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## Clinical guidance for responding to suffering in adults with cancer

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A CLINICAL GUIDANCE DOCUMENT DEVELOPED BY CANCER AUSTRALIA

This document supplements information contained in the *Clinical practice guidelines for the psychosocial care of adults with cancer*, 2003.<sup>1</sup>

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### PURPOSE

This document includes practice points and other clinical guidance based on the available evidence about the conceptualisation and assessment of suffering in the cancer context, and therapies or interventions that may help alleviate suffering. The document provides healthcare professionals with information designed to guide the provision of psychosocial clinical care relating to the domain of suffering for improved patient outcomes and support for families and carers. Cancer Australia has also developed related information about fear of cancer recurrence in adult cancer survivors.

<To be endorsed by relevant professional colleges/groups >

## BACKGROUND

Optimal cancer care is multi-dimensional and is provided by a wide range of healthcare professionals. It incorporates timely and effective attention, not only to patients' physical and psychological needs, but also to their social and spiritual or existential wellbeing. When patients, families and carers experience pressure or loss in any of these domains, or are overwhelmed by their circumstances, suffering can occur.

To date, there are no clinical practice guidelines in Australia for healthcare professionals for evidence-based advice about care that focuses specifically on the alleviation of suffering. This document provides foundational guidance that will help healthcare professionals identify these issues and respond in a way that aims to reduce suffering in patients, families and carers, and improve their wellbeing and quality of life. This document includes information about the conceptualisation and identification of suffering, ways to assess and respond to suffering, and referral options if this is required.

It should be noted that this clinical guidance has a multidisciplinary focus and is applicable to diverse treatment settings, including hospitals and private practices involved in cancer care. It is also relevant to health service staff and volunteers whose interactions with patients, families and carers can also impact both positively and negatively on experiences of suffering.

A systematic review<sup>2</sup> on the conceptualisation, assessment and interventions to alleviate suffering in the cancer context was undertaken, with additional articles provided by a multidisciplinary working group. These elements informed this guidance. For further details on the literature search, including research questions and the involvement of the working group in preparing this guidance, see the Summary of evidence.

### **A note on terminology**

There are various definitions of suffering, but for the purpose of this document, the following definition is provided:

*Suffering is a complex emotion that can include physical, psychological, social and spiritual reactions. Although suffering causes unique experiences of distress for the individual, it has many common features particularly associated with loss or perceived loss. These include loss of meaning or hope, loss of physical or emotional strength, loss of independence, isolation or changed relationships.*

*People who are suffering may also face reduced capabilities, for example in their mobility, speech, concentration or daily activities. These challenges and losses may overwhelm them, leading to a sense of personal depletion and reduced resilience.*

*Individuals' social and cultural environment, as well as their own beliefs and life experiences, may influence the way in which they deal with suffering.*

This definition is based on Working Group consensus (WG consensus) drawn from concepts discussed in 125 articles conceptualising suffering that were assessed in *Conceptualisation, assessment and interventions to alleviate suffering in the cancer context: a systematic literature review* (2012).<sup>2</sup>

It is acknowledged that there are other terms that are used synonymously with 'suffering', such as demoralisation; existential distress, pain or suffering; psycho-existential suffering; psycho-spiritual distress; spiritual pain; and total pain. As suffering is often linked to issues of spirituality, and many studies focus on this concept, the terms 'spirituality', 'spiritual issues', 'spiritual distress' and 'spiritual suffering' are also used. Potentially measurable symptoms that may point to suffering include hopelessness; despair; loss of meaning; loss of dignity; crisis of faith; and desire for hastened death.

In this document the term 'suffering' is mainly used but occasionally some other listed terms are referred to, due to the terminology used in particular studies or the context of the information.

Further, for the purpose of this document, the term 'families' is used to represent not only the relatives of a patient but also those people who are in an unpaid carer role who may or may not be related to the patient.

DRAFT

## PRACTICE POINTS

The identification, assessment and relief of suffering in the cancer context is a new and emerging area of research. These practice points are provided to help guide clinical decisions for psychosocial care relating to suffering in adults with cancer. Practice points are based on expert opinion when the evidence to make a clinical practice recommendation is insufficient or where the evidence is outside the scope of the systematic review.

Refer to the Summary of evidence section for supporting evidence and information relating to the practice points.

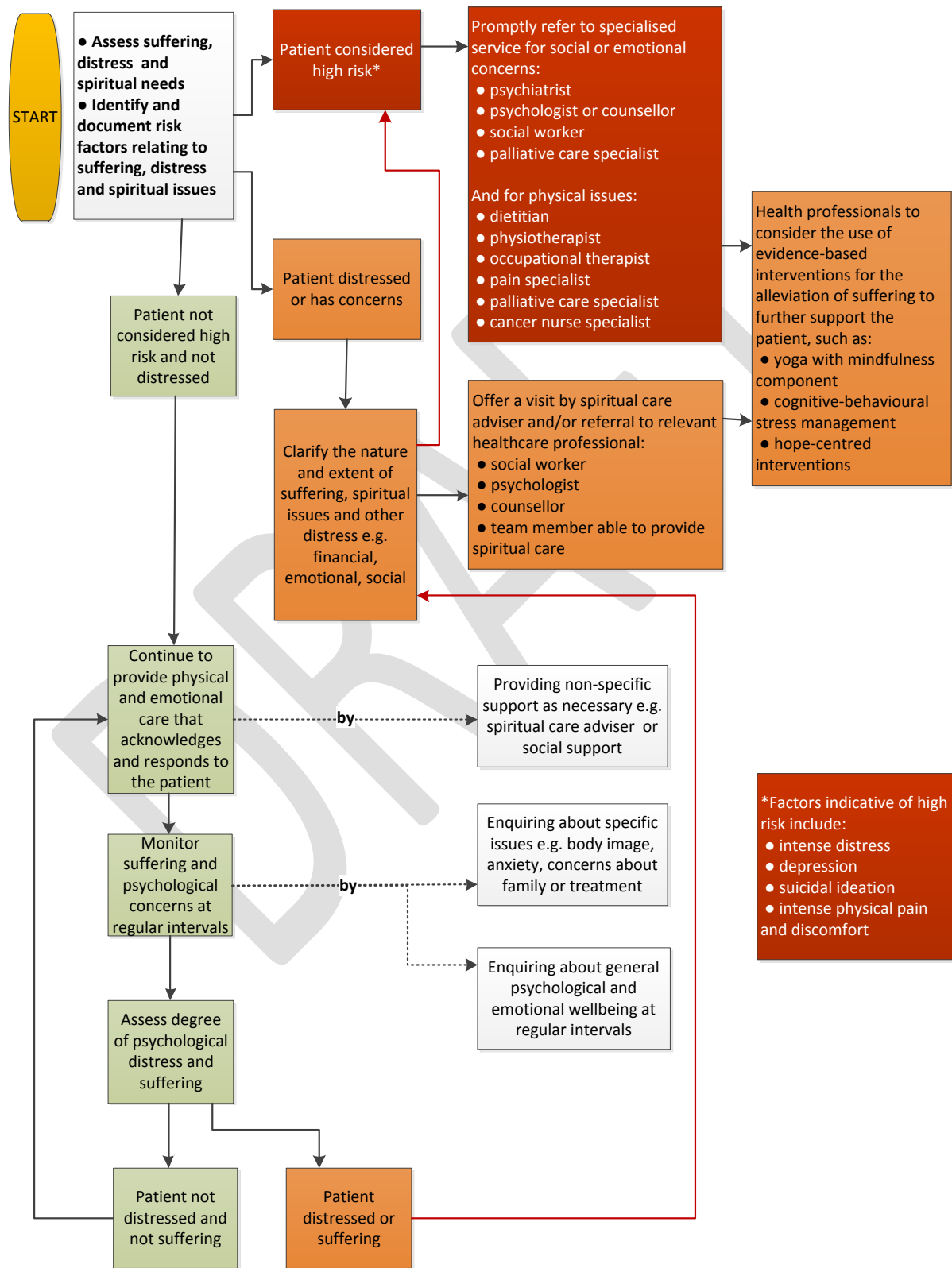
<b>PRACTICE POINT – The importance of responding to suffering</b>		<b>References</b>
<b>A</b>	Acknowledging and responding to suffering, including spiritual issues, in patients and their families is an important component of clinical care.	Naden 2006 <sup>3</sup> Daneault 2006 <sup>4</sup> Ehman 1999 <sup>5</sup> Grant 2004 <sup>6</sup> Ohlen 2004 <sup>7</sup>
<b>PRACTICE POINT – Identifying suffering</b>		
<b>B</b>	Recognising signs and symptoms of possible suffering, including verbal, emotional and behavioural cues, is an important role for healthcare professionals.	
<b>PRACTICE POINTS – Responding to suffering</b>		
<b>C</b>	It is advisable to briefly assess patients' level of suffering, including spiritual needs, soon after diagnosis. Additional assessments should occur on readmission, change in prognosis, at the end of a treatment protocol and at end of life.	McGrath 2003 <sup>8</sup> Murray 2007 <sup>9</sup> Adelbratt <sup>10</sup> Lethborg 2008 <sup>11</sup>
<b>D</b>	Consider using a validated assessment tool or incorporating open questions relating to suffering into a general conversation about care.	
<b>E</b>	Determine patients' needs for their psychosocial care and establish the personal resources and support networks they can draw on.	Ohlen 2002 <sup>12</sup> Lethborg 2008 <sup>11</sup>
<b>F</b>	Demonstrate an ongoing openness to listening and responding to patients' and families' suffering by acknowledging the issue, normalising their feelings, showing empathy and inviting patients and family members to voice concerns as they arise.	Naden 2006 <sup>3</sup> McCord 2004 <sup>13</sup> Ehman 1999 <sup>5</sup> Adelbratt 2000 <sup>10</sup>
<b>G</b>	Consult with family members, if available and with the patient's permission, to obtain further information about the patient that will assist in their spiritual care.	
<b>H</b>	Show respect by acknowledging patients' and families' different cultural and religious needs, and accommodating them where possible.	

<b>PRACTICE POINTS – Care coordination, referral and interventions (See also Referral flowchart)</b>		
<b>I</b>	Following assessment and with the patient's consent, ensure outcomes and other relevant information are recorded and communicated to other appropriate healthcare professionals.	
<b>J</b>	Confirm which healthcare professionals can respond to the different aspects of a patient's suffering. If a relevant discipline is not represented in the multidisciplinary team (MDT) or hospital/clinic, refer the patient to other appropriate means of care. This may include non-healthcare workers such as the multicultural liaison officer, Aboriginal liaison officer or chaplain/spiritual care adviser.	
<b>K</b>	<p>Consider the use of a psychological intervention designed to address suffering or one of its domains such as hopelessness.</p> <p>Levels of evidence for interventions:</p> <p>All Level II except  * = Level III  + = Level III-II</p>	<p>Herth 2000<sup>14</sup>  Ando 2010<sup>15</sup>  Breitbart 2012<sup>16</sup>  Breitbart 2010<sup>17</sup>  Henry 2010<sup>18</sup>  Rustoen 1998<sup>19</sup>  Duggleby 2007<sup>20</sup>  Badger 2011<sup>21</sup>  Ferguson 2012<sup>22</sup>  Northouse 2005<sup>23</sup>  Delbar 2001<sup>24</sup> *  Koinberg 2006<sup>25</sup> +  Hansen 2009<sup>26</sup>  Witek-Janusek 2008<sup>27</sup> +  Henderson 2012<sup>28</sup>  Garland 2007<sup>29</sup> +  Moadel 2007<sup>30</sup>  Chandwani 2010<sup>31</sup>  Antoni 2001<sup>32</sup>  Penedo 2006<sup>33</sup>  Antoni 2006<sup>34</sup>  Danhauer 2009<sup>35</sup>  Fallah 2011<sup>36</sup> +  Rummans 2006<sup>37</sup>  Hsiao 2012<sup>38</sup></p>
<b>L</b>	Consider the use of additional supportive care therapies that may be available at the hospital/clinic or through support groups or spiritual networks, which patients may find beneficial. Examples include healing prayer, meditation or music therapy.	

# REFERRAL FLOWCHART

This flowchart has been developed to outline the referral pathway for responding to suffering in adults with cancer. It is based on the referral pathway described on page 112 of the *Clinical practice guidelines for the psychosocial care of adults with cancer (2003)*.<sup>1</sup>

**Figure 1 – Referral flowchart for responding to suffering in cancer patients**



## **METHODOLOGY OF EVIDENCE REVIEW**

A systematic review, *Conceptualisation, assessment and interventions to alleviate suffering in the cancer context: a systematic literature review*,<sup>2</sup> was undertaken by the Psycho-oncology Co-operative Research Group (PoCoG) for Cancer Australia. This focused on the conceptualisation of suffering in cancer patients; assessment of suffering in cancer patients; and interventions aimed at the relief of suffering in cancer patients.

A search of the literature published between 1992 and 2012 was undertaken using electronic databases. The primary search included peer-reviewed articles published in the English language related to suffering in adults diagnosed with cancer and reporting on outcomes relevant to the following questions, which were developed by a multidisciplinary steering committee:

1. What are the current conceptualisations of suffering in people diagnosed with cancer?
2. What instruments/tools are available to assess the suffering of people diagnosed with cancer?
3. What interventions have been demonstrated to be effective in dealing with the suffering of people diagnosed with cancer?

The searches resulted in a final pool of 125 articles conceptualising suffering; 90 articles reporting on the instruments/tools available to assess suffering, its synonyms, and/or its symptoms; and 42 articles evaluating the effectiveness of interventions to alleviate the suffering of people diagnosed with cancer.

The evidence from the systematic review was further supplemented by the clinical expertise of Cancer Australia's *Cancer suffering and spirituality issues* multidisciplinary working group to provide additional input to the practice points.

## **SUMMARY OF EVIDENCE**

This summary of evidence provides information and vignettes relating to four key areas for healthcare professionals to consider in relation to suffering in adults affected by cancer:

1. The importance of responding to suffering
2. Identifying suffering
3. Responding to suffering
4. Care coordination, referral and interventions.

## 1. THE IMPORTANCE OF RESPONDING TO SUFFERING

PRACTICE POINT – The importance of responding to suffering		References
<b>A</b>	Acknowledging and responding to suffering, including spiritual issues, in patients and their families is an important component of clinical care.	Naden 2006 <sup>3</sup> Daneault 2006 <sup>4</sup> Ehman 1999 <sup>5</sup> Grant 2004 <sup>6</sup> Ohlen 2004 <sup>7</sup>
<b>OTHER KEY POINTS</b>		
Suffering is commonly experienced among cancer patients at all stages of the disease, including at end of life and in the survivorship phase following treatment.		Rousseau 2000 <sup>39</sup> McGrath 2003 <sup>8</sup>
Acknowledging and responding to suffering in a timely manner can help patients and families cope better with physical, social, emotional and spiritual issues.		NBCC 2003 <sup>1</sup> Zaider 2009 <sup>40</sup>
When patients and families are less distressed they are better able to draw on their existing personal resources to help them meet ongoing challenges.		NBCC 2003 <sup>1</sup> WG consensus
Unrecognised suffering can lead to increased suffering, and may contribute to the patient developing a mental illness such as depression.		Daneault 2006 <sup>4</sup> Arman 2002 <sup>41</sup>
Timely identification of suffering can prevent inappropriate psychiatric diagnoses and prescriptions.		Storey 2001 <sup>42</sup>
Both patients and healthcare professionals can be provided with an opportunity for personal growth through a sensitive and timely response to suffering issues.		Penson 2001 <sup>43</sup> Storey 2001 <sup>42</sup> Turner 2011 <sup>44</sup>

### VIGNETTES

#### Introduction

Attending to suffering has become an increasingly important component of treating people with cancer. It is considered an essential aspect of the patient-centred model of care, which supports the dignity of patients. Suffering, with its associated losses, can significantly reduce quality of life.<sup>39, 45</sup> Cancer can also cause great suffering for families. It is therefore important for their suffering not to be overlooked. Often, both patients and families feel more reassured when they know the suffering of their loved ones has been acknowledged and accommodated.

#### Time required

While time constraints and the difficult nature of dealing with suffering may appear as barriers,<sup>6, 39</sup> it is important for healthcare professionals to consider suffering as a key clinical



and moral issue in their work.<sup>3, 12, 45</sup> In many cases, extra time is not required to attend to suffering. Compassionate questioning, empathic comments and acknowledgement may be all that is needed for patients to rally their own resources.

Although suffering manifests in different ways, responding to suffering in a timely manner and allowing patients to express their emotions can bring relief to both patients and their families. Allowing patients to discuss issues of suffering appears to increase their ability to cope with the illness itself and with the other physical, social, emotional and spiritual difficulties that are linked to suffering.<sup>1</sup> Patients whose suffering has been validated may be more open to working collaboratively with the treating team.

#### Benefits for patients and families

When suffering is acknowledged and responded to, individuals tend to feel supported, less hopeless and less overwhelmed. If they are less distressed, patients are often better able to utilise their own physical, practical and emotional resources to address the ongoing challenges of their illness. This may reduce the need for external service provision and may result in reduced health costs and length of hospital stays. (WG consensus)

Maintaining the patient at the centre of clinical decision-making and taking time to align treatment goals with the patient's own priorities is likely to lead to improved satisfaction with care and more efficient use of health resources.

A team of empathetic and responsive healthcare professionals, in looking beyond symptom management to respond holistically to suffering, can guide patients through different issues such as coming to terms with their losses, affirming meaning and value in their lives, starting to regain a sense of wholeness, or creating a personally meaningful death.<sup>3, 43, 45-47</sup> Families will also benefit from knowing a patient's suffering was alleviated; this helps with anticipatory grief and the bereavement process.<sup>40</sup>

#### Benefits for patients and healthcare professionals

Allowing suffering issues to be discussed can provide both patients and healthcare professionals with an opportunity for personal growth.<sup>42</sup> Some studies suggest that being open to patients' suffering can increase healthcare professionals' clinical effectiveness and increase personal reward in their work.<sup>42-44</sup> However, adequate training and support, as well as the ability to reflect on their own spirituality and emotions, are important aspects for healthcare professionals to effectively focus on suffering in others without it leading to professional and personal burnout.<sup>42, 44</sup>

For information on how all members of the healthcare team can use appropriate behaviour, communication, and referral to help patients reduce the impact of their suffering, see the section Responding to suffering.

#### Implications of not responding to suffering

If healthcare professionals don't recognise or address suffering, this can have clinical implications. Unrecognised or concealed suffering may lead to increased distress, as patients struggle with a sense of isolation and disconnection from others who fail to grasp their despair.<sup>4, 41</sup> This can impact on families too. Patients' trust in their healthcare professionals can also diminish. These factors may contribute to the development of clinically significant mental illnesses such as depression or anxiety disorders.<sup>45</sup>

Conversely, understanding patients better through recognition of their suffering may ensure that they are not misdiagnosed with a psychiatric disorder and consequently receive inappropriate treatment.<sup>42</sup>

### **VIGNETTE – Graeme**

***The following case demonstrates the importance of being alert to the unique concerns of the individual, and how sensitive communication can provide a framework for healthcare professionals to explore and respond to suffering.***

58-year-old Graeme was a company director who was urgently referred from a country clinic to a city teaching hospital. He had a six-month history of progressive left lower limb pain and motor weakness, and upper thoracic pain. CT and MRI scans had identified a large left iliac bone mass and mid-thoracic spine mass with spinal cord compression. Graeme had a biopsy at the teaching hospital and the diagnosis was confirmed as a metastatic adenocarcinoma.

Graeme was informed that the cancer was incurable and treatment was likely to include steroids, morphine, radiotherapy and chemotherapy with palliative intent. He became agitated and angry when potential loss of lower limb, bladder and bowel function was discussed, shouting *"But this can't happen now. It just can't!"*

The oncologist listened to Graeme then responded, *"I can't imagine how distressing this must be for you. Are you able to tell me what the most urgent concern is for you right now?"* Graeme replied that he and his long-term partner, Ruth, were to be married in two weeks' time. He said he didn't know how he could tell Ruth about his diagnosis. After the oncologist offered to speak to Ruth, Graeme became less distressed and indicated that he wanted to find out more about what was ahead for him.

Over the next few days Graeme was treated for pain, and palliative radiotherapy was commenced. The Nurse Unit Manager noted that Graeme preferred to have the curtains drawn around his bed during the day. Although Ruth had arrived and spent most of the day in the ward, Graeme did not seem to converse much with her.

The Nurse Unit Manager introduced herself to Graeme and reflected on the speed with which he had been diagnosed and transferred to an unfamiliar environment: *"So much has happened so quickly it must be hard to get your head around it."* Graeme revealed that he felt guilty about taking so long to see the doctor about his symptoms, and that now he would be a burden on Ruth, adding *"That's if I even make it."* The Nurse Unit Manager asked *"What does your heart tell you?"* to which Graeme expressed a fear of dying, and the concern that the faith that had played an important part in his life wasn't helping him handle things. Graeme accepted the offer to speak with a hospital chaplain. Over several visits he was able to explore values and talk about regrets about the way he had lived his life, including the estrangement from his children from his first marriage. He also agreed to see the physiotherapist to better understand his current functional ability and learn about expectations for progress and any strategies to improve strength.

Despite initial reluctance to accept referral to the palliative care team he later expressed relief that he no longer had to *"pretend to hold it together"*. He felt that having more information about his prognosis helped him to plan more realistically for his work and finances, and make decisions about ongoing care which he chose to have back home. After Graeme returned home, his GP provided ongoing care. The GP encouraged him to talk about what mattered to him, allowing him to discuss his grief about leaving Ruth, and lost opportunities with his children.

## VIGNETTE – Sally

**The following case demonstrates how healthcare professionals can give a patient time and space to take in the frightening news of a terminal cancer diagnosis, complicated by concerns about financial and family security.**

A 51-year-old divorced mother, Sally, was diagnosed with a poorly differentiated squamous cell carcinoma in the anus, after 18 months of progressive left buttock neuropathic pain, increasing left lower limb weakness and urinary stress incontinence.

During her first consultation the oncologist, Dr Edwards, listened to Sally's account of the symptoms she had experienced and the time taken for the diagnosis of cancer to be made. Sally expressed anger about the delay in diagnosis, saying "I wouldn't be in this situation now if the doctors had picked this up earlier."

Dr Edwards decided that the first priority was acknowledging Sally's feelings rather than telling her that the delayed diagnosis had probably not affected the prognosis. Dr Edwards leaned forward and said: "I am so sorry that it took so long to work out what was going on. I wish I could say something to make it less painful." She paused before asking: "Are you able to tell me what is most distressing for you at present?" Sally was then able to discuss concerns about finances and the desire to return to work and her distress about stress incontinence. The continence nurse discussed strategies to assist Sally, acknowledging that incontinence posed major challenges both occupationally and socially. Achieving pain relief was complex, but Sally found that the persistence and empathic approach of the palliative care team made her feel valued and cared for: "You know, they make me feel like I am the only one they have to treat. After all this time I really do feel that someone is finally looking after me."

Once her pain was better controlled, Sally expressed apprehension about talking with her daughter about her condition. The social worker met with Sally and listened to her concerns, telling Sally that "This is such a hard conversation, and no mother wants to have it." She then provided information for Sally including community services and links to websites and other resources.

## 2. IDENTIFYING SUFFERING

PRACTICE POINT		Reference
<b>B</b>	Recognising signs and symptoms of possible suffering, including verbal, emotional and behavioural cues, is an important role for healthcare professionals.	
OTHER KEY POINTS		References
Suffering is a subjective experience potentially caused by physical pain, emotional and/or spiritual distress. Suffering may result in a range of negative emotions and changed behaviours.		Cassell 1999 <sup>48</sup> Bayes 1997 <sup>49</sup> Baines 2000 <sup>50</sup> Arman 2002 <sup>41</sup> Barton-Burke

	2008 <sup>51</sup>
Sometimes suffering is not immediately evident as some people struggle to articulate their experiences.	Arman 2003 <sup>52</sup> Dettmore 2011 <sup>53</sup>
Suffering may be reflected through hesitation, silence, ambivalence or general dissatisfaction. Verbal cues include questions about life, death, and spirituality, or talk about struggles, loss, low self-esteem and an empty future.	McGrath 2003 <sup>8</sup> Leung 2010 <sup>45</sup> Naden 2006 <sup>3</sup> Penson 200 <sup>43</sup> Arman 2002 <sup>41</sup> Storey 2001 <sup>42</sup> Puchalski 2006 <sup>54</sup> Ohlen 2002 <sup>12</sup> Barton-Burke 2008 <sup>51</sup> Baines 2000 <sup>50</sup> Adelbratt 2000 <sup>10</sup> Okon 2006 <sup>55</sup> Arman 2003 <sup>52</sup> Dettmore 2011 <sup>53</sup> Ohlen 2004 <sup>7</sup> Yang 2010 <sup>56</sup> Lo 2002 <sup>57</sup>
Demoralisation is an intense manifestation of suffering, which reflects patients' inability to see value in their lives, both past and future.	Kissane 2001 <sup>58</sup> Abbey 2006 <sup>59</sup> Frank 1974 <sup>60</sup> Clarke 2002 <sup>61</sup>

## Introduction

As suffering is a complex concept with many causes,<sup>3, 8, 10, 39, 41-43, 45, 48-51, 58, 59, 62-65</sup> it can be challenging to assess and identify patients in need of particular care.<sup>39, 42, 45, 65, 66</sup> Although the identification of suffering does not need to constitute a formal clinical diagnosis, recording its presence and actions in response to it are important.(WG consensus)

## Suffering is a subjective emotional experience

Suffering is considered to impact on the whole person, rather than just the physical body.<sup>48</sup> While it is often equated with physical pain, it can also have emotional, social and spiritual causes and consequences.<sup>39, 41, 51</sup> It is well established that when people are confronted with a life-threatening illness or with death, they commonly experience spiritual suffering and question life's meaning, even if they don't hold religious beliefs.<sup>39, 66</sup>

Unacknowledged suffering, in particular, can present as apparently intractable symptoms. (WG consensus) It is a subjective experience, influenced by life experiences, expectations and outlook. <sup>41, 48-51</sup>

### When suffering might occur

Suffering can occur at any stage of the cancer continuum. Even if patients have finished treatment with curative intent, are in remission and have a good prognosis, adjustment to a new way of life can be challenging and lead to suffering.<sup>8</sup> Health professionals, therefore, should be mindful of cancer survivors who do not seem to be doing as well as expected physically and emotionally when they return for check-ups, or who do not react as positively as expected when informed that test results are good. (WG consensus)

A diagnosis of advanced cancer typically increases suffering,<sup>4, 48</sup> including that of a spiritual nature. In these cases, an important role of healthcare professionals is to try to achieve a balance between facilitating the expression of grief and sustaining hope for both patients and families.<sup>58</sup>

A component of suffering is to question life's meaning and value, and to ponder aspects of spirituality. Suffering can also be experienced in the survivorship phase following treatment.<sup>8</sup> It is commonly experienced among cancer patients at all stages of the disease, and particularly at end of life.<sup>39</sup>

Seemingly trivial issues might trigger feelings of suffering in someone who previously appeared to be coping quite well. For example, delays at the clinic or difficulty finding parking, a busy clinician or receptionist who speaks abruptly, or reading about another person's difficult situation might take someone to the limits of their endurance.

### Suffering and emotions

Studies have shown that suffering may be manifested in a broad range of emotions including anger,<sup>43, 51, 58</sup> irritability<sup>1</sup>, anguish, shock, despair, sadness, vulnerability, insecurity, fear or grief,<sup>10, 12, 41, 48, 50</sup> panic, frustration, yearning, doubt, boredom or jealousy.<sup>62</sup> These emotions may be expressed verbally or through body language or behaviour.<sup>48, 54, 65</sup> For example, patients may grimace or cry,<sup>65</sup> withdraw socially<sup>1, 45</sup> or appear uncommunicative.<sup>55</sup> They may be resistant to advice, miss appointments or fail to comply with treatment recommendations.<sup>39</sup> In some patients, suffering may not be outwardly visible to healthcare professionals and family so it is important to try to elicit information about suffering, even if there are few external indicators.

### Articulating suffering

A number of studies have highlighted the difficulties people face in conveying their experiences of suffering.<sup>52, 53</sup> Evidence of these struggles during conversations include patient contradictions;<sup>3, 10, 53</sup> ambivalence;<sup>56</sup> hesitations, silences, evasions and fumbling for words;<sup>7, 55</sup> frantic attempts to change attitudes and behaviours;<sup>52</sup> repeated complaints about health services;<sup>7</sup> and questions about apparently minor aspects of the illness because major issues remain beyond patients' desired level of control.<sup>55</sup>

What people say can also be indicators of suffering or may help them in their search to understand, overcome and give meaning to their illness.<sup>51</sup> Patients may:

- ask existential or spiritual questions about the meaning of life and death, their place in the world, and why the cancer occurred<sup>5, 13, 41</sup>
- question their religion or religion in general, or seek spiritual answers<sup>43</sup>
- voice a deep concern for their family<sup>8, 10, 41, 50</sup>
- try to equate past wrongdoing with the cancer, asking "What have I done to deserve this?"<sup>9, 51, 57</sup>

- talk of their 'struggle',<sup>51</sup> 'battle' or 'loss'.<sup>41</sup> The loss could be physical, as in a body part<sup>41</sup>, it could be emotional, as in the loss of autonomy or identity,<sup>8, 10</sup> or it could be spiritual, such as a loss of meaning.<sup>10, 12, 39, 42, 43, 45, 67</sup>

Sometimes patients may employ coping strategies such as positive thinking, bargaining or denial to convince themselves that the situation is not as bad as it actually is.<sup>10</sup> At times, this may reflect unexpressed suffering.

#### Pain and suffering

Physical pain and emotional suffering are closely linked.<sup>42</sup> Pain is both a cause and manifestation of suffering, and has an adverse effect on general wellbeing.<sup>50, 68</sup> Besides pain, cancer patients may experience a range of symptoms such as nausea, pruritis, thirst, neuralgia, fever or breathlessness.<sup>1, 62</sup> Such ongoing pain and discomfort can contribute to other symptoms such as fatigue, insomnia, irritability, frustration, low mood, depression, anxiety and distress.<sup>1, 69</sup> If these symptoms are not adequately addressed, they may become the patient's primary focus.<sup>3, 12, 70-72</sup> Suffering is generated when the pain and discomfort seem uncontrollable and never-ending, and when patients can derive no meaning from the experience.<sup>39, 73, 74</sup>

#### Demoralisation and suffering

Some patients may display intense demoralisation and hopelessness, particularly if the cancer has been diagnosed as terminal.<sup>58, 59</sup> Demoralisation can occur if patients feel they are persistently failing to cope with stressors which they, or those close to them, expect them to handle effectively. It is associated with feelings of impotence, isolation and despair, damaged self-esteem, hopelessness, pessimism and loss of purpose in life.<sup>60</sup>

Demoralisation is considered to be distinct from clinical depression, with demoralisation characterised by a feeling of subjective incompetence and helplessness, and depression by the diminished ability to experience pleasure.<sup>58, 61</sup> A demoralised patient may talk about the burden they are to their family<sup>58</sup> and may say things like, "I can't see the point anymore," or "There's no reason to go on".<sup>58, 59</sup> Demoralised patients may not directly express a desire for death, but typically feel that their life has not been satisfying.<sup>58</sup>

There is a risk that demoralisation as a clinical problem is overlooked because the symptoms may be considered normal for someone in such a situation. However, using similar strategies for both people who are demoralised and those who are experiencing other kinds of suffering may be of benefit. Although the systematic review<sup>2</sup> did not find a significant effect for spirituality domains for Cognitive Behavioural Therapy<sup>58</sup> or dignity therapy,<sup>75</sup> which is designed to enhance end-of-life experiences for terminally ill people, these therapies are considered to be of value for demoralised patients (WG consensus). See the section on Care coordination, referral and interventions for more information.

#### Further reading

*Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer (2003)*<sup>1</sup> has more information on how people react to the challenges of cancer.

#### VIGNETTE - Maureen

**The following case describes how a patient's outburst about a trivial issue, related to feeling undervalued, may be masking bigger issues of concern.**

Maureen, a 56-year-old single woman with a poor prognosis lung cancer was referred to the

liaison psychiatry nurse after becoming acutely distressed, sobbing, and shouting at reception staff after a lengthy wait for her medical oncology outpatient appointment.

"They tell me I've only got six months to live, then they keep me waiting three hours for an appointment. Don't they realise that every minute is precious!" she had cried.

Maureen was given time to speak privately in a quiet space and to air her frustrations. The liaison nurse enquired, "*What has been the most difficult part of all this for you?*"

Maureen reported increasing dissatisfaction in recent weeks due to repeated delays and rescheduling of appointments. She was "worn down by waiting," which she found uncomfortable due to her uncontrolled cough and pain. She revealed that she felt fearful she would lose the support of friends who had driven her to appointments and also been inconvenienced by the delays.

The nurse was able to validate Maureen's frustrations and fears, flag with the team the uncontrolled symptom burden and provide referral for transport assistance so that Maureen's friends could maintain their role of emotional support rather than become overwhelmed with practical demands.

As her distress settled, Maureen expressed regret to the liaison psychiatry nurse regarding her outburst and confided that she felt very embarrassed. The nurse was able to facilitate re-establishing rapport between Maureen and the reception staff.

## VIGNETTE - Ellen

**The following case describes one example of how someone may articulate and deal with suffering and how this may be overcome.**

Ellen had been diagnosed with disseminated breast cancer. After suffering a pathological fracture of her humerus, she recovered but embarked on frenetic activity: paying bills, replacing the fridge and getting carpets cleaned. Her GP wondered: "Why now and why the rush?" She broached the subject by asking her: "*Is there anything you are scared of?*"

Ellen revealed she was a lapsed Catholic. "I'm worried I haven't made the grade and that I'll go to hell when I die." Her GP put her in touch with a priest, who promptly put Ellen's mind at ease. The priest reassured Ellen that many people felt like her in moments of crisis. "It might help to remember that God is forgiving," he said. "People also benefit from forgiving themselves too."

## 3. RESPONDING TO SUFFERING

PRACTICE POINTS		References
<b>C</b>	It is advisable to briefly assess patients' level of suffering, including spiritual needs, soon after diagnosis. Additional assessments should occur on readmission, change in prognosis, at the end of treatment and at end of life.	McGrath 2003 <sup>8</sup> Murray 2007 <sup>9</sup> Adelbratt 2000 <sup>10</sup> Lethborg 2008 <sup>11</sup>
<b>D</b>	Consider using a validated assessment tool or incorporating open questions relating to suffering into a general conversation about care.	
<b>E</b>	Determine patients' needs for their psychosocial care and establish the personal resources and support networks they can draw on.	Ohlen 2002 <sup>12</sup> Lethborg 2008 <sup>11</sup>
<b>F</b>	Demonstrate an ongoing openness to listening and responding to patients' and families' suffering by acknowledging the issue, normalising their feelings, showing empathy and inviting patients and family members to voice concerns as they arise.	Naden 2006 <sup>3</sup> McCord 2004 <sup>13</sup> Ehman 1999 <sup>5</sup> Adelbratt 2000 <sup>10</sup>
<b>G</b>	Consult with family members, if available and with the patient's permission, to obtain further information about the patient that will assist in their spiritual care.	
<b>H</b>	Show respect by acknowledging patients' and families' different cultural and religious needs, and accommodating them where possible.	



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OTHER KEY POINTS	References
Both clinical and non-clinical staff can play an important role in reducing suffering through small positive actions that show regard for patients and families.	
Establishing trust with patients and families helps to build a rapport with them and may facilitate conversations about suffering and spirituality.	
The support offered to patients may be in the form of interaction with other people, written information, referral to other healthcare professionals, supportive care interventions or a spiritual care adviser, or encouragement of continuing spiritual practice.	

### Introduction

Suffering can be acknowledged and ameliorated in different ways, from indirect, small gestures,<sup>4</sup> to direct attempts to respond to concerns through observing, questioning, discussing, listening and referral. Although healthcare professionals are encouraged to respond to suffering, no individual – or even the healthcare team as a whole – should assume responsibility for overcoming patients' and families' suffering and spiritual challenges.<sup>9, 54</sup> Often the problem of suffering does not need to be solved but simply heard. (WG consensus)

All staff coming into contact with patients and their families can play an important role in reducing suffering. This includes not only healthcare professionals but also receptionists, orderlies, cleaners, volunteers, security staff, drivers and other support staff. While non-health professional staff are not expected to address suffering or spiritual issues clinically, their interactions can impact on patients' experiences and their feelings of wellbeing and worth.

Examples of small positive actions include communicating with patients politely and warmly; acknowledging their presence and their situation;<sup>3, 12</sup> comforting patients if they are nervous or upset; apologising if there are delays; complimenting patients; and briefly conversing with patients on non-medical topics, such as family, hobbies, work or interests. <sup>4, 8, 76</sup> These actions show respect and help to build rapport.<sup>3, 12</sup>

For healthcare professionals, directly addressing suffering is an element of providing holistic care. Although it requires prioritisation, awareness and time,<sup>47</sup> showing understanding, empathy, compassion, care and kindness are key components of responding to suffering.<sup>4, 12, 64, 77</sup>

In many hospitals and cancer centres, a multidisciplinary team (MDT) is available to support not only patients but also team members.<sup>54, 66</sup> Spiritual care advisers should also be available for support when appropriate.<sup>78</sup> As such, addressing suffering becomes the concern of the whole team. Where an MDT does not exist, efforts should be made to ensure the needs of patients and families are not overlooked.

### Assessment of suffering and spiritual needs

#### *Methods of assessment*

Healthcare professionals are encouraged to use a simple but comprehensive assessment tool for patients.<sup>9</sup> Alternatively, an informal spiritual assessment, which involves listening to patients' stories and interpreting their issues, can be done at any time. As the

experience of suffering is entwined with culture, it is important to consider the cultural context in which assessment tools have been developed and validated. For example, measures developed in a Christian context may not be appropriate for those of a different faith or no faith.<sup>79</sup>

#### *Assessment tools*

There are a number of tools that have been developed to assess suffering, its synonyms and/or its symptoms. The difficulty of articulating suffering should be taken into account when considering the appropriateness of tools. Assessment in a clinical setting is ideally supplemented by open questions and by being alert to non-verbal and verbal cues of the patients.

The tools evaluated in the systematic review had substantive information about their psychometric properties available and were tested in clinical trials.<sup>2</sup> They have been categorised depending on the constructs they measured: Suffering; Hopelessness and demoralisation; Hope; Spiritual wellbeing; Meaning; Quality of Life including a spiritual/existential component; and Distress in palliative care. The tools were assessed against their appropriateness, reliability, validity, responsiveness, precision, interpretability, acceptability and feasibility.<sup>80</sup>

The appropriateness of any measure is dependent on a range of considerations including the context in which it is to be used (e.g. early-stage disease vs. survivorship vs. palliative care), its psychometric properties in this context, respondent burden, and the desired mode of administration. It should be noted that the evaluated measures have been used primarily for research purposes rather than being applied in clinical practice.

A number of tools are listed in Appendix 1. These are suggested based on their suitability and validation to measure suffering or its various synonyms in cancer populations. While these tools constitute sound measures of suffering, other measures could also be considered to suit clinical practice goals. The systematic review includes details of all 58 measures that were assessed for their usefulness in measuring aspects of suffering.<sup>2</sup>

#### **Informal assessment**

Informal assessments can be based on conversational questions about suffering and spirituality and observations of suffering in patients.<sup>5, 12, 81</sup> Such an assessment allows healthcare professionals to concurrently respond to elements of suffering, provide spiritual care and increase patients' coping ability by listening, providing input and acknowledging the importance of the issues raised.<sup>8, 64</sup>

Patients can also give indirect clues about suffering or spiritual needs, for example, through body language or items at their bedside such as religious paraphernalia or self-help books. Patients' behaviour, words or tone may indicate their need or desire to talk about suffering.<sup>43, 81</sup> These clues can provide healthcare professionals with openings to a conversation.

#### **Timing of assessment**

Although a full assessment takes time, it should be a priority.<sup>47</sup> (WG consensus) If time is critical, a couple of minutes can still elicit useful information and be of benefit to patients.<sup>54</sup>

There is a perception that the healthcare system does not allow healthcare professionals the time or emotional resources to deal with the suffering and spiritual care of patients.<sup>4, 6, 43, 45, 47, 58</sup> However, assessment of these issues should occur as soon as possible after diagnosis, and

be repeated at least at the end of treatment, at recurrence and during the terminal stage. Early assessment and discussion of issues allows the healthcare team to identify and address a range of problems early on, to gain an understanding of patients' coping ability, to track their emotions, spiritual wellbeing and different needs over the course of their illness, and to arrange follow-up care.<sup>8, 13, 43</sup>

Understanding the possible emotional and spiritual responses that patients may have at different stages of cancer can help healthcare professionals anticipate when individual patients are likely to need more support.<sup>9</sup> For example, studies have shown that acknowledging a terminal prognosis earlier rather than later ultimately contributes to relief of suffering.<sup>4</sup> The recognition of death can offer a shift in perspective from small concerns to a deep appreciation of life.<sup>10</sup> For those approaching death, issues such as forgiveness and reconciliation, and finding meaning and hope, often become critical.<sup>10, 57</sup>

For many cancer survivors, existential concerns may arise after treatment.<sup>8</sup> This can be particularly difficult as family, friends and acquaintances often expect that cancer survivors will easily put their experiences behind them and resume life as it was before treatment.

### **Choosing the right place**

Healthcare professionals need to be mindful of where discussions about suffering and spiritual issues take place.<sup>8, 73, 82, 83</sup> Ideally patients have privacy from other patients and they should be asked if they want family present.<sup>84, 85</sup> Sometimes a private setting is not available or the patient's condition makes it difficult to move to a private room. In such cases, acknowledging the setting and asking the person if they wish to talk now or at some other time is necessary. The issues may be so pressing that the patient prefers to talk, even in a suboptimal setting. (WG consensus)

Patients should be as comfortable as possible; if they are in physical discomfort, they will find it harder to focus on non-physical aspects of suffering.<sup>12, 71, 72</sup> Being seated with the patient and having a similar eye level is important.<sup>85</sup>

### **Starting a conversation**

Although opening a conversation about suffering or spirituality may seem daunting, simply asking the patient if the topic can be brought up is suggested.<sup>8</sup> Patients often do want to talk about existential issues, including death, with healthcare professionals.<sup>10, 13, 39, 46</sup>

### **Open-ended questions**

Generally, open-ended questions encourage patients to express themselves more clearly and in more detail. These are different from closed questions, which may only elicit one- or two-word responses. Open-ended questions are more conversational and suggest a genuine interest in the topic. Even though healthcare professionals may have a suggested series of questions to ask, letting the patient guide the conversation may allow exploration of their concerns more naturally and help them to better understand their troubles.<sup>57, 86</sup>

### **Content of questions**

A number of authors provide guidance as to the types of questions that will help enable patients to explore or share concerns, including those about spirituality and meaning.<sup>9, 12, 39, 42, 54, 57, 64, 85</sup> Depending on the time available and the flow of the conversation, all questions listed here need not be asked, nor do they need to be asked in the order presented.

### **Opening questions:**

These might provide insight into how patients are affected by their illness and what influences their medical decisions and outlook:

- What should I know about you as a person to help me take the best care of you that I can? <sup>85</sup>
- What has been the hardest part of this experience for you? <sup>57</sup>
- Who else or what else will be affected by what is happening with your health? <sup>85</sup>

### **Questions related to spirituality:**

Further questioning could focus more specifically on spirituality and meaning. The following list of questions is not exhaustive but is drawn from Puchalski's Faith, Importance, Community, Address/Action in care (FICA) tool,<sup>54</sup> evaluated by Borneman;<sup>87</sup> the HOPE questions described by Anandarajah;<sup>81</sup> and related questions from Ohlen,<sup>12</sup> Lo <sup>57</sup> and Chochinov.<sup>85</sup> These spiritual assessment tools were not included in the systematic review <sup>2</sup> because they were not designed to assess suffering specifically, nor are they validated with measurable outcomes. However, as prompts, they can potentially elicit useful information from patients.

For simplicity, the FICA tool headings are used to categorise the questions.

#### *Faith, Belief, Meaning:*

- Do you consider yourself spiritual or religious? Do you have spiritual beliefs that help you cope with stress? <sup>54</sup>
- What gives your life meaning? <sup>54</sup>
- What are your sources of hope, meaning, comfort, strength, peace, love and connection? <sup>81</sup>
- What do you hope for? <sup>57</sup>

#### *Importance and influence:*

- What importance does faith or belief have in your life?
- What role do your beliefs play in your healthcare decision-making? <sup>54</sup>
- What aspects of your personal spirituality and practices are most helpful to you? <sup>81</sup>
- What are the things at this time in your life that are most important to you or that concern you most? <sup>85</sup>

#### *Community:*

- Are you part of a spiritual or religious community? Is this of support to you and how? Is there a group of people you really love or who are important to you? <sup>54</sup>
- Are you involved in an organised religion? <sup>81</sup>
- Who else should we get involved at this point, to help support you through this difficult time? <sup>85</sup>

*Address/Action in care:*

- How would you like your healthcare provider to use this information about your spirituality as they care for you? <sup>39, 54</sup>

**Questions relating to a person's sense of self-worth and meaning:**The following questions may assist in opening a discussion to help a person re-establish their sense of value and meaning:<sup>42, 64</sup>

- What is a personal quality you cherish about yourself?
- What is a joy you have in your life right now?
- What was the best period of time or the best thing that happened to you in your life?
- What are some of the lessons you've learned in life?
- Who or what have you believed in or loved? (This could be faith, ideology, institutions, people, places, music, ideas)
- What are the things you have done – created, accomplished, journeys?

**Questions relating to guilt and shame:**Some patients may feel guilt or stigma associated with the cancer. This can contribute to feelings of low self-worth and shame, and may affect their outlook and their ability to cope. Patients may think they deserve the cancer due to their lifestyle or they may worry that it is caused by past wrongdoings.<sup>6, 9</sup> Some careful questioning can help elicit if these are concerns:

- This is obviously distressing. I wonder if you feel able to share with me some of the things that are tough for you at present.
- Over time, many people have told me that the cancer diagnosis has particular meaning, maybe because of cultural or religious beliefs, or even past experiences. Sometimes people tell me about distressing feelings like guilt or even shame. Are these sorts of issues a concern for you?

**Acknowledging changes in the patient:**Changes in patients should also be acknowledged. These changes, which might include their experience or expression of suffering, their need to find meaning, or their ability to cope, can fluctuate. Healthcare professionals need to acknowledge and address these changes as they happen.<sup>11</sup>

Examples:

- This must be frightening for you. I can only imagine what you must be going through.<sup>85</sup>
- It's natural to feel pretty overwhelmed at times like these.<sup>85</sup>
- You seem more fearful/at ease than the last time we spoke. What has changed for you? (WG consensus)

## Communicating and connecting with patients

### *Supporting connections*

Being connected to other people and life's activities can help reduce suffering and existential loneliness. The healthcare team can offer this connection, and may be able to facilitate further connections, such as with family and other patients.<sup>11, 12</sup> These relationships, even if new, may offer joy and pleasure, and may reduce a person's vulnerability to suffering.<sup>12, 61</sup>

People who are dying commonly want to know that they won't be forgotten. It is helpful to explore the different relationships and affiliations they have or have had, and to reassure them that they will be remembered by others.<sup>43, 67</sup> This affirmation can improve quality of life.<sup>10</sup> Facilitating communication between family members and patients can help comfort the patient too.<sup>40</sup> Even patients who have few personal connections can be encouraged to reflect on the impact that they likely left across many years of life. These, for example, could be among friends and relatives, at school, work, or the neighbourhood.

### VIGNETTE - Maria

**The following case demonstrates the importance of support networks for people with cancer, and how carers can be affected by suffering too.**

Maria was a 40-year-old woman who had recurrent glioblastoma multiforme, which resulted in severe expressive dysphasia and child-like behaviour. Maria's husband had not coped as her carer and had abandoned her and their 12-year-old daughter, leaving her parents to look after them both.

Maria's parents took her to an oncologist for a third opinion. She had been treated elsewhere with surgery, radiation and chemotherapy, but because of her disabilities and her slim prospect of recovery, palliative care had been recommended. "That's a very sad story. How are you coping?" the oncologist asked Maria's parents. "Well, we are managing OK, but we think Maria's actually improving. She says a few words to us now and she is eating better." "How about we re-assess her with another MRI scan?" The oncologist suggested.

Feeling supported by this oncologist, Maria's mother revealed that they had not seen the palliative care team or any other doctors apart from her GP for the past eight months because they felt the other specialists had given up on Maria. "We pray every day for her," her father said, "We don't want to give up hope."

The oncologist asked, "Does praying give you the strength to cope?" Maria's parents agreed that their faith was an important part of their lives. "It's important to keep praying because of the support it gives you," the oncologist responded. He also explained the benefits of palliative care for both Maria and themselves, reassuring them that seeing the palliative care team did not mean that they were being abandoned by the medical team.

Having felt heard and more hopeful about the options for Maria, her parents agreed to talk to the palliative care team with the oncologist once the results were back from Maria's MRI scan.

### *Establishing trust and unconditional acceptance*

A caring, compassionate and attentive attitude will promote the development of a trusting relationship, enabling healthcare professionals to recognise and respond to spirituality and suffering.<sup>3, 39, 42, 57, 77</sup> Being fully present is critical,<sup>8, 12, 39, 43, 47, 54, 58</sup> as is demonstrating that patients have been heard.<sup>43</sup> This is important for physical suffering too, as having someone who is willing to listen may reduce the pain threshold to a tolerable level.<sup>43</sup> Such care and comfort can help people be eased, or lifted out, of their suffering.<sup>12, 43</sup>

Strategies to establish trust and rapport with patients include:

- using terminology patients and families understand<sup>54</sup>
- relating to patients with humility, respect and care rather than with authority<sup>42, 54</sup>
- affirming patients by communicating with them as a person – a fellow human being – rather than as the illness they have, and telling them that you care<sup>3, 4, 12, 43, 45, 54</sup>
- not being dismissive, distracted by electronic devices, or appearing not to have time available for the patient<sup>3, 39</sup> (WG consensus)
- respecting different social and cultural behaviours and values<sup>39</sup>
- listening to and respecting patients' view or feelings even if they are different from one's own<sup>3, 39, 43, 57</sup>
- helping patients feel safe in a new and unfamiliar environment<sup>3</sup>
- giving hope to patients and families, including the assurance they will not be abandoned even when cure is no longer possible<sup>3</sup>

### VIGNETTE - Warwick

**The following case illustrates the compassionate role of healthcare professionals to ensure close connectedness and a mutual understanding with the patient about what they're facing.**

Warwick was a 53-year-old man having concurrent chemotherapy and radiotherapy for a squamous cell carcinoma of the pyriform fossa. When the radiation therapist greeted him on his arrival for his third treatment session, Warwick averted his gaze and said, "Let's get on with it."

The therapist asked him to sit down and pulled over a chair to sit next to him. She said, "*This treatment is really hard. A lot of people really struggle with it. I know that sometimes it can feel as though you're just a number, but I really want to hear how you're doing. And I'm putting it on the table right now – you don't have to pretend it's OK if it's not.*"

Warwick looked at the therapist and nodded. "I've had a few struggles in my life but I think this is one of the toughest. It's good to know others find it tough."

### **Responding with empathy**

To show active listening, respond to patients with empathy.<sup>55, 57, 85</sup> Even if there is not an answer or a solution to the patients' needs, acknowledging this shows that the message has been heard.<sup>39, 43, 47, 57</sup>

Being open to a patient's particular way of expressing their suffering, hearing about their anger, guilt, fear, loneliness, despair and anxieties about death and other issues, and acknowledging these emotions but not judging them, can help immensely.<sup>10, 43, 55, 58, 64</sup>



Normalising patients' concerns may also permit the patient to talk further<sup>57, 85, 86</sup> and will help uphold their dignity.<sup>88</sup>

Some suggested responses include:

- That is an important, profound question, but I don't know the answer to it.<sup>43</sup>
- That sounds like a painful situation.<sup>57</sup>
- Sometimes it must feel as though it's a terrible dream. (WG consensus)
- I imagine it would be puzzling not to know.<sup>57</sup>

#### *Avoiding premature reassurance*

When patients question their worth, wonder whether they're being punished for their illness, or voice shame, it is often instinctive to want to reassure them immediately that this is not the case. To patients, however, this premature reassurance may seem dismissive and they may feel misunderstood. This can lead them to not talk further about their concerns. Health professionals may not only have lost an opportunity for patients to unburden themselves of guilt, anger or unexpressed worries,<sup>43, 57</sup> but may unwittingly emotionally distance themselves from patients.<sup>43, 45</sup>

When healthcare professionals do not rush to reassure patients, it suggests that their comments or questions are not too trivial or too large to be dealt with.<sup>86</sup> Discussing suffering does not make it worse (WG consensus) and acknowledging the issue can be beneficial and therapeutic to the patient.<sup>57</sup>

#### VIGNETTE – Trudi

**The following case shows the importance of acknowledging a patient whose behaviour or dialogue reflects an aspect of suffering, without trying to prematurely reassure them that there is nothing to worry about.**

Trudi was a 34-year-old woman with advanced cervical cancer. She had a recto-vaginal fistula and was ashamed of the odour in her room, apologising to the healthcare professionals who came into her room. When one of the nurses who came to check on her heard Trudi apologise, she sat down and said: "I can't imagine how hard this is for you. What's the thing that upsets you the most?"

Trudi expressed gratitude to be able to talk about her fear that she was disgusting. She said, "When the other nurse said she couldn't smell anything, I knew she was lying and it made me feel even worse – as though I was too disgusting to even talk to."

#### *Supporting appropriate hope*

Patients and families both need some degree of hope. Even in severe illness, people can still have hopes, although these may change over time.<sup>10</sup> Depending on the situation, hopes may be long-term or for day-to-day wishes. For example, a patient might hope for pain to be controlled, for family members to understand and forgive them, or to be able to attend an important occasion such as a wedding. (WG consensus)

Sometimes, however, patients and families may have unrealistic hopes. They may deny the reality of the situation, and this may cause them to make treatment decisions or request certain interventions that the healthcare professionals disagree with or believe to be futile.<sup>57</sup> It is important to show respect to patients and to acknowledge the significance of their

beliefs if this is influencing their decisions about care. It will also help if healthcare professionals align their hopes with the hopes of the patient and family. This can assist them to discuss other possible hopes that are more achievable and realistic.<sup>54, 57</sup>

#### VIGNETTE – Greg

The following case demonstrates the importance of acknowledging and supporting hope for a patient and their family, and responding to treatment decisions.

38-year-old Greg had a metastatic colorectal cancer that had failed to respond to several lines of chemotherapy including a recent trial. Greg was devastated to receive the results of his latest scan which demonstrated further disease progression. He said to the oncologist, "I just don't accept that there are no other options for me. I have a wife and two young children."

The oncologist was silent for a moment, then leaned forward and said, "Greg, if anyone could have beaten this by sheer force of willpower, it would have been you. You have soldiered on despite some dreadful side effects. But it wouldn't be right for me to just keep giving more and more treatment when it has made you so sick and not helped the disease. I would give anything for it to be different. But now I think we have to focus on other ways we can help you and your family."

#### **Silence in communication**

Although it is important to acknowledge patients, sometimes silence and stillness can be a significant communication tool.<sup>39, 53, 64</sup> Simply being there for patients and being open to their pain can help them through a spiritual crisis.<sup>43, 89</sup>

Back et al (2009)<sup>90</sup> suggest there are three types of silences, all of which can affect communication:

- Awkward silence – intention of silence not clear; may reflect distraction, hostility, judgement, ambivalence, disapproval or withholding
- Invitational silence – allows the patient time to think about or feel what is happening, often after an empathic response
- Compassionate silence – using a spontaneous moment in a conversation that allows for a shared feeling between a clinician and patient, or for the clinician to generate compassion for the patient.

If silence has the right intention it can be meaningful or therapeutic for the patient and for those who care for them.<sup>90</sup>

#### **Difficulties communicating**

There are various reasons why discussions about suffering or spirituality may not take place or may be awkward for both healthcare professionals and patients. Being aware of these barriers can help healthcare professionals overcome them. Importantly, members of the healthcare team should offer patients and families multiple opportunities to talk about their spiritual distress in the event that they are concealing it.<sup>5, 39</sup>

#### **Health professional barriers**

**Feeling overwhelmed:** Sometimes healthcare professionals can feel overwhelmed by the suffering of their patients and their inability to fix it. This feeling of powerlessness can contrast

sharply with the more usual task-driven focus in clinical care.<sup>3, 4, 6, 45, 58</sup> A balance needs to be found between offering spiritual care and doing the right thing by the patient,<sup>45</sup> and yet maintaining objectivity, wellbeing and resilience.<sup>45</sup>

### **Fears:**

Many healthcare professionals find it difficult to discuss and ask questions about patients' suffering and spirituality due to a variety of fears.<sup>39, 43, 45, 58, 65</sup> They may feel particularly unskilled and uncomfortable when patients are near the end of life and have intensified spiritual and religious concerns.<sup>57</sup> They may believe they are honouring a patient's dignity and privacy by not talking about spirituality and suffering issues.<sup>45</sup> Some fears include:

- Having their own emotional responses triggered, or responding to patients based on their own experiences rather than objectively<sup>43, 45, 47</sup>
- Being asked questions about their own spiritual beliefs and practices<sup>54</sup>
- Not being able to cope with patients' strong emotions such as guilt, anger or anxiety
- Being blamed for upsetting the patient<sup>43</sup> or making the suffering worse (WG consensus).

### Patient barriers

**Suffering is perceived to be secondary:** Some patients and families may feel that spirituality and suffering are an inevitable part of the illness, so they may not raise these issues even though they are thinking about them.<sup>6</sup> Healthcare professionals who indicate an openness and willingness to hear about suffering help validate patients' and families' experiences and legitimise their desire to raise spiritual concerns.<sup>6, 13, 57</sup> Most patients are open to discussing such topics with healthcare professionals who show interest, empathy and respect, who communicate well, and who take time to listen.<sup>39</sup>

**Concern about healthcare professionals:** Some patients may avoid talking about suffering because they feel it may cause anxiety for staff and they don't wish to be a burden;<sup>10, 47</sup> they do not think it is appropriate in a clinical context;<sup>54</sup> or they do not think staff have the knowledge, courage, understanding or time to deal with it.<sup>46</sup>

Patients may also detect non-verbal cues related to personal bias, judgemental attitudes or avoidant behaviour that the health professional may hold.<sup>3, 43</sup> This may prevent them feeling safe enough to talk about their spiritual needs.<sup>42, 43</sup>

**Not wanting to talk:** Some patients do not wish to talk about their suffering, emotions or spirituality or receive spiritual care at all.<sup>8, 45, 66</sup> This may be because of a desire to take control of their situation<sup>8, 45</sup> or because their feelings are intensely personal and they don't feel comfortable sharing them.<sup>5, 57, 66</sup> Sometimes patients are simply too exhausted to express themselves<sup>46</sup> or they need time to deal with their situation before talking about it with others.<sup>8</sup>

Patients may also feel unable to discuss these issues with their family.<sup>8, 41, 43</sup> Wanting to protect the family from difficult discussions is one reason.<sup>8</sup> Friends and family – and indeed patients themselves – may attempt to maintain a positive outlook, but in some cases this can instil a sense of unrealistic hope that can disguise suffering or make it difficult to articulate.<sup>10</sup>

Another important aspect to patients feeling comfortable about discussing their concerns is their desire for a shared understanding with the listener about what they are going through.<sup>8</sup>

<sup>46, 55</sup> If patients sense indifference, they are likely to feel lonely or let down. This may then contribute to increased suffering, and an inability or reduced desire to talk about their suffering or spiritual issues in the future.<sup>8, 46, 55</sup>

**When patients can't talk:** If a patient is physically unable to communicate, it is important for healthcare professionals to talk with family, if available, to try to establish any beliefs and wishes that are a true reflection of the patient and not necessarily the relatives.<sup>57</sup> This is particularly important if an advanced care directive has not been developed.

#### Further reading

*Eliciting and responding to emotional cues*<sup>86</sup> and *Breaking bad news*<sup>91</sup> provide evidence-based guidance on effective communication between patients and healthcare professionals, which may be of use when discussing suffering and spirituality issues.

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#### 4. CARE COORDINATION, REFERRAL AND INTERVENTIONS

PRACTICE POINTS		References
<b>I</b>	Following assessment and with patients' consent, ensure outcomes and other relevant information are recorded and communicated to other appropriate healthcare professionals.	
<b>J</b>	Confirm which healthcare professionals can attend to the different aspects of a patient's suffering. If a relevant discipline is not represented in the multidisciplinary team (MDT) or hospital/clinic, refer the patient to other appropriate means of care. This may include non-healthcare workers such as the multicultural liaison officer, Aboriginal liaison officer or chaplain/spiritual care adviser.	
<b>K</b>	<p>Consider the use of a psychological intervention designed to address suffering or one of its domains, such as hopelessness.</p> <p>Levels of evidence for interventions:</p> <p>All Level II except            * = Level III            + = Level III-II</p>	<p>Herth 2000<sup>14</sup>            Ando 2010<sup>15</sup>            Breitbart 2012<sup>16</sup>            Breitbart 2010<sup>17</sup>            Henry 2010<sup>18</sup>            Rustoen 1998<sup>19</sup>            Duggleby 2007<sup>20</sup>            Badger 2011<sup>21</sup>            Ferguson 2012<sup>22</sup>            Northouse 2005<sup>23</sup>            Delbar 2001<sup>24*</sup>            Koinberg 2006<sup>25+</sup>            Hansen 2009<sup>26</sup>            Witek-Janusek 2008<sup>27+</sup>            Henderson 2012<sup>28</sup>            Garland 2007<sup>29+</sup>            Moadel 2007<sup>30</sup>            Chandwani 2010<sup>31</sup>            Antoni 2001<sup>32</sup>            Penedo 2006<sup>33</sup>            Antoni 2006<sup>34</sup>            Danhauer 2009<sup>35</sup>            Fallah 2011<sup>36+</sup>            Rummans 2006<sup>37</sup>            Hsiao 2012<sup>38</sup></p>
<b>L</b>	Consider the use of additional supportive care therapies that may be available at the hospital/clinic or through support groups or spiritual networks, which patients may find beneficial. Examples include healing prayer, meditation or music therapy.	

OTHER KEY POINTS	Reference
Complex emotional needs may be best attended to by a psychologist, counsellor or a psychiatrist.	

#### Discussion with the healthcare team

Record general information from patients' suffering and spiritual assessments in their medical notes, and share relevant information with the wider healthcare team about patients' ongoing needs.<sup>43, 58</sup> If patients have divulged confidential information, their permission should be obtained before sharing it with others. (WG consensus)

Listen to feedback from all members of the team, including those in non-healthcare roles to allow important insights into a patient's wellbeing to be discussed. For example, a patient may confess to the receptionist that they are fearful or overwhelmed, but they may not feel comfortable confiding in their doctors or nursing staff.<sup>86</sup>

Discuss avenues for ongoing care, including who in the team will take responsibility for particular aspects. This could include referral outside of the healthcare team.

These strategies will help the team address suffering more effectively and ensure that this aspect of care is not overlooked or doubled up.

#### Discussion with patients and families

Discuss the suggested strategies for care with patients, as well as with families if patients prefer this. This should include information about treatment, side effects, referral to other healthcare professionals, how aspects of suffering might be alleviated, and how spiritual needs can be incorporated into care.

Allow patients and family members to ask questions and explain why some treatment options may not be available to them.

Agree on a plan of action, including how the patient is to be referred to other healthcare professionals, i.e. will they make contact themselves or will the healthcare team organise the referral.

#### Consideration of referral

Depending on patients' needs and the expertise of the healthcare team, it may be appropriate to refer them to other healthcare professionals outside the team, including those trained in spiritual wellbeing. Patients may also be referred to healthcare professionals with expertise in specific psychological therapies designed to reduce suffering.<sup>9</sup>

Establishing optimal methods for referring patients is vital for ensuring good psychosocial care for patients,<sup>1</sup> although local availability may limit options. See Figure 1 Referral flowchart for responding to suffering in cancer patients for recommended considerations and referral to different healthcare professionals to ensure patients' suffering and their spiritual needs are adequately responded to.

For further information about referral for broader psychosocial care, see the *Clinical practice guidelines for the psychosocial care of adults with cancer* (2003).<sup>1</sup>

## Referral options

### **Physical issues**

For physical issues, a physiotherapist, speech pathologist, dietitian, occupational therapist, pain specialist or palliative care specialist may be required.<sup>1</sup>

### **Social or emotional issues**

For social or emotional concerns, a social worker, hospital liaison officer, psychologist, counsellor or pastoral care worker may be helpful.<sup>8, 58</sup> In the case of severe anxiety or depression, which may require pharmacologic psychiatric intervention, a referral to a psychiatrist is recommended.<sup>58</sup>

## VIGNETTE – Lara

### **The following case demonstrates a dual approach to responding to suffering.**

Lara was a 69-year-old married woman with advanced melanoma who recently celebrated the birth of her third grandchild. Her four young adult children lived both locally and several hours' drive away.

At her initial assessment the nurse identified a range of physical symptoms requiring attention. Lara's low mood and pervasive anxiety seemed connected to her physical pain and sleeplessness. However, although her physical comfort improved with treatment, her overall distress remained. The nurse referred Lara to a counsellor.

Lara said to the counsellor, "I don't know how they'll cope when I'm gone." Acknowledging the centrality of Lara's role within her extended and geographically dispersed family the counsellor said, "*It sounds like you've been keeping a lot of balls in the air at once.*"

From this recognition Lara went on to reflect on the multiple deaths that had occurred within this family in recent years, her sense that she was the family go-between and her overwhelming concern that her family would fragment and disintegrate after her death.

### **Palliative care**

#### *Palliative care*

Palliative care aims to relieve the suffering of the whole person, and may represent a therapeutic option to the suffering patient. The World Health Organization recommends application of palliative care principles "as early as possible in the course of any chronic, ultimately fatal illness".<sup>73</sup>

### **Peer support**

#### *Peer support*

Support groups and one-on-one mentoring may offer the benefits of sharing, insights, communication and camaraderie, and often provide ongoing companionship for people following their treatment.<sup>64</sup> It should be noted, however, that some patients may find support groups difficult when they are confronted by other people's illness.<sup>8</sup> Groups may be open to general or specific cancer populations, for example, based on cancer type, age or cultural background. Some groups are also open to, or just for, partners or carers. Groups may be available face-to-face, via telephone or online. These are often organised by hospitals or

Cancer Councils. Cancer Councils and some other tumour-specific consumer organisations also provide one-on-one mentoring between trained volunteers with a personal experience of cancer and current cancer patients.

Some hospitals have volunteer visitors who can sit with patients, help pass the time, chat, or even offer foot and hand massages.

### **Spiritual support**

#### *Spiritual issues*

For matters of spiritual distress or despair, a spiritual care adviser from the hospital, a representative from the patient's religious community, or a community elder should be contacted with the patient's permission. Ideally the healthcare team can then collaborate with them.<sup>58</sup>

Encourage patients to continue their religious or spiritual rituals, and offer the support of a hospital spiritual care adviser and/or a religious leader or Aboriginal elder in the local community.<sup>54, 67</sup> Find out what is required for any ritual practices. For example, can patients access the hospital prayer/quiet room or chapel, or do they just require some space near their bed?<sup>92</sup> Can allowances be made for the type of ritual requested, such as a smoking ceremony, (WG consensus) use of a prayer mat<sup>92</sup> or the burning of incense?<sup>93</sup> Does the patient want solitude or the company of others? Can flexibility be given to the number of visitors allowed at one time?<sup>94, 95</sup>

Acknowledge that for some patients, getting in touch with their spiritual side may not be through formal religious ritual, but through creative pursuits such as listening to music, reading, journaling or art.<sup>54, 67</sup>

Provide written information that helps to instil hope and provide comfort for the patient.<sup>64</sup> An example is [Spirituality and Health](#) from American Family Physician.

#### VIGNETTE – Gwen

The following case demonstrates how a referral can come about when a patient talks about spiritual beliefs and values.

Gwen was a 62-year-old single woman who was being treated by Penny, a 24-year-old physiotherapist, for lymphoedema following treatment for breast cancer. When Penny asked Gwen about her self-massage Gwen responded that she didn't bother with it, adding "It's God's will that I suffer".

Gwen was reluctant to explain her comment to Penny, saying instead "Do you believe in God? If you don't you wouldn't understand." Penny responded, "I guess everyone has different life experiences and values. What matters to me now is trying to understand something which is causing you real anguish."

Gwen revealed that in her twenties she had had an affair with a married man, but had been too ashamed to ever confide about it to anyone. Penny replied, "I think that is too much to bear on your own" and gently encouraged Gwen to seek guidance and support from her local pastor.



## Interventions

To date there has been little research on interventions that specifically aim to alleviate suffering. Of the 42 relevant intervention studies identified in the systematic review, only two addressed suffering as a target of the intervention, while the majority (n=40) were directed at its symptoms.<sup>2</sup>

The interventions in the 42 studies were evaluated in either controlled trials or randomised controlled trials (level II and level III studies). They have been categorised into seven broader types of interventions:

- 1) Psycho-educational (n=9)
- 2) Meaning-centred (n=5)
- 3) Stress-reduction, including yoga, mindfulness, meditation, cognitive-behavioural stress management (n=10)
- 4) Hope-centred (n=3)
- 5) Supportive-expressive (n=5)\*
- 6) Spiritual (n=5)
- 7) Other (n=7)<sup>+</sup>

\* Includes a paper that is also included in the psycho-educational group.

+ Includes a paper that is also included in the stress reduction group.

In favour of interventions that may alleviate suffering, the systematic review found that:

- Some psycho-educational interventions may positively impact on spiritual distress and hopelessness in some circumstances.
- Meaning-centred interventions may significantly and positively impact on meaning in advanced cancer patients.
- Stress-reduction interventions may offer a promising way of enhancing spiritual wellbeing and meaning/benefit finding.
- Hope-centred interventions may significantly and positively impact on hope in cancer patients at different stages of the cancer continuum.

However, the systematic review determined that:

- No accurate conclusions can be drawn regarding the impact of supportive-expressive therapies on factors such as hope, spiritual wellbeing, self-transcendence, and purpose in life.
- Outcomes for spiritual interventions are inconsistent, particularly in regards to spiritual wellbeing.
- No significant outcomes were reported for relief of suffering in other assessed interventions such as art therapy, music therapy, creative arts and writing, animal therapy and touch therapy.

Further details of these interventions can be found in Appendix 2.

### **Development of skills**

In addition to the practice points drawn from the systematic review <sup>2</sup> and Working Group consensus, the multidisciplinary working group also encourage that healthcare professionals endeavour to improve their skills in communicating with patients and families about suffering and spirituality issues.

In particular, the support of the multidisciplinary team is very important. Facilitating debriefing, the discussion of complex cases or mentoring by drawing on the expertise within the MDT is suggested. Taking the time to learn about the nature and manifestations of suffering, and its typical effects at different stages of cancer, either individually or within the team can benefit one's clinical practice. Further, healthcare professionals are encouraged to explore one's own experiences and views of suffering and how this may impact on one's response to patients.

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## **STRENGTHS AND LIMITATIONS OF THE EVIDENCE**

### ***Conceptualisation of suffering***

In the Cancer Australia systematic review,<sup>2</sup> in order to overcome the lack of integrated literature on the conceptualisation of suffering in the context of cancer, it was necessary to synthesise common elements across a number of definitions of suffering, its synonyms and symptoms. While this method allowed for a wider range of relevant sources and a broader synthesis of available information, concepts relating to suffering, such as existential and spiritual suffering and distress, are not identical. Potentially useful nuances of these concepts have therefore not been fully explored.

Many study designs were included in the systematic review, including 50 qualitative studies, 21 theoretical/opinion pieces, 20 literature reviews, 18 case reports, 13 cross-sectional studies, one combination case report/theoretical/opinion piece, one prospective cohort study and one retrospective cohort study (total 125). Levels of evidence were also not considered relevant as the goal of this part of the review was to distil definitions and concepts of suffering emerging from the range of literature.

While the inclusion of this broad range of studies was useful in conceptualising suffering, any qualitative analysis contains an element of subjectivity. Although steps were taken to reduce the subjectivity of this analysis, including the double coding of themes and involvement of the multidisciplinary working group, it is possible that a different team may have reached different conclusions.

### ***Assessment of suffering***

Two measures that directly measured suffering and provided sufficient psychometric data were identified in the systematic review. Because of this small number, it was necessary to include tools that measured the various synonyms or symptoms of suffering. While these concepts are related closely to suffering, they are not identical and caution should be taken when deciding on the correct tool to use.

As a result of the large number of tools the systematic review identified (n=42), levels of evidence were not assigned to individual studies. Rather, data pertaining to the psychometric properties of individual measures has been extracted, as this was deemed the best way of presenting evidence about the appropriateness of each outcome measure. While the tools presented in this document have been validated in a cancer population and have sound psychometric properties, the majority have been validated in a research context rather than in a clinical setting.

### ***Interventions***

The search for interventions to alleviate suffering focused on a list of 'synonyms' and 'symptoms' of suffering. This was necessary because of the small number of interventions (n = 2) directly targeting suffering. This strategy allowed for the consistent inclusion of any measure or intervention targeting hope, meaning, or spiritual wellbeing, and appeared the most reliable of the possible search strategies identified. However, this strategy meant that interventions were excluded where they targeted more 'conventional' measures of distress (e.g. anxiety, depression). Outcomes such as self-efficacy and self-esteem were also excluded, as although improvements in self-efficacy and self-esteem may be associated

with alleviation of suffering, its synonyms, and/or symptoms, these variables themselves were not seen as synonymous or symptomatic of suffering.

The majority of intervention studies were randomised controlled trials or controlled trials. Levels of evidence and quality were assigned to these studies, which allowed for more in-depth analysis. Most studies were based on level II evidence, while a small number of interventions were based on level III evidence as they were assessed in pseudo-randomised controlled trials or non-randomised experimental trials. Study quality was generally strong.

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## **AREAS OF FURTHER RESEARCH**

Based on the evidence included in the systematic review, the following future research areas were identified:

- Clarifying the impact of psycho-educational interventions on spiritual wellbeing, sense of coherence and hopelessness
- The impact of supportive-expressive interventions on hope, spiritual wellbeing, self-transcendence and purpose in life
- Whether stress reduction interventions can be generalised to wider patient cohorts and if other specific patient populations benefit differently from such interventions
- Particular subsets of patients who would benefit the most from meaning-centred interventions that focus on measures of hopelessness, desire for death, and will to live
- Examining individual differences in coping styles between study populations to further explore the results of interventions that aim to alleviate suffering.

DRAFT

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This guidance was developed by Cancer Australia in consultation with the Review and update clinical practice guidelines – Cancer suffering and spirituality issues Working Group, a multidisciplinary working group convened by Cancer Australia.

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### External review

Cancer Australia acknowledges those who gave their time to provide comment on the draft guidance document as part of the external review process.

## Topic-specific guideline development process

Priority topic areas for guideline development are determined in consultation with key stakeholders including experts in relevant disciplines and consumer representatives. A specific multidisciplinary working group, including consumers, is established for each topic identified and is involved in all aspects of guideline development. A systematic evidence review is undertaken for each guideline. All members are asked to declare any conflicts of interest and these declarations are recorded. The content of the guideline is not influenced by any external funding body. The guideline is reviewed externally by key stakeholders and the wider community and endorsement is sought from relevant professional colleges and groups in Australia.

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## GLOSSARY

**Anticipatory grief** – Describes the grieving process experienced by someone prior to a loss actually occurring.

**Art therapy** – Used to help patients manage physical and emotional problems by using creative activities to express emotions and concerns.

**Body-mind-spirit therapy** – Focuses on developing a positive view of suffering from cancer as an opportunity for a healthy lifestyle based on the interrelationships between body, mind and spiritual wellbeing and purpose and meaning in life.

**BDI** - Becks Depression Inventory.

**BHS** - Becks Hopelessness Scale.

**Burnout** – Ascribed condition of physical, mental and emotional exhaustion experienced by a healthcare professional that may potentially lead to dysfunction.

**Cancer continuum** – Describes the course of illness experienced by those with cancer, which may encompass the stages from the initial diagnosis to the treatment, survivorship and end-of-life care for cancer patients.

**Chaplain** – Spiritual care professional that aims to help patients with spiritual and existential distress and suffering.

**Clinical depression** – Intense feelings of sadness, reduced ability to experience pleasure and very low mood for longer than two weeks in duration.

**Cognitive behavioural therapy** – A form of psychotherapy that helps patients change their behaviour by altering the way they think about certain things. It is used to treat mental, emotional, personality, and behavioural disorders.

**Cognitive-behavioural stress management** – A type of stress reduction intervention often in a group setting that may involve a variety of cognitive-behavioural strategies such as meditation, relaxation and interpersonal communication that recognises and alters responses to negative thoughts.

**Distress** – Emotional, mental, social or spiritual suffering. Distress may range from feelings of vulnerability and sadness to stronger feelings of depression, anxiety, panic and isolation.

**Early-stage cancer** – The initial stages of cancer growth that usually have not spread to distal parts of the body.

**Existential distress** – Feelings of hopelessness, burden to others, loss of sense of dignity or self-identity, and in some cases, desire for death or loss of will to live.

**Existential issues** – Issues that derive from feelings of isolation, death, desire for meaning and purpose in one's life.

**EWS** - Existential Well-Being Scale.



**FACIT** – Functional Assessment of Chronic Illness Therapy.

**HADS** – Hospital, Anxiety and Depression Scale.

**HDRS** - Hamilton Depression Rating Scale.

**HOPES** - Hunter Opinions and Personal Expectations Scale.

**Haptotherapy intervention** – The use of touch to enhance the physical and emotional wellbeing of a patient.

**Holistic care** – Care that incorporates different types of therapies and services to ensure that the patient's physical, emotional, spiritual and practical needs are met.

**Hope-centred intervention** – Designed to enhance aspects of hope in patients with cancer delivered by both individual and group interactions.

**Imam** – An Islamic religious leader belonging to the religion of Islam.

**Loss of dignity** – A symptom of suffering that describes the inability to value the meaning and purpose in one's life.

**Loss of meaning** – Belief that life is no longer worth living; describes feelings of loss of meaning, purpose and role in one's life.

**McGill QOL** - McGill Quality of Life Scale.

**Meaning-centred intervention** – Designed to build and sustain meaning and spirituality into end-of-life care for patients with advanced cancer. Interventions may include therapist-guided life review (i.e. life review and dignity therapy), individual psychotherapy focusing on meaning, and meaning-centred group psychotherapy.

**Meaning in life - Presence** – This measures the presence of meaning in someone's life, i.e. how much people feel their lives have meaning.

**Meaning in life - Search** – This measures the people's search for meaning, i.e. how much they strive to find meaning and understanding in their lives.

**Multicultural liaison officer** – Person whose role is to increase the connectedness between a patient and their respective healthcare team.

**Meditation** – The action or practice of focusing on body movements and breathing to increase one's awareness of the present moment, alleviate stress and promote relaxation.

**Mindfulness based therapy** – Promotes the concept of being “mindful,” and heightened awareness of the present. Employs practices to relax the body and mind to counteract stress.

**Multidisciplinary care** – A team approach to cancer treatment and planning.

**Multidisciplinary team (MDT)** – A comprehensive team of healthcare professionals that may consist of but is not limited to palliative care specialists, psychiatrists, psychologists, counsellors, dietitians, physiotherapist, pain specialists, speech pathologists, occupational

therapists, hospital liaison officers and social workers.

**Music thanatology** – Delivered by a specially trained harpist who provides music in palliative care settings, often using the harp.

**Music therapy** – The use of music by healthcare professionals to promote quality of life and healing for patients.

**NHS** - Nowotny Hope Scale.

**Non-verbal cue** – An intangible or tangible indicator conveyed without speech that provides emotional or other information about a person, for example, body language, facial expression or non-verbal noise (intangible), or dress or jewellery (tangible).

**Pain specialist** – A health professional who specialises in the treatment and alleviation of pain and associated symptoms.

**Palliative care** – An approach that improves the quality of life of patients and their families facing problems associated with a life-threatening illness. Involves the treatment of physical, psychosocial and spiritual aspects of wellbeing.

**Palliative care specialist** – A health professional who specialises in the management but not the curing of pain for those with a serious or life-threatening disease.

**Pastoral care** – a person providing a patient-centred, holistic approach to care that complements the care offered by other helping disciplines while paying particular attention to spiritual care. It focuses on empowering people in whatever situation they find themselves.

**Patient-centred model of care** – Innovative approach to the planning, delivery, and evaluation of health care that focuses on mutually beneficial partnerships among healthcare providers, patients, and families.

**PHQ** - Patient Health Questionnaire.

**Premature reassurance** – Reassurance delivered by a healthcare professional that is interpreted as dismissive and unhelpful by the patient due to its seeming lack of empathy.

**Priest** – An ordained minister of the Catholic, Orthodox, or Anglican Church who has the authority to carry out sacred rituals specific to a religion.

**Psychiatrist** – A medical doctor who specialises in the prevention, diagnosis, and treatment of mental, emotional, and behavioural disorders.

**Psycho-educational intervention** – Behavioural interventions designed to maintain and improve quality of life, including psychological, physical, social, and spiritual wellbeing, through repeated sharing of key information.

**Psychologist** – A health professional who can discuss emotional and personal matters with a patient and their family and can help with making decisions to promote their wellbeing.

**Psychometric property** – A measure of the appropriateness, reliability and validity of a tool (e.g. used to assess suffering) used to evaluate an outcome or a construct.

**Psychosocial** – Treatment that is intended to address psychological, social and some spiritual needs.

**Quality of life** – An individual's overall appraisal of their situation and subjective sense of wellbeing. Quality of life encompasses symptoms of disease and side effects of treatment, functional capacity, social interactions and relationships, and occupational functioning.

**Recurrence** – Cancer that has come back after treatment.

**Risk factors** – Variables that increase someone's chance of developing a disease such as cancer, some of which are modifiable (e.g. lifestyle) and others which aren't (e.g. gender).

**Rabbi** – A Jewish religious leader belonging to the religion of Judaism.

**Relaxation** – A form of therapy where emphasis is put on teaching the patient how to relax both mentally and physically, and to control breathing, with the aim of reducing emotional distress, and improving control of symptoms such as anxiety or pain.

**Self-transcendence** – One's ability to overcome personal issues and adversity to enhance broader life perspectives.

**SAHD** - Schedule of Attitudes Toward Hastened Death.

**SOC** - Sense Of Coherence

**Spiritual care** – Care focused on the religious and spiritual needs of a patient and their family to address existential issues and meaning and purpose in life.

**Spiritual distress** – Disruption in the life principle that pervades a person's entire being, which may cause someone to express concerns about the meaning of life and death, the meaning of suffering or one's own existence, and to seek spiritual assistance.

**Spirituality** – Having to do with deep, often religious, feelings and beliefs, including a person's sense of peace, purpose, connection to others, and beliefs about the meaning of life. Spirituality is subjective and can be expressed in many unique ways.

**Suffering** – Physical, psychological, social and spiritual reactions that may encompass demoralisation; existential distress, existential suffering or existential pain; psycho-spiritual distress; psycho-existential suffering; spiritual pain; and total pain.

**Spiritual intervention** – Designed to address the spiritual concerns of patients by incorporating an explicitly spiritual component to elevate feelings of hope, happiness, life satisfaction and health.

**Spitzer QLI** - The Spitzer Quality of Life Index.

**Stage** – The extent of a cancer and whether the disease has spread from an original site to other parts of the body.

**Stress reduction intervention** – Designed to help enable people to manage different stressors by helping them develop a conscious awareness (i.e. mindfulness) of their behaviour, emotions and responses in a non-judgemental and accepting manner. .

**Supportive care** – Improving quality of life for people with cancer from different perspectives, including physical, social, emotional, financial and spiritual.

**Supportive-expressive intervention** – Encompass both supportive group and individual therapy designed to enhance overall Quality of Life.<sup>96</sup> Interventions may include individually-delivered telephone therapy, forgiveness therapy, face-to-face and telephone delivered support groups.

**Support group** – A group of individuals with a common experience who meet regularly, often with a leader to guide the discussion, to provide support and emotional caring for each other. Groups may be organised through hospitals, cancer control organisations or by individuals. Group members include patients and/or partners and carers. Other components of support may include provision of practical or material aid, information, guidance, feedback and validation of the individual's stressful experiences and coping choices.

**Survivorship phase** – In cancer, survivorship focuses on the health and life of a person with cancer beyond the diagnosis and treatment phases. Survivorship includes issues related to follow-up care, late effects of treatment, second cancers, and quality of life. Family members, friends, and caregivers are also part of the survivorship experience.

**Tai chi** – A Chinese derived exercise that utilises breathing, visualisations and movements to enhance overall wellbeing.

**Terminal illness** – Diagnosis of an incurable disease that will ultimately lead to death.

**Working Group consensus** – Endorsement of a specific statement (or information) by a multidisciplinary working group of clinical experts and consumers, in the absence of direct supporting evidence.

**Yoga** – A practice with Hindu origins that aims to bring the body, mind and spirit into a state of tranquillity and peacefulness through gentle and controlled body movements.

## APPENDIX 1 – Measures of suffering and its various analogues

Note – Abbreviations of measurement scales are listed at the end of this Appendix and in the Glossary.

### Measures of Suffering

Pictorial Representation of Illness and Self Measure (PRISM), Büchi et al, 2002<sup>97</sup>

The PRISM is a novel method of measuring patient suffering. In this task, the patient is asked to imagine that an A4 board represents their life and that a fixed yellow disk in the bottom right hand corner represents their 'self'. They are asked to place another disk on the board to represent the current importance of their illness in their life. The distance between these two disks provides a Self Illness Separation (SIS) score.<sup>98</sup> The revised PRISM-R2 provides three sizes of disk to indicate perceived severity of illness;<sup>99</sup> both tasks take 4–8 minutes.<sup>98</sup> Although face-to-face administration may be preferable,<sup>99</sup> the PRISM and its variants have been administered via mail.<sup>99, 100</sup>

The PRISM was validated in a sample of patients with a variety of chronic physical illnesses (n=700) showing strong test-retest reliability ( $r = 0.95$ ), inter-rater reliability ( $r = 0.79$ ) and convergence with other measures including SF-36 (physical  $r=0.35$ , mental  $r=0.20$ ), HADS Depression ( $r=-0.31$ ) and SOC ( $r=0.23$ ).<sup>97</sup> Qualitative data showed that patients had a consistent understanding of the task and aligned with the conceptualisation of suffering found in the literature with low scores associated with intrusiveness, lack of control and interference. PRISM-R@ was validated in a large population based sample of patients with various cancers (n=1299) showing convergence with the SF-36 (physical  $r=0.17$ , mental  $r=0.19$  and the Quality of life- Cancer survivors questionnaire ( $r=0.26$ ).<sup>99</sup>

The advantages of this measure include its brevity, simplicity, and ease of use.<sup>98</sup> In addition, by not specifying items and domains it allows for a subjective assessment of suffering due to illness regardless of how patients individually define this.<sup>99, 100</sup>

Other available measures of suffering were Mini-Suffering State Examination (MMSE).<sup>101</sup>

### Measures of Hopelessness and demoralisation

Hopelessness Assessment in Illness Questionnaire (HAI), Rosenfeld et al, 2011<sup>102</sup>

Hopelessness Assessment in Illness (HAI) Questionnaire was developed specifically for terminally ill cancer patients in a palliative care setting. To avoid results being confounded by prognosis of the patient, this scale was designed to measure hopelessness relatively distinct from prognostic awareness (PA) and psychometric analysis shows a promising ability to do so. The scale can be self-administered or read aloud to the patient. HAI uses anchored hierarchical statements rather than a question-answer response format, with patients choosing which of three statements most applies to them, for example 'I don't feel discouraged about my future', 'I sometimes feel discouraged about my future' or 'I often feel discouraged about my future'. The eight items explore four aspects of hopelessness; affective elements of despair, will to live, sense of futility and cognitive rigidity.

The items for the scale were developed through a three-stage process: 1) qualitative analysis of interviews were conducted with palliative care experts and patients with advanced cancer to determine the aspects of hopelessness to be included 2) classical test theory and

item response analysis in order to refine the initial 20 item scale (n=314) and 3) validation in a separate sample of cancer patients (n=228).<sup>102</sup> The scale showed concurrent validity with other scales of helplessness BHS(r=0.78) and BHS-7 (r=0.70) and with a clinical rating of hopelessness (CRH) (r=0.74) (based on a Wilson et al's 2004 brief structured interview). These measures showed lower correlations with measures of prognosis and illness severity, suggesting the HAI was successful in its goal of reducing the confounding impact of prognosis on hopelessness. HAI also showed significant correlations with depression and psychological distress measures (HADS r=0.65 to 0.61), FACIT Spiritual Well-Being scale r=-0.64, SAHD r=0.60). Importantly, after controlling for other predictors (depression, social support and prognostic awareness) HAI accounted for more of the variance in SAHD than other measures of hopelessness (HAI= 13%, BHS= 8%, CRH=5%) and more variance in the suicidal ideation than the BHS but not the CRH (HAI=16%, BHS= 4%, CRH=20%).

The major strength of the HAI is its strong content validity due to the systematic development of the items. The brevity (8 items) is also an important strength when considering use in a palliative care population and while anchored statements increase the length of the instrument, subjective reports from the researchers indicate that this style of statement increases the ease of comprehension for the terminally ill patient. Considering its brevity, HAI shows strong internal consistency ( $\alpha=0.87$ ) and substantially greater ability to predict outcome variables than other measures of hopelessness. HAI has the potential for a brief screening tool in the clinical setting although further research is required to determine how best this may be implemented.

Demoralisation Scale, Kissane et al, 2004<sup>103</sup>

The Demoralisation Scale was developed specifically for use in cancer patients and consists of 24 brief items that can be self-administered. A brief introduction prompts patients to indicate how frequently each item applies to them over the last two weeks using a 5-point response scale (never, seldom, sometimes, often, all the time). The advantage of the Demoralisation Scale is its comprehensiveness, with 24 items and five distinct domains determined through factor analysis, allowing for a detailed examination of the patient. Example items include 'my role in life has been lost' (loss of meaning), 'I tend to feel hurt easily' and 'I feel guilty' (dysphonia, explore non-specific emotions of distress and regret), 'I feel quite isolated and alone' (disheartenment), 'I no longer feel emotionally in control' (hopelessness) and 'I am a worthwhile person' (sense of failure, reversed).

The Demoralisation Scale was primarily developed based on the authors' clinical experience and knowledge of the literature and involved 15 cancer patients in the review process, asking them to comment particularly on the comprehensibility and acceptability of items. Items were revised until the authors reached a consensus on items that represented the construct (face validity). The original validation study took place in a clinical setting with advanced cancer patients (n=100) recruited from pain and palliative care or psycho-oncology clinics in Australia.<sup>103</sup> The scale shows strong psychometric properties with high internal reliability in each factor ( $\alpha=0.71$  to 0.89) and concurrent validity with a number of other measures including HOPES (r=-0.65), McGill QOL (r=-0.76), BDI (r=0.76), PHQ (r=0.79), BHS (r=0.67) and SAHD(r=0.577).<sup>103</sup> Similar results were found in a subsequent validation study conducted in Ireland (n=100).<sup>104</sup> While the original study Kissane et al (2004)<sup>103</sup> suggested that demoralisation was distinct from depression, Mullane et al (2009)<sup>104</sup> found the interpretation of the data to be inadequate finding convergence between the two constructs in their sample and upon reanalysis of the Kissane et al (2004)<sup>103</sup> data.

**Other available measures of hopelessness and demoralisation:** Beck Hopelessness Scale (BHS);<sup>105</sup> Cancer Care Monitor (CCM) – Despair Subscale;<sup>106</sup> Demoralisation Scale;<sup>107</sup> Single-item screening tool for hopelessness (Structured Interview for Symptoms and Concerns, SISC);<sup>108</sup> Subjective Incompetence Scale (SIS).<sup>109</sup>

## Measures of Hope

Herth Hope Index (HHI), 1992<sup>110</sup>

The Herth Hope Index (HHI) is an abbreviated short version of the 30-item Herth Hope Scale.<sup>111</sup> HHI is designed specifically for use in a clinical setting with specific attention given to designing simple items and items relating to adults experiencing alterations in health status. This self-report measure consists of 12 items and uses a four-point Likert scale, 'strongly disagree (1)' to 'strongly agree (4)'. The tool's three subscales were determined through factor analysis and correspond with Dufault and Martocchio's (1985) model of hope. The temporality and future subscale comprises items that focus on the positive perception of the self and others and the experience of time on hope, such as 'I believe that each day has potential'. The positive readiness and expectancy subscale includes items to measure feelings of expectancy and action orientation to affect outcomes such as, 'I have a sense of direction'. Interconnectedness, contains items that measure the mutuality of hopes and the life situations that surround, influence and are a part of a person's hope such as, 'I am able to give and receive care / love'.

The content and face validity was assessed by two panels, consisting of research experts, clinicians and consumers and was pilot tested to insure the usability of the tool. The HHI has been validated in both non-cancer<sup>110</sup> and cancer populations<sup>112</sup> with preliminary results supportive of the scale's reliability and validity. The scale shows good internal consistency, both for the entire sample ( $\alpha = 0.97$ ) and each domains ( $\alpha = 0.78 - 0.86$ ).<sup>110</sup> Concurrent validity has been shown with the original HHS ( $r=0.91$ ), EWS  $r=0.84$ ) and the NHS ( $r=0.81$ ).<sup>110</sup> Divergent validity was shown with depression assessed by the BHS. These findings suggest that this 12-item scale is as powerful as the Herth Hope Scale, the 30-item version it was based on.<sup>111</sup> Further, a recent review suggests that HHI has been used in a number of studies in the cancer context to date.<sup>113</sup>

Other available measures of hope include Adult Dispositional Hope Scale (ADHS);<sup>114</sup> Herth Hope Scale (HHS);<sup>111</sup> Hope Differential (HD);<sup>115</sup> Hope Differential-Short (HDS);<sup>116</sup> Miller Hope Scale (MHS);<sup>117</sup> Nowotny Hope Scale (NHS).<sup>118</sup>

## Measures of Spiritual wellbeing

Functional Assessment of Chronic Illness Therapy – Spiritual Wellbeing (FACIT-Sp), Peterman et al, 2002<sup>119</sup>

The Functional Assessment of Chronic Illness Therapy – Spiritual Wellbeing Scale (FACIT-Sp) comprises 12 self-report items with two subscales. The 8-item Meaning/Peace subscale assesses a sense of meaning, peace, and purpose in life with items including 'My life has been productive and 'I am able to reach down deep into myself for comfort'. The 4-item Faith subscale measures several aspects of the relationship between illness and one's faith and spiritual beliefs with items including 'I find strength in my faith or spiritual beliefs and 'I know that whatever happens with my illness, things will be okay'. The scale is can be

completed as a self-report measure, with a five-point Likert scale of 0 'not at all' to 4 'very much' reflecting the patient's experiences in the seven days prior to the interview.

The scale was developed in a comprehensive process involving interviews with cancer patients, psychotherapists, and religious experts.<sup>119</sup> The scale and its subscales show adequate internal consistency ( $\alpha=0.81$  to  $0.88$ ). None of the correlations between the Meaning/Peace subscale and other measures of spirituality and religion assessed in one validation study met the criteria established by the authors of that study for a significant degree of shared variability.<sup>119</sup> They suggest that this scale measures a concept distinct from those assessed by other measures (i.e., the sense of meaning and purpose provided by spirituality, as well as a sense of connection to something bigger than one's self that is associated with feelings of harmony and peace). However, they base this conclusion on the face validity of the scale, and suggest that further research into the construct validity of the scale is required. It has been argued by others that the Meaning/Peace subscale represents existential wellbeing, while the faith subscale represents religious wellbeing, a construct more closely related to individual religiosity.<sup>120</sup> Confirmatory factor analysis has subsequently been used to support a hypothesised three-factor model for the FACIT-Sp, comprising cognitive (i.e., meaning) and affective (i.e., peace) aspects of spirituality as well as faith.<sup>121, 122</sup> Responsiveness to change has also been found in a number of studies.<sup>15 16 17 18</sup>

A major advantage of FACIT-Sp is that it was developed and validated in a large sample size with a large proportion of cancer patients (1,167 patients, 83% with cancer), consists of only 12 items, is used frequently in the context of cancer, and has substantive data available about its psychometric properties. FACIT-Sp is also a part of the large FACIT measurement suite, which has well-published and rigorous standards of measurement development.

**Other available measures of hope include** Are you at peace? Single item;<sup>123</sup> JAREL Spiritual Wellbeing Scale;<sup>124</sup> Spiritual Wellbeing LASA item<sup>125, 126</sup> Peace, Equanimity and Acceptance in the Cancer Experience (PEACE);<sup>127</sup> Self Transcendence Scale (STS),<sup>128, 129</sup> Spirit 8;<sup>130</sup> Spiritual Health Inventory (SHI) Patient form, Nurse form;<sup>131</sup> Spiritual Perspective Scale (SPS);<sup>132</sup> Spirituality Transcendence Measure (STM);<sup>133</sup> Spiritual Wellbeing Scale (SWBS).<sup>134, 135</sup>

## Measures of Meaning

The Life Attitude Profile – Revised (LAP-R), Reker, 1992<sup>136</sup> [as cited in <sup>137</sup> and <sup>138</sup>]

The Life Attitude Profile – Revised (LAP-R) is a self-report multi-dimensional measure of meaning that assesses both meaning and purpose in life, along with the motivation to find meaning and purpose in life. The measure aims to assess meaning in life independent of personal values, and is based on the conceptualisation that meaning in life is a commitment to one's goals and fulfilment. The measure consists of 48 questions using a seven-point Likert scale from 'strongly agree' to 'strongly disagree' and takes about 15 minutes to complete. Six subscales are included in the measure: purpose, coherence, choice/responsibleness, death acceptance, existential vacuum and goal seeking. The measure also allows two composite scores: Personal Meaning Index and Existential Transcendence.<sup>136</sup> Example questions include:

- My past achievements have given my life meaning and purpose (purpose)
- I have a framework that allows me to understand or make sense of my life (coherence)



- I determine what happens in my life (choice/ responsibility)
- Since death is a natural aspect of life, there is no sense worrying about it (death acceptance)
- I feel the lack of and a need to find a real meaning and purpose in my life (existential vacuum), and
- I am eager to get more out of life than I have so far (goal seeking)

The LAP-R a revised version of the 56 item The Life Attitude Profile<sup>139</sup> was originally validated in a sample of university students. The scale shows good internal consistency ( $\alpha = .77$  to  $.91$ ) and test-retest reliability (4-6 weeks  $r = .77$  to  $.90$ ).

One strength of this measure is the availability of normative data from non-clinical samples.<sup>137</sup> The Personal Meaning Index has been used in the cancer context<sup>140, 141</sup> and in a number of languages.<sup>142-144</sup> It has sound psychometric properties, and in a recent review of measures it was considered the measure of choice for researchers seeking to explore the link between global meaning and other variables in the context of cancer.<sup>137</sup>

Functional Assessment of Chronic Illness Therapy – Spiritual Well Being Scale (FACIT-Sp): Meaning/Peace subscale, Peterman et al, 2002<sup>119</sup>

FACIT-Sp Meaning/Peace subscale consists of eight items assessing the sense of meaning, peace and purpose in life. The scale can be completed as a self-report measure, with a five-point Likert scale of 0 'not at all' to 4 'very much' to reflect the experiences of the patient in the seven days prior to the interview.

The focus of the measure is on global, rather than specific, meaning, with cancer not specifically linked to the concepts of any of the included items.<sup>137</sup> The advantage of this measure is that it is part of the large FACIT measurement suite, which has well-published and rigorous standards of measurement development.

**Other available measures of meaning include** Chinese Cancer Coherence Scale (CCCS);<sup>79</sup> Constructed Meaning Scale;<sup>145</sup> Illness Cognition Questionnaire (ICQ);<sup>146</sup> Internal Coherence Scale (ICS);<sup>147</sup> Life Attitude Profile (LAP) (228); Life Evaluation Questionnaire (LEQ);<sup>148</sup> Meaning in Life questions<sup>149</sup> Meaning in Life Questionnaire (MLQ) (231); Meaning in Life Scale (MiLS);<sup>150</sup> Meaning in Suffering Test (MIST);<sup>151</sup> Perceived Meanings of Cancer Pain Inventory (PMCPPI);<sup>152</sup> Personal Meaning Profile<sup>(153 cited in 154);</sup> Positive Meaning and Vulnerability Scale;<sup>155</sup> Purpose in Life Test (Lee and Pilkington);<sup>156</sup> Purposelessness Boredom and Understimulation scale (PUB)<sup>157</sup>; Schedule for Meaning in Life Evaluation (SMiLE);<sup>158</sup> Sense of Coherence Scale (Orientation to Life Questionnaire);<sup>159</sup> Sources of Meaning Profile (SOMP) and Sources of Meaning Profile – Revised (SOMP-R) (<sup>160 cited in 137 and 161</sup>); World Assumptions Scale.<sup>162</sup>

## Measures of Multi-dimensional measures of quality of life including a spiritual/existential dimension

McGill Quality of Life Questionnaire (MQOL), Cohen et al, 1996,<sup>163</sup> Cohen et al, 1997<sup>164</sup>  
The McGill Quality of Life (MQOL) questionnaire<sup>165</sup> was developed specifically to assess multiple quality of life domains in patients facing life-threatening illness. The measure is brief and a low burden on the patient, with only 17 items asking patients to recall their feelings in the past two days. The questions cover four subscales: physical (seven items), psychological



## Measures of Distress in palliative care

Schedule of Attitudes toward Hastened Death (SAHD), Rosenfeld et al, 1999,<sup>177</sup> Rosenfeld et al, 2000<sup>178</sup>

The Schedule of Attitudes toward Hastened Death (SAHD) was developed to provide a standardised tool to assess medically ill patients' desire for hastened death in response to the growing public debate regarding assisted suicide and euthanasia. The SAHD was intended to encompass several potential aspects of the desire to hasten death, including concerns regarding QoL, social and personal factors, and thoughts or actions taken to hasten one's death, however no subscales are included.

The measure is brief, with only 20 items in a true/false answer format. Unlike other measures of desire to hasten death, the SAHD measures this desire on a continuum, with scores ranging from 0 to 20 rather than as a dichotomous variable (yes/no). Higher scores are indicative of an increased desire for death. The scale also allows for potential comparisons to be made between low, moderate and high levels of desire for death. Example items include:

- I feel confident that I will be able to cope with the emotional stress of my illness
- I am seriously considering asking my doctor for help in ending my life
- I hope my disease will progress rapidly because I would prefer to die rather than continue living with this illness
- I want to continue living no matter how much pain or suffering my disease causes
- dying seems like the best way to relieve the emotional suffering my illness causes

The scale has been validated in both non-cancer (n=195)<sup>177</sup> and cancer populations (n=92).<sup>178</sup> The scale shows good internal consistency ( $\alpha = 0.88-0.89$ ).<sup>177,178</sup> In cancer patients the SAHD correlated strongly with the DDRS, a clinician-rated measure of desire for death ( $r=0.67$ ) and was highly correlated with the measures of depression and hopelessness including HDRS ( $r=0.49$ ) and BHS ( $r=0.55$ ). Measures of physical wellbeing were also correlated with SAHS in the expected direction.

The 0-20 scale in the SAHD allows for greater variability in the desire for death ratings, which may be more meaningful for research. While further research may provide validation for use in a clinical setting, currently this tool is only validated for use in research.

**Other available measures of distress in palliative care include** Single-item screening tool for desire for death (Structured Interview for Symptoms and Concerns, SISC).<sup>108</sup>

## Abbreviations of measurement scales

**BDI** - Becks Depression Inventory

**BHS** - Becks Hopelessness Scale

**EWS** - Existential Well-Being Scale

**FACIT** – Functional Assessment of Chronic Illness Therapy

**HADS** - Hospital Anxiety and Depression Scale

**HDRS** - Hamilton Depression Rating Scale

**HOPES** - Hunter Opinions and Personal Expectations Scale

**McGill QOL** - McGill Quality of Life Scale

**NHS** - Nowotny Hope Scale

**PHQ** - Patient Health Questionnaire

**SAHD** - Schedule of Attitudes Toward Hastened Death

**SOC** - Sense Of Coherence

**Spitzer QLI** - The Spitzer Quality of Life Index

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## APPENDIX 2 – Interventions

### Psycho-educational interventions

A psycho-educational intervention can be defined as a behavioural intervention focusing on the improvement of quality of life, including psychological, physical, social and spiritual wellbeing, which incorporates skilful information giving, discussion of concerns, problem solving, coping skills training, expression of emotion, and social support.<sup>179, 180</sup> Examples include health education programs, telephone counselling and patient empowerment programs. Some interventions target both patients and partners or carers, while others focus only on the individual with the cancer diagnosis.

The nine studies included in the review had different aims and used different tools to assess the outcomes. Seven were randomised controlled trials, one a pseudo-randomised controlled trial, and one a non-randomised experimental trial. The results are inconsistent, particularly regarding spiritual wellbeing, and therefore overall interpretation is difficult. Only five studies assessed spiritual wellbeing specifically, with two finding a positive impact<sup>21, 22</sup> and the other three resulting in non-significant changes.<sup>180-182</sup> In one study<sup>23</sup> a significant change in the intervention group was reported for hopelessness, at least initially. In another study<sup>183</sup> there was a non-significant change in hopelessness in the intervention group.

However, there were no significant outcomes reported for other measures across all studies. It appears, therefore, that spiritual wellbeing and hopelessness may be positively impacted by certain psycho-educational interventions in some circumstances, but findings are inconsistent and further research is recommended.

The studies listed in Table 2 below include those demonstrating significant changes in the intervention group of at least one of the measured outcomes of suffering.

See the systematic review for full details of assessed studies.<sup>2</sup>

**Table 2: Summary of psycho-educational intervention studies reporting significant findings in the intervention group measuring outcomes of suffering**

Study	Intervention	Control	Measures	Outcome
<p>Badger (2011)<sup>21</sup> USA</p> <p><b>Study type</b> RCT</p> <p><b>Level of evidence</b> Level II</p> <p><b>Quality</b> Strong</p>	<p>Two telephone-delivered interventions compared with each other to assess effectiveness of maintaining and improving quality of life for prostate cancer survivors and carers:</p> <p>A) Interpersonal counselling and cancer education, addressing mood and emotional expression, and facilitating ability to process and adapt to stressful situations.</p> <p>B) Health education providing written material about prostate cancer and other cancer topics, but no counselling provided.</p> <p>Both interventions delivered over two months; weekly for survivors; fortnightly for carers.</p>		<p>Quality of Life – Breast Cancer (QOL-BC) spiritual wellbeing scale</p>	<p>Significant improvement over time in spiritual wellbeing for health education group for both survivors and carers. Improvements also in depression, negative affect, stress and fatigue.</p> <p>No significant changes over time for the interpersonal counselling group, but survivors did have high QOL at baseline which did not deteriorate over time, and also showed improvements in depression.</p>
<p>Ferguson (2012)<sup>22</sup> USA</p> <p><b>Study type</b> RCT</p>	<p>Breast cancer survivors &gt; 18 months post-chemotherapy offered brief cognitive behaviour therapy in the form of Memory and Attention Adaptation Training (MAAT)</p>	<p>Waitlist control</p>	<p>Quality of Life – Cancer Survivors (QOL-CS), Multiple Ability Self-Report Questionnaire (MASQ), Center for Epidemiological Study –</p>	<p>Significant improvement in intervention group on spiritual wellbeing subscale of QOL-CS and high participant satisfaction of intervention.</p>

Study	Intervention	Control	Measures	Outcome
<p><b>Level of evidence</b> Level II</p> <p><b>Quality</b> Strong</p>	<p>for management of cognitive dysfunction following chemotherapy. Aim is to give participants compensatory strategies to address chronic memory dysfunction.</p> <p>Four fortnightly visits with phone contact between visits.</p>		<p>Depression (CES-D), Spielberger State-Trait Anxiety Inventory (STAI), Treatment Satisfaction scale.</p>	
<p>Northouse (2005)<sup>23</sup> USA</p> <p><b>Study type</b> RCT</p> <p><b>Level of Evidence</b> Level II</p> <p><b>Quality</b> Strong</p>	<p>Patients with advanced breast cancer and their families completed the FOCUS program to improve family communication, optimistic thinking and coping skills; identify family strengths; and increase knowledge of disease, symptoms and self-care.</p> <p>Delivered by three monthly nurse visits and two follow-up phone calls.</p>	<p>Usual care</p>	<p>Results measured using Appraisal of Illness Scale or Appraisal of Caregiving Scale, Mishel Uncertainty in Illness Scale, Beck Hopelessness Scale, the Brief COPE, the FACT scale version three and the SF-36 Health Survey.</p>	<p>Significantly less patient hopelessness and less negative appraisal of illness than the control group at three months follow-up, but not sustained at six months follow-up.</p> <p>No difference in quality of life between intervention and control groups.</p>
<p>Delbar (2001)<sup>24</sup> Israel</p> <p><b>Study type</b> RCT</p> <p><b>Level of Evidence</b> Level III</p>	<p>Nurses visit patients with early-stage cancer to address patient complaints and symptoms. Aim is to increase patients' internal resources to improve self-care and coping through providing information and emotional support.</p>	<p>Usual care only, with patients filling out SOC, MHLC and SCA measures at baseline and six months later.</p>	<p>Results measured using Sense of Coherence scale, Multidimensional Health Locus of Control scale, and Symptom Control Assessment, all provided at baseline and six months later after</p>	<p>Decreased intensity of all symptoms, and increased independence, familial help, and knowledge among intervention group, in contrast to either stability or deterioration in control group.</p> <p>Improvements over time in Sense</p>

Study	Intervention	Control	Measures	Outcome
<p><b>Quality</b> Strong</p>	<p>Fortnightly visits for three months.</p>		<p>intervention.</p>	<p>of Coherence measure in intervention group, but a decrease in SOC over time for control group.</p> <p>However, intervention and control groups not directly compared, and baseline scores differed significantly.</p> <p>Intervention worthy of further investigation.</p>
<p>Koinberg (2006)<sup>25</sup> Sweden</p> <p><b>Study type</b> Non-randomised experimental trial</p> <p><b>Level of evidence</b> Level III-2</p> <p><b>Quality</b> Good</p>	<p>Early breast cancer patients assigned to either a multidisciplinary education program or twice yearly follow-up with physician. Education program included four weekly lectures about different breast-cancer related issues.</p>	<p>Traditional follow-up care</p>	<p>Sense of Coherence (SOC), Functional Assessment of Cancer Therapy General Scale (FACT-G), Self Care Aspects questionnaire (SCA)</p>	<p>No significant differences between intervention and control regarding Sense of Coherence at baseline or at one-year follow-up.</p> <p>Although there was no significant change in the intervention group, there was a statistically significant worsening of SOC in control group.</p>



## Meaning-centred interventions

The aim of meaning-centred interventions is to build and sustain meaning and spirituality into end-of-life care for patients with advanced cancer.<sup>17</sup> Interventions studied ranged from therapist-guided life review (e.g. life review and dignity therapy), individual psychotherapy focusing on meaning, and meaning-centred group psychotherapy.

In the five studies included in the review a range of different tools and measures were implemented to assess suffering outcomes.

Overall, four of the five Level II studies<sup>15-18</sup> provided evidence suggesting that meaning-centred interventions can significantly and positively impact on meaning in advanced cancer patients. However meaning-centred interventions did not impact on patients' hopelessness, desire for death or will to live.

In Table 3, meaning-centred intervention studies with statistically significant changes to at least one of the measured suffering outcomes in the intervention group compared with the control group are described.

See the systematic review for full details of assessed studies.<sup>2</sup>

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**Table 3: Summary of meaning-centred intervention studies reporting significant findings in the intervention group measuring outcomes of suffering**

<b>Study</b>	<b>Intervention</b>	<b>Control</b>	<b>Measures</b>	<b>Outcome</b>
<p>Ando (2010)<sup>15</sup> Japan</p> <p><b>Study type</b> RCT</p> <p><b>Level of Evidence</b> Level II</p> <p><b>Quality</b> Strong</p>	<p>68 terminally ill cancer patients assigned to either a one week Short-Term Life Review for the enhancement of spiritual wellbeing or a control group, to assess the effect of the therapy on anxiety, depression, suffering, and elements of a good death.</p>	<p>Received general support in the first and second sessions (therapist interviewed patients regarding physical/mental status and mood in a supportive way).</p>	<p>Functional Assessment of Chronic Illness Therapy-Spiritual (FACIT-Sp) scale, the Hospital Anxiety and Depression Scale (HADS) and items from the Good Death Inventory (Hope, Burden, Life Completion, and Preparation).</p>	<p>Intervention group showed significantly greater improvement compared with the control group in The FACIT-Sp, Hope, Life Completion, and Preparation scores.</p> <p>HADS, Burden, and Suffering scores in the intervention group also had suggested greater alleviation of suffering compared with the control group.</p>
<p>Breitbart (2010)<sup>17</sup> USA</p> <p><b>Study type</b> RCT</p> <p><b>Level of Evidence</b> Level II</p> <p><b>Quality</b> Strong</p>	<p>Patients with advanced (stage III or IV) solid tumour cancers were randomly assigned to either an 8-week Meaning Centred Group Psychotherapy (MCGP) or a supportive group psychotherapy (SGP). MCGP aimed to enhance a sense of meaning, peace and purpose in patients' lives at end of life.</p> <p>Patients were screened for spiritual wellbeing, meaning, hopelessness,</p>	<p>Supportive group psychotherapy (SGP) consisting of eight weekly 90-min sessions on discussion of issues/themes that emerge for patients coping with cancer.</p>	<p>Beck Hopelessness Scale (BHS), FACIT-Sp, Schedule of Attitudes toward Hastened Death (SAHD), The Life Orientation Test (LOT) and the HADS.</p>	<p>Patients in the MCGP resulted in significantly greater improvements in their spiritual wellbeing and a sense of meaning.</p> <p>Treatment gains were even more substantial (based on effect size estimates) at the second two month follow-up assessment.</p> <p>Improvements in anxiety and desire for death were also significant at the two month follow- up (and increased over</p>

Study	Intervention	Control	Measures	Outcome
	desire for death, optimism/pessimism, anxiety, depression and QOL, and were assessed before and after the intervention, and 2 months later by a psychiatrist or clinical psychologist.			time). There was no significant improvement on any of these variables for patients participating in SGP.
<p>Breitbart (2012)<sup>16</sup> USA</p> <p><b>Study type</b> RCT</p> <p><b>Level of Evidence</b> Level II</p> <p><b>Quality</b> Strong</p>	<p>Patients with stage III or IV cancer were assigned to seven sessions of Individual Meaning-Centered Psychotherapy (IMCP) or therapeutic massage (TM). Patients were assessed before and after the intervention and 2 months post-intervention.</p>	<p>Patients received TM only.</p>	<p>Primary outcome measures assessed FACIT, Spiritual Wellbeing Scale (SWB) and the McGill Quality of Life Questionnaire (MQOL).</p> <p>Secondary measures included the HADS, the BHS, the Memorial Symptom Assessment Scale (MSAS), and a clinical status assessment (e.g. cancer diagnosis, treatment history).</p>	<p>At post-treatment, IMCP participants had significantly greater improvement than the control condition for primary outcomes of spiritual wellbeing (meaning, faith and quality of life measures).</p> <p>Significantly greater improvements for IMCP patients were also observed for the secondary outcomes of symptom burden and symptom-related distress however not for anxiety, depression, or hopelessness.</p> <p>However at the 2-month follow-up assessment, the improvements observed for the IMCP group were no longer significantly greater than those observed for the TM group.</p>
<p>Henry (2010)<sup>18</sup> Canada</p> <p><b>Study type</b> RCT</p>	<p>The Meaning-Making intervention (MMi) is a brief, individualised and manualised therapeutic approach designed to facilitate the search for meaning following a cancer diagnosis.</p>	<p>Usual care (hospital or community-based supports).</p>	<p>The primary outcome of existential distress was measured by the FACIT-Sp-12 Meaning subscale and the MQOL Existential subscale.</p>	<p>Compared to the control group, patients in the experimental group had a better sense of meaning (FACIT-Sp-12 Meaning subscale) in life at one and three months post-intervention.</p>

Study	Intervention	Control	Measures	Outcome
<p><b>Level of Evidence</b> Level II</p> <p><b>Quality</b> Strong</p>	<p>A randomised controlled trial with 24 patients (12 experimental and 12 control) was conducted. Patients newly diagnosed with Stage III or IV ovarian cancer received varied 1–4 intervention sessions of 30–90 min (individualized to respect the patient's psychological and physical capacity to address issues) with a therapist promoting self exploration.</p>		<p>The HADS and the General Self-Efficacy Scale (GSES) were used to measure anxiety, depression and self-efficacy.</p>	

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## **Stress reduction interventions, including yoga, mindfulness, meditation and cognitive-behavioural stress management**

The aim of some stress-reduction interventions is to enable people to better manage different stressors by helping them develop a conscious awareness (i.e. mindfulness) of their behaviour, emotions and responses in a non-judgemental and accepting manner.<sup>27</sup> These and other stress-reduction interventions may include elements of relaxation to reduce psychosocial stress.<sup>184</sup> Examples of practices incorporating mindfulness and/or relaxation include meditation, cognitive-behavioural stress management and yoga.

The 10 studies in which a type of stress-reduction intervention was trialled varied in nature and modality. In nine of the studies, significant effects were found on at least one outcome measure relating to spirituality. In particular, in four studies<sup>27,28-30</sup> significant effects were reported for spiritual wellbeing, while in one study no effect was found.<sup>184</sup> In four studies there was a significant effect for benefit finding.<sup>31,32,33,34</sup> In one study a significant effect for meaning/peace<sup>35</sup> was described and in another a significant effect for meaningfulness and comprehensibility (sense of coherence [SOC])<sup>28</sup> was found. The maintenance of each of these effects in patients varied.

The results suggest that stress-reduction interventions are a promising way of enhancing spiritual wellbeing and meaning/benefit finding.

In Table 4, stress-reduction interventions demonstrating significant changes of at least one of the measured outcomes of suffering in the intervention group are listed.

See the systematic review for full details of assessed studies.<sup>2</sup>

**Table 4: Summary of stress reduction intervention studies reporting significant findings in the intervention group measuring outcomes of suffering**

<b>Study</b>	<b>Intervention</b>	<b>Control</b>	<b>Measures</b>	<b>Outcome</b>
Antoni (2001) <sup>32</sup> USA  <b>Study type</b> RCT  <b>Level of Evidence</b> Level II  <b>Quality</b> Strong	Patients with early breast cancer completed a cognitive-behavioural stress management intervention in groups. Sessions included relaxation training and strategies to cope better with cancer-related stress, increase confidence and express emotions.  Ten weekly 2-hour sessions.	One condensed (5-hour) stress reduction seminar	Results measured using a 17-item Benefit Finding scale, and an Emotional Processing item (both developed for this study), Profile of Mood States (POMS), Center for Epidemiological Study – Depression (CES-D), Impact of Events Scale (IES), Life Orientation Test – Revised (LOT-R).	Intervention and control had similar reports of benefit finding at baseline but intervention group had significantly higher benefit finding scores at 3-month follow-up, but this had faded by 9 months.
Antoni (2006) <sup>34</sup> USA  <b>Study type</b> RCT  <b>Level of Evidence</b> Level II  <b>Quality</b> Strong	As above and also including some non-early stage but non-metastatic breast cancer patients.	One condensed (5-hour) stress reduction seminar	Results measured using a 17-item Benefit Finding scale, Sickness Impact Profile, Positive States of Mind (PSOM), Affects Balance Scale (ABS), and Measure of Current Status (MOCS).	A significant effect for benefit finding in the intervention group that was sustained over time.
Henderson (2012) <sup>28</sup> USA  <b>Study type</b>	Early breast cancer patients received mindfulness-based stress reduction intervention that included meditation and	Usual care with monthly supportive	Sense of Coherence (SOC), Functional Assessment of Cancer Therapy (FACT-B) including spiritual items, Beck Depression Inventory	Improvements from baseline in the spirituality subscale of FACT-B, resulting in large differences from both control groups, including more active

Study	Intervention	Control	Measures	Outcome
<p>RCT</p> <p><b>Level of evidence</b> Level II</p> <p><b>Quality</b> Strong</p>	<p>yoga.</p> <p>Seven 3-hour sessions and full-day silent retreat over 8 weeks, plus three 2-hour booster sessions over three months.</p>	<p>phone calls, or a group nutrition education intervention including group cooking and counselling</p>	<p>(BDI), Beck Anxiety Inventory (BAI), Symptom Checklist 90 Revised (SCL-90-R), Rosenberg Self-Esteem Scale, UCLA Loneliness Scale, Mental Adjustment to Cancer Scale (Mini-MAC), Courtauld Emotional Control Scale (CEC)</p>	<p>cognitive coping. Other contrasts that were significantly better than both control groups included meaningfulness, anxiety and emotional control. Significant differences in spirituality outcomes were maintained at 12 months between intervention and control groups, but other benefits were not maintained.</p>
<p>Penedo (2006)<sup>33</sup> USA</p> <p><b>Study type</b> RCT</p> <p><b>Level of evidence</b> Level II</p> <p><b>Quality</b> Strong</p>	<p>Early prostate cancer patients participated in a group cognitive-behavioural stress management intervention to learn about prostate cancer and treatment, stress management and relaxation skills, and share experiences, with the aim of improving benefit finding and quality of life.</p> <p>Ten 2-hourly weekly sessions</p>	<p>Half-day educational seminar</p>	<p>Benefit Finding Scale from the Positive Contributions Scale - Cancer, Charlson Comorbidities Index, Measure of Current Status, and Functional Assessment of Cancer Therapy – General (FACT-G)</p>	<p>Intervention group experienced significant increases in benefit finding while control did not change significantly. Quality of life was also positively associated with the intervention.</p>
<p>Witek-Janusek (2008)<sup>27</sup> USA</p> <p><b>Study type</b> Non-randomised experimental trial</p>	<p>Early breast cancer patients participated in a group mindfulness-based stress reduction intervention to learn mindfulness, breath awareness, meditation and mindful yoga, with the aim of improving immune function, quality of life</p>	<p>Assessment only control groups, either cancer patients having</p>	<p>Quality of Life Index Cancer Version, Jalowiec Coping Scale (JCS), Mindful Attention Awareness Scale (MAAS), plus immune and cortisol measures.</p>	<p>Intervention group reported significantly more improvement over time in the psychological-spiritual domain of QOL than the controls. Intervention also reported more improvements in coping effectiveness than controls.</p>

Study	Intervention	Control	Measures	Outcome
<p><b>Level of evidence</b> Level III-2</p> <p><b>Quality</b> Strong</p>	<p>and coping skills.</p> <p>Eight 2.5-hourly weekly group sessions plus one full-day session</p>	<p>usual care or healthy, age-matched women (to provide normative data for immune variables)</p>		<p>Intervention women also showed improvements in immune function compared to the control.</p>
<p>Garland (2007)<sup>29</sup> Canada</p> <p><b>Study type</b> Non-randomised experimental trial</p> <p><b>Level of evidence</b> Level III-2</p> <p><b>Quality</b> Strong</p>	<p>Breast cancer (majority) and other cancer patients participated in their choice of either a mindfulness-based stress reduction (MBSR) intervention program or a healing arts (HA) program with the aim of enhancing spirituality and post-traumatic growth (benefit finding), and decreasing stress and mood disturbance.</p> <p>MBSR included discussion, meditation and yoga. Eight 1.5-hour group sessions plus one 3-hour silent retreat.</p> <p>HA included self-discovery and empowerment through creative process (writing, drawing, movement). Six 2-hour weekly group sessions.</p>	<p>MBSR vs HA</p>	<p>Functional Assessment of Chronic Illness Therapy – Spiritual Wellbeing (FACIT-SP), Post-Traumatic Growth Inventory-Revised (PTGI-R), Symptoms of Stress Inventory (SOSI), Profile of Mood States (POMS)</p>	<p>Both groups had a significant increase on overall post-traumatic growth (benefit finding). While the MBSR group improved significantly more on measures of spirituality, anxiety, anger, stress and mood disturbance, the HA group remained relatively stable in these domains.</p>



Study	Intervention	Control	Measures	Outcome
<p>Chandwani (2010)<sup>31</sup> USA</p> <p><b>Study type</b> RCT</p> <p><b>Level of evidence</b> Level II</p> <p><b>Quality</b> Strong</p>	<p>Breast cancer patients receiving radiotherapy participated in one-on-one yoga sessions with an instructor, focusing on postures, breathing, meditation, and relaxation.</p> <p>Up to 12 sessions of 1-hour duration over a six-week period, plus practice at home.</p>	Waitlist control	Benefit Finding Scale (BFS), Medical Outcomes Study 36-item (SF-36), Brief Fatigue Inventory (BFI), Pittsburgh Sleep Quality Index (PSQI), Center for Epidemiologic Studies Depression Scale (CES-D), Spielberger State-Trait Anxiety Inventory, Impact of Events Scale	<p>Significant differences between intervention and control 3 months after radiotherapy (T4) in benefit finding. Intervention group also reported more intrusive thoughts than control group 1 month after radiotherapy (T3), and there was a significant positive correlation between intrusive thoughts at T3 and benefit finding at T4.</p> <p>Intervention group also maintained better QOL throughout treatment and into recovery.</p>
<p>Danhauer (2009)<sup>35</sup> USA</p> <p><b>Study type</b> RCT</p> <p><b>Level of evidence</b> Level II</p> <p><b>Quality</b> Strong</p>	<p>Breast cancer patients participated in restorative yoga, a gentle yoga practice focusing on postures, breathing and deep relaxation.</p> <p>10 weekly 75-minute group classes.</p>	Waitlist control	Functional Assessment of Chronic Illness Therapy-Spiritual Wellbeing (FACIT-Sp), SF-12 health survey, Functional Assessment of Cancer Therapy-Breast (FACT-B), FACT-Fatigue, Center for Epidemiologic Studies Depression Scale (CES-D), Pittsburgh Sleep Quality Inventory (PSQI), Positive and Negative Affect Schedule (PANAS)	<p>Women with higher negative affect and lower emotional wellbeing at baseline derived greater benefit from participating in intervention than control group with similar baseline levels.</p> <p>There were significant group effects for the FACIT-Sp peace/meaning subscale favouring the yoga group. Significant group effects were also found in CES-D, PANAS-PA and SF-12 mental health scales for the yoga group. The yoga group also had significant within-group improvements in fatigue.</p>
<p>Moadel (2007)<sup>30</sup> USA</p>	<p>Breast cancer patients participated in hatha yoga classes focusing on stretches, postures, breathing and</p>	Waitlist control	Functional Assessment of Chronic Illness Therapy-Spiritual (FACIT-Sp), Functional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F),	Yoga intervention was associated with beneficial QOL outcomes, and control group experienced greater decrease in social wellbeing than

Study	Intervention	Control	Measures	Outcome
<p><b>Study type</b> RCT</p> <p><b>Level of evidence</b> Level II</p> <p><b>Quality</b> Strong</p>	<p>meditation.</p> <p>12 weekly sessions of 1.5 hours duration plus home practice.</p>		<p>Functional Assessment of Cancer Therapy (QOL), Distressed Mood Index</p>	<p>intervention.</p> <p>However, primary analyses of entire sample did not predict improvements in spiritual wellbeing at three-month follow-up (T2).</p> <p>Secondary regression analyses on a subsample of patients not on chemotherapy showed intervention group was predictive of T2 spiritual wellbeing.</p>

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## Hope-centred interventions

Hope-centred interventions encompass both individual and group interactions designed to instil, enhance and maintain aspects of hope in patients with cancer. Interventions in the systematic review included active participation in individual hope-generating activities and face-to-face group sessions exploring different aspects of hope.

In the three studies evaluating hope-centred interventions significant findings were reported across this intervention category. In one study post-intervention (after one week) improvements were reported in hope (HHI) and existential wellbeing (MQOL) measures, but follow-up assessments were not undertaken.<sup>20</sup> In another study designed to enhance hope using the HHI scale, an effect was found two weeks post-intervention (i.e. 10 weeks from baseline), which was maintained at 3, 6, and 9 months.<sup>14</sup> In another study designed to enhance hope using the Nowotny Hope Scale (NHS), an effect was found two weeks post-intervention (i.e. 10 weeks from baseline). However, this was not maintained at 8 months.<sup>19</sup>

Overall, these studies provide evidence suggesting that hope-centred interventions can significantly and positively impact on hope in cancer patients at different stages of the disease trajectory. For example, this effect was found in newly diagnosed patients<sup>19</sup>, those experiencing recurrent disease,<sup>14</sup> and those receiving palliative care.<sup>20</sup>

In Table 5, hope-centred intervention studies that have statistically significant changes to at least one of the measured suffering outcomes in the intervention group compared with the control group are described.

See the systematic review for full details of assessed studies.<sup>2</sup>

**Table 5: Summary of hope-centred intervention studies reporting significant findings in the intervention group measuring outcomes of suffering**

<b>Study</b>	<b>Intervention</b>	<b>Control</b>	<b>Measures</b>	<b>Outcome</b>
<p>Duggleby (2007)<sup>20</sup> Canada</p> <p><b>Study type</b> RCT</p> <p><b>Level of Evidence</b> Level II</p> <p><b>Quality</b> Strong</p>	<p>The aim of the study was to evaluate the effectiveness of a psychosocial supportive intervention called the Living with Hope Program (LWHP) in increasing hope and quality of life for older adult, community-living and terminally ill cancer patients.</p> <p>60 terminally ill cancer patients were randomly assigned to a treatment group or a control group. LWHP consisted of viewing a video on hope and doing one of three hope activities in a one-week period (write letters, collect meaningful items for a hope box, or create an 'About Me' collection). Measures were collected at the first visit in the patients' homes by research assistants and one week later.</p>	<p>Standard care</p>	<p>(Herth Hope Index [HHI]) and quality-of-life scores (McGill Quality of Life Questionnaire [MQOL]), Qualitative Open-Ended Hope Questions and Palliative Performance Scale.</p>	<p>Patients receiving the LWHP had statistically significant higher hope and quality-of-life scores at visit 2 than the control group. Additionally the majority (61.5%) of patients in the treatment group reported the LWHP increased their hope.</p>
<p>Herth (2000)<sup>14</sup> USA</p> <p><b>Study type</b> RCT</p> <p><b>Level of Evidence</b> Level II</p>	<p>Nursing intervention program (quasi-experimental study) designed to enhance hope and quality of life in patients with a first recurrence of cancer.</p>	<p>Attention control group (informative sessions about cancer and treatments), or usual treatment (regular care and hospital follow-up)</p>	<p>The Herth Hope Index (HHI) and the Cancer Rehabilitation and Evaluation Systems, Short Form (CARES-SF) were administered prior to intervention, immediately after intervention and at 3, 6, and 9-month intervals.</p>	<p>Treatment and control groups differed significantly for hope and QOL. Both the level of hope and QOL were significantly increased immediately after intervention and over time (3, 6 and 9 months).</p>

Study	Intervention	Control	Measures	Outcome
<b>Quality</b> Strong				
Rustoen (1998) <sup>19</sup> Norway  <b>Study type</b> RCT  <b>Level of Evidence</b> Level II  <b>Quality</b> Strong	The aim of the study was to evaluate the effect of nursing intervention on hope and quality of life in cancer patients.  Patients were randomly allocated to an intervention group (designed to increase hope), an attention control group (Learning to Live with Cancer program), or the control group (usual treatment).  Questionnaires were completed twice prior to the intervention, then two weeks and six months post intervention.	Usual treatment (regular care and hospital follow-up).	Nowotny Hope Scale, Ferrans and Powers Quality of Life Index and the Cancer Rehabilitation and Evaluation Systems, short form.	Level of hope was significantly increased for members of the hope group just after the intervention but not 6 months afterwards. Despite patients' positive evaluation of the intervention, there was no impact on quality of life.

### **Supportive-expressive interventions**

Supportive-expressive approaches encompass both supportive group and individual therapy designed to enhance overall QOL.<sup>96</sup> Interventions include telephone therapy, forgiveness therapy, face-to-face, telephone and internet-based support groups. Interventions may target individual patients or both patients and their partners or caregivers

Of the five supportive-expressive interventions, there was only one study in which a significant effect on hope (HHI) was found immediately post-intervention.<sup>26</sup>

Because of the strong variation between the aims and modalities of the included studies, no accurate conclusions could be drawn regarding the impact of supportive-expressive therapies on variables such as hope, spiritual wellbeing, self-transcendence and purpose in life.

In Table 6, supportive-expressive intervention studies with statistically significant changes to at least one of the measured suffering outcomes in the intervention group compared with the control group, are described.

See the systematic review for full details of assessed studies.<sup>2</sup>

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**Table 6: Summary of supportive-expressive intervention studies reporting significant findings in the intervention group measuring outcomes of suffering**

Study	Intervention	Control	Measures	Outcome
<p>Hansen (2009)<sup>26</sup> USA</p> <p><b>Study type</b> RCT</p> <p><b>Level of Evidence</b> Level II</p> <p><b>Quality</b> Good</p>	<p>This study tested the effectiveness of a four week forgiveness therapy (60 minute once a week individual sessions) in improving the quality of life of elderly terminally ill cancer patients. Participants were randomly assigned to a forgiveness therapy group or to a wait-list control group.</p> <p>All participants completed instruments measuring forgiveness, hope, quality of life, and anger at pre-test, post-test 1 and post-test 2 delivered by a psychologist.</p>	<p>Wait-list control group (received forgiveness therapy in the second four week period).</p>	<p>Herth Hope Index, State Anger Scale, and the McGill Quality of Life Scale.</p>	<p>Forgiveness therapy group showed greater improvement than the control group on all measures.</p> <p>After receiving forgiveness therapy, participants in both forgiveness treatment conditions demonstrated significant improvements on all measures (forgiveness, hope, quality of life, and anger reduction).</p>

## Spiritual interventions

The aim of spiritual interventions is to address the spiritual concerns of patients and increase hope, happiness, life satisfaction and mental health,<sup>36</sup> and wellbeing, coping ability and quality of life.<sup>185</sup>

These interventions may take the form of multidisciplinary educational sessions, support groups, body-mind-spirit therapy, spiritual counselling, and a brief semi-structured inquiry into religious/ spiritual concerns.

In three of the five spiritual interventions, significant findings were reported for aspects of suffering: in an Islamic spiritual education intervention significant effects were reported for hope;<sup>36</sup> in a multidisciplinary educational session addressing the five QOL domains including spirituality, significant effects were found for spiritual wellbeing four weeks after baseline on one of the measures (LASA) although not on another (FACIT-Sp total);<sup>37</sup> and in a study on a body-mind-spirit therapy intervention, a significant effect was found on the search for meaning subscale component of the Meaning in Life scale.<sup>38</sup> However, overall results of these studies are inconsistent, particularly in regards to spiritual wellbeing.

A Cochrane review on spiritual and religious interventions for the wellbeing of adults in the terminal phase of disease,<sup>185</sup> which was not included in the systematic review, has also found inconclusive evidence that interventions with spiritual or religious components enhance wellbeing. However, only two cancer-related studies were assessed.

One, an interdisciplinary palliative care service that included counselling and attendance by a palliative care physician, palliative care nurse, social worker and chaplain, found no difference between the intervention and usual care groups for physical, emotional/relationship, spiritual and QOL scales. However, the intervention group demonstrated higher patient satisfaction, reduced ICU admissions and lower total health costs.<sup>186</sup>

A study that compared massage with guided meditation or friendly visits in terminally ill patients initially found no difference between interventions, but on reanalysis using other methods, determined that massage may offer benefits over the other interventions.<sup>187, 188</sup>

In Table 7, spiritual intervention studies with statistically significant changes to at least one of the measured suffering outcomes in the intervention group compared with the control group are described.

See the systematic review for full details of assessed studies.<sup>2</sup>



**Table 7: Summary of spiritual intervention studies reporting significant findings in the intervention group measuring outcomes of suffering**

Study	Intervention	Control	Measures	Outcome
<p>Fallah (2011)<sup>36</sup> Iran</p> <p><b>Study type</b> Non-randomised, experimental trial</p> <p><b>Level of Evidence</b> Level III-2</p> <p><b>Quality</b> Adequate</p>	<p>Sixty breast cancer survivors were voluntarily assigned into case and control groups to assess the effectiveness of an Islamic perspective spiritual intervention on the increase of hope, life satisfaction and happiness through eight weekly sessions of 1.5 hours.</p> <p>Women were assessed before and after using spiritual experience, hope, happiness and life satisfaction questionnaires.</p>	<p>No exposure to Islamic perspective spiritual intervention.</p>	<p>Adult Dispositional Hope Scale (Snyder's Hope scale), Satisfaction with Life Scale, Oxford Happiness Revised Scale and Spiritual Experience Scale.</p>	<p>The spiritual intervention resulted in significant increase of hope, happiness and life satisfaction in the case group women suffering from breast cancer compared to the control group.</p>
<p>Hsiao (2012)<sup>38</sup> Taiwan</p> <p><b>Study type</b> Randomised controlled trial</p> <p><b>Level of Evidence</b> Level II</p> <p><b>Quality</b></p>	<p>Forty-eight breast cancer patients who completed active cancer treatment were randomly assigned to receive eight weekly body-mind-spirit (BMS) group therapy sessions lasting two hours or one educational session.</p>	<p>Interpersonal education sessions on health behaviours</p>	<p>Beck Depression Inventory-II (BDI-II), and the Meaning in Life questionnaire (MLQ) including subscales MLQ-Presence and MLQ-Search.</p>	<p>Greater MLQ Search scores were found in the BMS group compared to the EDU group during fifth month of follow-up. However this effect was not reported for MLQ-Presence scores.</p>

Study	Intervention	Control	Measures	Outcome
Strong				
<p>Rummans (2006)<sup>37</sup> USA</p> <p><b>Study type</b> Randomised controlled trial</p> <p><b>Level of Evidence</b> Level II</p> <p><b>Quality</b> Strong</p>	<p>This study aimed to evaluate the feasibility and effectiveness of a structured, multidisciplinary intervention targeted to maintain overall QOL.</p> <p>Radiation therapy patients with advanced cancer and an estimated 5-year survival rate of 0% to 50% participated in eight 90-minute sessions that included physical exercises, educational information, cognitive behavioural therapy to increase coping, and group discussion. QOL was assessed at baseline, week 4 (end of intervention), week 8, and week 27.</p>	<p>Standard medical care (oncology specialist referral and cancer support groups).</p>	<p>Single-item linear analog scale (Linear Analog Scale of Assessment or modified Spitzer Uniscale).</p> <p>Secondary outcome measures Symptom Distress Scale, the Profile of Mood States (POMS) – Short Form and the FACIT-Sp scale.</p>	<p>Overall QOL at week 4 was maintained by the patients in the intervention whereas QOL significantly decreased for patients in the control group at this time point.</p> <p>Intervention participants maintained their QOL, and controls gradually returned to baseline by the end of the 6-month follow-up period.</p>

## Other interventions

Interventions encompass music therapy, art therapy, a creative arts study involving a mixture of movement to music, writing and drawing; expressive writing, assessing the impact of systematic assessment of patients, one animal assisted activity study (e.g. dog visits) and one haptotherapy (i.e. touch) study.

In seven studies that were evaluations of 'other' interventions no significant outcomes were reported for suffering outcomes.

In two studies<sup>29, 189</sup> an effect was not found for spiritual wellbeing (FACIT-Sp total). In a further study an effect was not found for peace/meaning (FACIT-Sp).<sup>190</sup> In yet another study no effect was found for spirituality (ESI-R, including an existential wellbeing dimension).<sup>191</sup> Furthermore, no effect on sense of coherence (SOC)<sup>192</sup> or meaning in life (HDI)<sup>193</sup> was reported in two other studies and neither for spiritual needs (SNI).<sup>194</sup>

There is therefore no systematic evidence of a positive impact on outcome variables of relevance to this review for any of these interventions, including music therapy; art therapy; creative arts (involving a mixture of movement to music, writing and drawing); expressive writing; systematic assessment of patients; animal assisted activity; and haptotherapy.

See the systematic review for full details of assessed studies.<sup>2</sup>

Although the current evidence to support the use of the described interventions for alleviating suffering is limited or weak, a number of hospitals in Australia provide these types of therapies with the aim of assisting patients in stress reduction and emotional expression. Examples include:

- Jacaranda Lodge, Sydney Adventist Hospital, Sydney –music therapy, massage, reflexology
- Sydney Cancer Centre, Royal Prince Alfred Hospital, Sydney – music therapy, qi gong, wellbeing group
- Peter MacCallum Cancer Centre, Melbourne –massage, reflexology
- St John of God Hospital, Geelong – music thanatology
- Flinders Medical Centre, Adelaide – Arts in Health program
- Solaris Care, Sir Charles Gairdner Hospital, Perth –healing touch therapy, art therapy.

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