-sufficient. Beverly does not drive but catches the local bus to the charity shop. Social connectedness and staying active are most important to Beverly. When Beverly first developed the wound, she put a clean bandage on it and thought it would go away.

Chronic wounds are simply wounds that do not proceed to heal along the normal wound trajectory [18] which encompasses haemostasis,

inflammation, reconstruction, and maturation [19]. Wounds can become chronic for a variety of reasons: physiological, behavioural, societal, and environmental. Chronicity of a wound can also be influenced by the health system structure and ability to access treatment [20]. Because of these factors, once present, chronic wounds are very difficult to heal, and may take considerable time, or not heal at all [18].

The presence of a chronic wound significantly impacts the wellbeing of individuals, with pain, anxiety, and disappointment being common [21]. Those with malignant fungating wounds, in particular, feel a loss of control over their body and their lives [22], with social implications of malodour and other physical symptoms [23]. At first, people with chronic wounds may accept the inconvenience of a wound. However, as the wound duration increases, coping becomes more difficult and withdrawal from their social environment may occur as fears of non-healing increase [21]. Although the goal of care for most people with wounds is healing, for malignant or non-healing wounds, managing the physical symptoms is very important [1, 23, 24], with the aim of living positively with the wound [25]. Palliation goals for non-healing chronic wounds centre around preventing new wounds from developing, preventing existing wounds from deteriorating, and symptom management to address comfort and quality of life [26]. Therefore, the overall wellbeing of the person living with the wound is just as important an outcome as wound healing itself [26].

Wellbeing means that people have the physical, psychological, social, and spiritual resources they need to meet a particular physical, psychological, and/or social challenge [27]. The definition of wellbeing in relation to wound management is outlined in Box 1. The first three interrelated domains of wellbeing have been articulated by the World Health Organization [28] as:

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

And spiritual wellbeing was added and defined by International Consensus [1]:

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

Box 1. Wellbeing in relation to wound management.

As defined in *Optimising wellbeing in people living with a wound. An expert working group review* [1]:

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

Beverly thought that her wound would heal after a few weeks, but she has had it for over three months and she’s so sick of it, and worried it will never heal. The pain has limited her going out and she can only volunteer at the charity shop for a couple of hours a week. She relies on a friend to pick her up and drive her as she can no longer catch public transport. She finds this distressing as she prefers to be self-reliant. Even having to wear the bandages worries her, as it shows that something is wrong. She tries to hide them by wearing long skirts and thick stockings, not able to wear the normal trousers she prefers because she can’t fit them over the bandages. Sometimes the wound leaks through the bandage and starts to smell. She has been attending the local doctor’s surgery to get some wound advice and dressings but getting there is hard, and she still needs to change the dressing herself.

An attempt has been made to separate the issues associated with living with a chronic wound into physical, psychological, social, and system domains, however, as outlined by Beverly's case, many issues fall under multiple domains. Further, some issues lead to the development of others across the domains. This reinforces how challenging it is to understand the complex impacts of chronic wounds on people's lives. Clinicians must consider the whole person for management to be truly person-centred [29], and thereby more likely to support people to achieve their goals of care. Unfortunately, the majority of existing studies focus on quality of life when living with a wound, which emphasises deficits in peoples' lives, rather than a holistic, asset-based approach associated with wellbeing [17]. We will convey the evidence related to issues affecting the lives of people living with a chronic wound, and show how they impact lives using our case study of Beverly.

Physical Wellbeing

Beverly finds the open wound a bit painful and moving too much hurts. The lack of sleep due to the itchiness and pain in her wound makes her so tired and irritable the next day. She's worried about taking pain medication, as these kinds of tablets can be addictive. She covers her wound with a dressing and bandages, but it leaks quite a lot and the bandages can't contain it all. When the fluid sits for a time it begins to smell and hardens the dressing, which makes the area even more painful to walk with, as well as being very embarrassing. She has had multiple infections, and where previously the wound was clean and red, it now has a persistent smelly grey base and the dressings don't make much of a difference. Beverly stopped volunteering at the charity shop as she doesn't want to be with people for long periods of time in case they notice the leaking or smell. She now relies on a walking frame for mobility as the heavy bandages make her feel as if she will fall. She is beginning to put on weight which is also impacting on her arthritic joints. The ulcer is getting larger and her legs are also swelling. It is hard to shower because she must keep the bandages dry and this is very difficult.

Chronic wounds can impact negatively upon the physical wellbeing of people with wounds, with pain/irritation, wound exudate malodour [25, 30], limitations on mobility and sleep disturbances commonly

being raised as issues [31–33]. A poorer quality of life is correlated to dressing change frequency, pain, wound dressing comfort, wound symptom, bleeding, and malodour in individuals with malignant fungating wounds [34]. The effect of each factor can vary, depending on the wound size, depth, location and duration [35]. As shown by Beverly's case, these factors combine to impact on physical functioning. Listed below are issues that have been predominantly identified in the literature. It is important to note this list is not exhaustive, and other issues may also occur:

Pain. Wound pain is reported to vary in type, intensity and duration, and is described in different ways by people with chronic wounds. For example, pain may be experienced as burning, shooting, stabbing, knife-like, throbbing, dull, niggly, gnawing, aching, annoying, hot poker, pins, nerve pain, sticky, or stinging [36]. For some people, pain can be constant, spontaneous, or persistent [37], while others can have pain-free periods interrupted by periods of sudden onset of severe pain with no apparent trigger [36].

Wound pain may be lessened through a number of approaches; however, it can also worsen in the presence of infection, with some treatments, and when undertaking physical activity [36]. It is important to note that if pain is exacerbated or triggered by physical activity, this may also influence the ability of people with chronic wounds to be more active [32, 36]. This, in turn, may lead to further complications that negatively impact physical wellbeing. Pain at dressing changes has been identified as the worst part of having a wound [38].

Finally, pain management may be inadequate in people with chronic wounds [39, 40], with prescription rates and use of analgesia low in people living with wounds [36]. Some individuals are reluctant to use pain medication, concerned they will become addicted [25]. Lack of pain management may impact on attempts at physical activity by virtue of anticipation of the perceived pain [25]. Anxiety can also contribute to this anticipated pain and it is therefore important that this emotion is addressed [41].

Impaired physical mobility. Physical mobility may be impaired either because of ulcer characteristics, the dressing, or self-imposed isolation in response to the impact of symptoms [31]. Limited physical mobility can restrict the ability to undertake activities of daily living including

employment, participation in recreational activities, and social interaction [30–32, 36].

- ***Ulcer characteristics.*** Itchiness, exudate and swelling of the leg are common in people with leg ulcers [32, 36], with itching and pain affecting sleep, leading to increased tiredness during the day, in turn leading to more rest, thereby reducing physical activities [36]. In people with malignant fungating wounds dealing with the physical symptoms of pain, exudate, odour [25], itch, and bleeding is very challenging [23].
- ***Dressings.*** Undertaking outdoor activities may be off-putting owing to the need for dressing changes in people with chronic wounds as they wait for healthcare professional appointments [32]. Bandages can restrict movement in some people living with chronic wounds [40, 42]. Depending on the dressings used, clothing choice can be restricted, including the ability to wear normal footwear, particularly with bandaging [36, 40, 43]. Bathing can be difficult, as people are advised to keep the dressing dry in between dressing changes, the frequency of which can vary from daily to once a week [40, 43, 44].
- ***Self-imposed isolation.*** This is particularly evident if people living with a wound are unable to maintain their own hygiene, which is not uncommon, given that they are asked to keep their dressings dry for days at a time, limiting their ability to bathe [40]. The dressings are often cumbersome and unsightly, and if exudate levels are high and sub-optimally managed, people living with chronic wounds are less likely to leave their homes [43–45]. The limitations on what clothing and footwear may be worn may further lead to people living with chronic wounds isolating themselves [36]. If sleep is disturbed by the wound pain and/or itchiness, then resting during the day may contribute to people isolating themselves [32, 36]. Some people living with a wound reduce the amount of activity they undertake, further limiting outside activities because of an expressed fear of falling and traumatic injury

which could lead to a worsening of their wound or prevent it from healing [42].

Psychological Wellbeing

Beverly is now unable to get around much at all. During the day she has more time to think about her wound and the pain and this makes her feel down and makes the pain worse. Her anxiety that the wound will never heal consumes her. The added weight gain, loss of mobility, limited hygiene and bulky clothes combined make her feel like she is ugly, and useless as a person.

Psychological and social wellbeing have some overlapping aspects. The psychological includes the emotional impact wounds have on persons living with a wound as well as on their carers and family members. These emotions are pivotal in social wellbeing. This interconnectedness makes it difficult to separate some aspects. For example, when wounds do not heal in the expected timeframe, people may withdraw socially and at the same time, experience increased feelings of fear [21]. In addition, poor psychological health is associated with higher risk of depression, less perceived social support, and greater social isolation [46]. While there are many aspects of chronic wounds that lead to a deterioration in psychosocial wellbeing, it is not all negative. Some people with wounds can find satisfaction in their changed circumstances after accepting their situation and adapting their expectations [36]. Further, while depression is common, some people living with wounds remain hopeful of a positive outcome [31].

The impact of chronic wounds on many peoples' psychological wellbeing is significant [1, 21]. Depression, anxiety [47], low mood, and poor quality of life are common in people living with a chronic wound [31, 33, 34]. Further, changes in mood, acceptance, body image, and issues with self-esteem have been identified in reviews of the literature [36]. Body image and self-esteem are particular issues in malignant fungating wounds [22]. Many of the problems experienced stem from

the physical wound characteristics [23, 25, 33], as well as the treatment regimens implemented to manage the wounds [32]. The psychological impact of living with a chronic wound includes, but is not limited to:

Depression

Depression is a common mental condition, “characterized by sadness, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, feelings of tiredness and poor concentration” [48]. It is estimated that up to 30% of all people living with chronic wounds develop depression and/or anxiety [49–51]. An international multi-centre study about the psychological burden of skin diseases identified people living with leg ulcers as having the highest odds ratio for depression when compared with other skin conditions. [47]. Feelings of depression, despair and hopelessness were associated with lack of sleep and subsequent fatigue due to the wound [52]. Again, physical symptoms were the main cause of sleep problems, including pain and itching [36].

Negative Emotions

The physical aspects of chronic wounds can trigger stress and other negative emotions. Anxiety was also associated with the fear that others could smell the ulcer or that there would be exudate leakage [39]. Odour and excessive exudate where leakage occurs remind people that they have a wound, and raise feelings of disgust [53], self-loathing and low self-esteem [23, 54]. The ongoing nature of the wound leads to feelings of frustration because the wound appears to be “forever healing” [55] and to concerns that the wound won’t ever heal [40] or will deteriorate.

Social Wellbeing

Beverly’s family live so far away, so it is difficult for them to help and she is now reliant on neighbours to help her shop and cook. She has also had to accept a carer to shower her because of her poor mobility. She does not feel that she has control over her life. The issues with her wound prevent Beverly from participating in any social activities, and this makes her feel very lonely.

This component involves the ability of people to participate in and engage with family, society, friends, and, if employed, other colleagues at work. The ability to engage with everyday functioning can be restricted either owing to the wound, the dressing or to a self-imposed isolation in response to the impact of symptoms [25, 31].

In the initial stages of developing the wound, people have hope that it will heal in a timely fashion. However, as the wound becomes chronic, relationships with family and friends can become strained as people need to rely on them for help with cooking and cleaning [40, 43]. Further, declining contact with others occurs when people living with wounds lose confidence and hope [56]. They may also hide the true impact of how the wound makes them feel, with some feeling ashamed to talk about their wounds [57].

Self-imposed isolation is common, where people living with wounds may avoid interaction with others because of, either the embarrassing symptoms associated with the wound itself or the physical aspects of the wound and the dressings (or indeed both). The embarrassment can stem from malodour, exudate leakage [25, 58], or blood leakage [25, 37], as well as the unsightly appearance of the dressings [59]. The dressing factors raised previously can negatively impact on body image and life-satisfaction, and contribute to social withdrawal [22, 36, 40, 59–61]. The combination of all of the above factors can also limit mobility, and thereby limit the person's ability to undertake their normal social activities [23, 40, 58].

Spiritual/Cultural Wellbeing

Beverly finds solace in her faith. It is hard for her to go to church, with the pain while walking and her worry about the wound leaking, but she makes the effort. She finds she can share her real worries about her leg with the priest, and it gives her some release from her stress.

Spirituality may provide positive and negative contributions to the wellbeing of people living with chronic wounds. In some individuals, they may believe that they are responsible for their wound and consider it a punishment for their actions from a higher being [62]. Conversely,

spirituality may provide hope of healing, resilience, and endurance to deal with the symptoms [63]. It is important to understand beliefs, religious and otherwise, of individuals living with their chronic wound, as this impacts on the management of their condition and the support resources available to them [1]. For example, this may involve avoiding appointments on days of religious significance or ensuring permission is sought when using treatments that use animal products [64]. Spirituality and cultural wellbeing are less well studied, and would benefit from more research to identify the way they influence choices and practices related to wound management [1].

How People with Chronic Wounds Seek, Access, and Experience Care

Beverly. The doctor referred Beverly to receive home nursing given that her wound had not progressed and she required closer monitoring of her blood sugar levels. Beverly was embarrassed that she needed help, but she was finding it hard to cope with everything, including paying for all the dressings and the doctors' appointments—everything is so expensive. The nurse attended a full assessment and discovered that Beverly's peripheral vascular system was compromised, meaning she needed to wear compression bandages to support her veins to heal. This was the first time Beverly had been told the reason her wound was not healing. The nurses educated Beverly on wound healing, the importance of nutrition and keeping active. They discussed Beverly's options with her and developed a plan of care that considered Beverly's goals. The nurses continued to visit her to attend to dressings and apply the bandages. The pain and exudate from the wound was reduced and Beverly was able to begin to socialise once more.

In low-income countries, access to healthcare may also be limited due to distance [65], and care is frequently sought from traditional healers, and less from government facilities and private health practitioners [30]. Delays in seeking treatment are very common for a number of reasons. People often turn to the use of traditional medicine first [65, 66] because they strongly believe in their ability to control the disease [67], but also due to social and financial constraints [30, 65] and fear of amputation

[66]. Culture also impacts a person's perception of disease and therefore whether and from whom they seek and accept treatment [68].

Generally, in middle- to high-income countries, the General Practitioner is the most common source of care [69]. Many self-treat, often due to lack of healthcare resources, the cost involved, and dissatisfaction with previously received medical care [70]. Self-treatment may also occur to maintain independence, and for convenience regarding treatment schedules—although most have sought professional healthcare input for assessment and advice at some time [71].

Access to Evidence-based Care

Assessing, diagnosing, and managing wounds are complex activities that need to be enabled by the healthcare system and institutional capacity. In order to be proficient, healthcare workers require significant knowledge, skills, and expertise [72]. There are few healthcare providers in developed countries who have this expertise, let alone in low- and middle-income countries, which means that people with chronic wounds have difficulties accessing quality care [69, 73, 74]

The Cost of Care

Whether in high- or low-income care settings, subsidies for costly dressings, bandages, and footwear are often not available to people living with a wound and their families although they are essential for proper care, wound healing, and prevention of recurrence [20, 75]. Even where these costs are subsidised, full out-of-pocket expenses are not usually recouped [76], making evidence-based care unaffordable and therefore inaccessible [20, 75]. Costs associated with chronic wound treatment also include travel to and from and accommodation for appointments, fees for medical and specialist reviews, loss of wages, equipment purchases or hire, and medication to treat infections [76]. In the end, these factors can lead to significant and even catastrophic healthcare expenditure for people living with chronic wounds.

How People with Chronic Wounds Experience Care

As mentioned earlier, wellbeing is more than just health, and involves the physical, psychological, social, and spiritual domains. Health is only one part of wellbeing, yet our health system focusses almost exclusively on the physical and poorly on psychological, social, and spiritual wellbeing, i.e. the biomedical model [29]. Negative experiences of people seeking care for their chronic wounds from healthcare providers is common. There is a lack of understanding of the priorities of people living with wounds by healthcare providers, limiting effective support [77]. People with chronic wounds can feel that physicians do not understand how they perceive their situation, and that there is the need for improved communication and greater involvement in decisions about their care [78]. Individuals may receive conflicting information [71, 78], need to wait too long for an appointment [71], and perceive poor outcomes from care [65, 70, 71].

The World Health Organization aspires to the biopsychosocial model of care [79] to promote the wellbeing of community members [80]. This approach is person-centred, with the needs of community members driving the care that they require, which includes the physical, psychological and social aspects of wellbeing [1, 28]. Involving people in their care and supporting easy access to the right care with the right person at the right time is essential to achieve optimal outcomes [81].

Summary

Chronic wounds impose all-pervasive physical, psychological, social, and spiritual impacts on individuals, their families, and friends. These are mostly mediated by wound symptoms such as excessive exudate and odour, infection, pain, and lack of healing. As described earlier, there are vicious feedback loops and interactions between the symptoms and peoples' physical, psychological, social, and spiritual wellbeing. Further, there is a widespread knowledge and training deficit regarding appropriate holistic and multidisciplinary wound care, and wounds impose a high financial burden on individuals and society.

Health systems are generally focussed on the medical model, meaning that they consider mostly the disease and not the person living

with the disease. Care needs to include a biopsychosocial approach, where effective assessment, diagnosis and management that engages with people living with wounds and considers what is important to them is implemented.

Maggot therapy can play an important role in the provision of such efficacious, affordable and person-centred wound care that improves the physical, psychological, social, and spiritual wellbeing of people living with wounds provided it is properly integrated into the healthcare system. How this may be achieved is discussed in Chapter 6 of this book [82]. Maggot therapy can speed up debridement and promote wound healing, reduce exudate and odour, and control infection, all of which have a significant impact on the wellbeing of people with chronic wounds. Most important, though, in the context of this discussion, maggot therapy requires full consent and acceptance by individuals and their families. This is difficult to achieve if people with wounds are not involved in care decision making. To that end, Chapter 19 [83] examines ethical considerations involved in using medicinal maggots as a wound care therapy, including the importance of consent by the individual for this therapy.

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