

# Existential and Spiritual Aspects of Palliative Care

National guideline

30 September 2018



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### **Methodology**

Evidence-based (GRADE methodology) and consensus-based

### **Responsibility**

Guideline Working Group for Existential and Spiritual Aspects of Palliative Care [IKNL( member of PZNL)]

Version 2.0

### **Disclaimer:**

Information from many English-language sources was consulted and integrated (with citations) into the original Dutch version of this Guideline. Translation of the Guideline into English may have inadvertently produced text closely resembling the original sources. If this has occurred, the translators and IKNL offer their humble apologies to the authors of those sources.



# Table of Contents

<b>Introduction</b>	<b>6</b>
<b>1 Module 1 Introduction</b>	<b>9</b>
1.1 When is attention to existential/spiritual matters called for?	9
1.2 How do I recognise and identify questions and/or needs concerning existential/spiritual matters?	12
<b>2 Module 2 Origins and process</b>	<b>15</b>
2.1 How does an existential or spiritual process arise and unfold?	15
2.2 How does one recognise a spiritual crisis?	17
2.3 How does one address hope with patients receiving palliative care?	19
<b>3 Module 3 Assessment, attention and accompaniment, referral and reporting</b>	<b>21</b>
3.1 How do I talk to patients about existential/spiritual matters?	21
3.2 How does the role of a doctor or nurse differ from the role of a care giver who is specialised in providing existential and spiritual support?	24
3.3 What assessment tools can be helpful for exploring the spiritual dimension?	29
3.4 What is the effect of interventions for existential/spiritual support on the quality of life of patients receiving palliative care?	34
3.5 When do I refer a patient to a specialised care giver (spiritual counsellor, medical social worker or psychologist)?	40
3.6 How should one respond when a existential/spiritual crisis is suspected?	45
3.7 How do I report spiritual care?	48
3.8 How do I present my observations at a meeting of a multidisciplinary team, a palliative home care group or other collaborative body?	50
<b>4 Module 4 Prerequisites</b>	<b>52</b>
4.1 What are the prerequisites for facilitating the provision of existential/spiritual support?	52
<b>Appendix</b>	<b>58</b>
A1 The working group	59
A2 Declarations of interest	60
A3 Methods and methodology	61
A4 Evidence tables	69
A5 Problem inventory and questions	80
A6 Authorising organisations	81
A7 Implementation and evaluation	82
A8 Mount Vernon Cancer Network questionnaire	86
A9 The Ars Moriendi model	87
A10 FICA	88
A11 Religions and philosophies of life	89
A12 List of Organisations mentioned in this publication	95

# Introduction

## Introduction

This revised guideline for existential and spiritual aspects of palliative care is intended as a reference for all health care professionals who are engaged in providing palliative care. According to the definition in the Netherlands Quality Framework for Palliative Care [Kwaliteitskader palliatieve zorg 2017], palliative care addresses the physical, psychological, social and spiritual dimensions of suffering. In the Dutch language 'spiritual' can refer to matters of meaning and purpose (zingeving) as well as other dimensions of spirituality (spiritualiteit). Various definitions of both terms exist; in some, matters of meaning and purpose are seen as a component of spirituality, and in others the reverse is true. Both aspects are very much determined by cultural context. There is no consensus on them in the Dutch language area, and the boundaries run right through professional disciplines. Moreover, both terms give rise to resistance in various groups, and for various reasons. In this guideline we have therefore chosen to use the two terms synonymously (and expressed in this English version with the compound 'existential/spiritual').

## Definition

This guideline makes use of the following definition of spirituality:

*'Spirituality is the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred.'* [Nolan 2011]

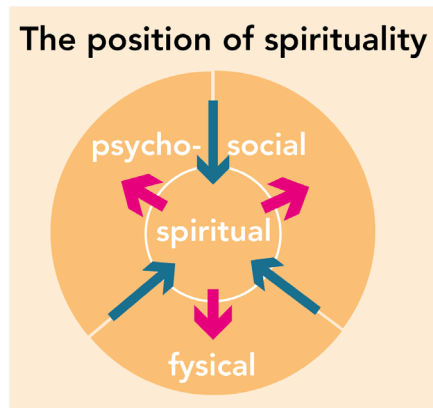
The spiritual field is multi-dimensional, containing:

- a Existential challenges (e.g. questions concerning identity, meaning, suffering and death, guilt and shame, reconciliation and forgiveness, freedom and responsibility, hope and despair, love and joy)
- b Value based considerations and attitudes (what is most important for each person, such as relations to oneself, family, friends, work, things, nature, art and culture, ethics and morals, and life itself)
- c Religious considerations and foundations (faith, beliefs and practices, the relationship with God or the ultimate). [Nolan 2011]

After considering several definitions, the working group chose Nolan's definition for the following reasons:

- 1 It is the most recent European consensus-based definition in the context of palliative care, and moreover it is very similar to the most recent worldwide consensus-based definition of spirituality in the context of health care as a whole. [Puchalski 2014]
- 2 Its description of the multi-dimensionality of spirituality provides helpful supplementary information for those unfamiliar with these dimensions.
- 3 In it, perception and experience are included as an important component.
- 4 The addition of 'dynamic' emphasises that spirituality is a process, and that its nature changes.

The spiritual dimension of human nature is often regarded as being hidden because it underlies the physical, psychological and social sphere and is not always directly visible, accessible or talked about (see Figure 1). This figure illustrates that spirituality is a hidden, intimate, unifying 'foundational layer': the personal 'inner perspective' of the physical, psychological and social dimensions of human existence [Leget 2008]. How these four dimensions are connected is determined and coloured by human culture and context.



Figuur 1.1

The position of spirituality

### **The revised guideline: objective and scope, target audience and approach**

#### Objective and scope

A guideline is a recommendation intended to provide support in addressing the most important problems actually encountered in daily practice. This guideline is based on the expertise of the members of the working group, and as far as possible is supported by evidence and consensus-based research.

The guideline Existential and Spiritual Aspects of Palliative Care makes recommendations on assessment, care and accompaniment for all patients (above 18 years) who are receiving palliative care and for whom questions and/or problems have arisen concerning existential and spiritual matters, regardless of the underlying condition and in every care setting. The objective of the guideline is to improve the quality of care provided.

This guideline has been written with a view to providing support to all palliative patients regardless of their philosophy of life, religion or culture. When a patient's experience and choices concerning end-of-life care are influenced by a background other than traditional local religion and culture, please consult, in addition to this guideline, supplemental information relevant to patients you encounter in your cultural context (e.g. Pharos (Pharos is the Dutch national centre of expertise on health disparities)).

#### Target audience

This guideline is primarily intended for all professionals who provide palliative care, such as general practitioners (GPs), specialists in elderly care medicine, other medical specialists, nurses, nurse specialists, physician associates, spiritual counsellors, Netherlands Comprehensive Cancer Organisation advisors, social workers, psychologists and physiotherapists. The guideline is also relevant to care providers from other disciplines and volunteers who work with people receiving palliative care. Anyone who is attending to the physical and psychosocial well-being of patients also has to be aware of the existential issues that may arise. When determining appropriate care and treatment it is crucial to know what people find important and what makes their life meaningful. This guideline is therefore based on the premise that existential and spiritual support is the responsibility not only of spiritual counsellors but of all care givers. This is a joint, interdisciplinary responsibility.

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The patients' perspective was also included during the formulation of this guideline, as described in the next section. However, as the guideline has been written primarily for the professionals listed above, patients may find it less easy to read.

#### Patients' perspective

Patient input was incorporated during all phases of the development of this module. Among the members of the guideline working group were two patient representatives. Patient input is necessary for the development of high-quality guidelines, as good care satisfies the wishes and requirements of both patients and care givers.

The following approach was used to obtain information and to incorporate the interests of patients:

- At the start of the guideline development process, patient representatives submitted problems.
- The patient representatives were present at all meetings of the guideline working group.
- The patient representatives evaluated the draft texts so as to ensure that the patients' perspective was optimally represented in the formulation of the final text.
- Feedback was sought from the Dutch Federation of Cancer Patient Organizations (NFK) during the consultation phase.

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# 1 Module 1 Introduction

## 1.1 When is attention to existential/spiritual matters called for?

### Question

When is attention to existential/spiritual matters called for?

Method: consensus-based

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### Recommendations

- Devote attention to existential/spiritual matters with every patient receiving palliative care, and at all times
  - Show interest in the existential/spiritual processes as they unfold and focus your attention on the needs of the patient/friends and family at that particular moment, taking into account the patient's actual situation, condition and other problems
- 

### Summary of the literature

No systematic literature research was undertaken for this question because the answer to the question is not based on empirical research findings, but rather on the WHO definition of palliative care. The working group based their considerations on their practical experience, where possible confirmed by a (non-systematic) review of the literature. The level of attention, when it is called for, is based on the ABC model (see Chapter 3.2). Patients receiving palliative care and their loved ones are uniquely confronted by the fact of human mortality. As a result, much of what they have hitherto taken for granted in terms of the meaning of life becomes less certain. Recent studies have revealed that over 40% of patients with an advanced stage of cancer experience spiritual suffering [Breitbart 2004, Hui 2011, Delgado-Guay 2016, Kruizinga 2017].

Patients find it important that attention is paid to existential matters as part of the care they receive [Huber 2016; ZonMW 2016]. When palliative care patients are asked about what topics are important to them, they express the need to speak about spiritual matters, the purpose of life, relationships and their thoughts about death [Huber 2016; ZonMW 2016]. Thoughts about death may be an indication of spiritual struggle, but are often related to other aspects of palliative care. Matters that are related to a wish to die include depression, social isolation, loss of dignity, loss of the will to live, the feeling of being a burden on others, feelings of dependence and hopelessness [Rodin 2008, LeMay 2008, Boston 2011].

### Considerations

Spiritual needs are often not expressed in a concrete question; sometimes because a person is not aware of the need, or because they think mentioning it will not be of any help. Apart from that, concerns may be intimate matters about which people may not be able or willing to talk to everyone. For care givers it is very challenging to be aware of the often-subtle differences between the questions relating to these various areas of care, particularly because spiritual questions and needs are often embedded in other bio-psycho-social dimensions. Expressions of many sorts – for example suffering from pain, loss of control of bodily functions, acceptance, emotions, identity, self-esteem, coping or family – are matters that often seem easier to 'delegate' to other care givers and then believe that one has paid sufficient attention to the problem. This, however, is not always the case.

Spirituality can be conceptualised as being hidden beneath, and often expressed in, the physical, psychological and social dimensions.

According to the definition used in the Netherlands Quality Framework for Palliative Care and also by the World Health Organization, spirituality is an intrinsic component of palliative care. The working group

believes that it is relevant to devote attention to existential/spiritual matters with every patient receiving palliative care, and at all times. Patients' dignity is threatened when no interest is shown in what it means to them to be in the phase of receiving palliative care. Patients' needs and those of their close ones vary widely, depending on the situation, condition and other problems of the patient.

It can be particularly important to attend to spiritual matters at significant moments (such as moving to a care facility or hospice, or performing a farewell ritual during the terminal phase); moreover, rituals that empower a patient or a loved one can fulfil an important function (see also Module 3.2). The website [www.huisarts-migrant.nl](http://www.huisarts-migrant.nl) has a page of general advice (in Dutch) and issues to be aware of concerning rituals associated with dying and mourning (<https://www.huisarts-migrant.nl/rituele-rond-sterven-en-rouw/>).

Finding the right words is a challenge when offering spiritual support. It can be helpful to strike a balance between approaches based on 'relationships' and on 'interventions', inspired by the division made by McSherry [2013]. 'Relationships' represent human qualities of care givers such as warmth, empathy and attunement. A relationship between care giver and patient that is characterised by these qualities can contribute to a patient's feeling of spiritual well-being, because patients feel seen and affirmed and have a sense of connection. These can contribute to experiencing meaningfulness, hope and dignity. 'Interventions' refer to the more diagnostic and clinical aspects of spiritual care. This approach begins by assessing spiritual needs or specific care required, and involves symptom reduction, interventions and effectiveness. Both approaches are important in spiritual care.

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## 1.2 How do I recognise and identify questions and/or needs concerning existential/spiritual matters?

### Question

How do I recognise and identify questions and/or needs concerning existential/spiritual matters?

Method: consensus-based

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### Recommendations

- Be alert, in all communication with patients and their near ones, of metaphors and images which may point to life/existential questions and meaning-giving processes.
  - Pay attention to implicit and non-verbal expressions/signs and relevant symbols in the immediate surroundings, or in a person's clothing or appearance, and show respectful interest.
  - Be alert to the fact that life/existential questions or spiritual needs may underlie problems that present as physical, emotional/psychological or social symptoms.
- 

### Summary of the literature

Two approaches are possible concerning the spiritual process of patients in palliative care and of their near ones: one from the perspective of spiritual needs in the broad sense, and the other from the perspective of spiritual suffering.

- 1 Spiritual needs in the broad sense are not always expressed explicitly. In addition, in many cases they are intermingled with other needs. In his theoretical reflection on spiritual needs from a sociological perspective, Kellehear [2000] distinguishes between:
  - a situational needs (purpose, hope, meaning and affirmation, mutuality, connectedness, social presence)
  - b moral and biographical needs (peace and reconciliation, reunion with others, prayer, moral and social analysis, forgiveness, closure)
  - c religious needs (religious reconciliation, divine forgiveness and support, religious rites/sacraments, visit by clergy, religious literature, discussion about God, eschatology, eternal life, hope).
- 2 In the palliative care approach, spiritual suffering is inseparable from the physical, emotional and social components of suffering. In other words, suffering is a complex phenomenon that is associated with an aversive emotional state, where specific causes may be present in different domains, all of which threaten the integrity of the individual [LeMay 2008].

Several authors have presented varying descriptions in which spiritual suffering is distinguished as one factor within 'total' suffering. Kissane [2000] uses the term 'existential distress' to describe the mental turmoil experienced by individuals who are facing impending death, often accompanied by feelings of remorse, powerlessness, futility, and by a sense that life is meaningless. Kearney and Mount [2000] understand 'spiritual pain' as a disconnection, and a resulting alienation within individuals from that aspect of their deepest selves that gives meaning, hope and purpose. Murata [2003] offers a further specification by defining 'spiritual pain' as 'pain caused by the extinction of the being and the meaning of the self.'

### Considerations

People derive their sense of meaning/spirituality from all sorts of sources of inspiration – from the mundane to the transcendent. Some people find meaning in their emotions and feelings (for example through praying, enjoying nature, literature, music, art), others in activities (meditation, performing rituals or devoting themselves to a good cause), and yet others in the intellect (contemplation, study). Spirituality

permeates existence as a whole. It is dynamic and has more to do with the factors underlying a person's approach to life than with an area of a person's life that can be seen as distinct from other parts.

In some phases of palliative care, a period of intensive existential questioning and a need to find meaning can be observed. Deep meaning may be ascribed to small, seemingly random circumstances or events; there is a 'density of meaning' whereby transcendent meaning is attached to these coincidences, sometimes to such an extent that it leads to renewed inspiration.

Based on practical experience, the working group believes that:

- continuing physical, emotional or social symptoms that are not responsive to treatment may be an indication of underlying spiritual questioning or struggle.
- existential and spiritual questions/needs are not always expressed verbally; non-verbally they may manifest as:
  - situational needs (purpose, hope, meaning and affirmation, reciprocity, tranquillity, connection, social presence)
  - moral and biographical needs (peace and reconciliation, migration history, being reunited with others, prayer, taking stock, forgiveness, closure)
  - belief-based needs (religious atonement, divine forgiveness and support, religious rituals/sacraments, meditation, contemplation, visit from a pastoral worker/teacher, spiritual literature, a talk about God, eternal life, reincarnation, connection, hope).
- in all communication with patients and their near ones (including non-verbal communication) there may be an underlying matter of a spiritual nature. In particular, special attention should be paid to figurative language and imagery.
- patients express and experience existential/spiritual matters in various ways not necessarily related to cultural differences. For some, their emotional experience is dominant; others are oriented toward doing and yet others toward thought and reflection.
- some patients are less able to communicate their needs clearly (due to factors such as mental capacity, skills, or cultural or linguistic barriers) and need assistance.

In light of these observations, the working group believes that it is important to be alert to:

- all communication by patients and their near ones that includes metaphors and images, as these can be indications of life/existential questions and meaning-giving processes
- implicit and non-verbal expressions and relevant symbols in the immediate surroundings, or in a person's clothing or appearance
- physical, emotional or social symptoms as an expression of patients' underlying or related life/existential questions or spiritual needs.

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## 2 Module 2 Origins and process

### 2.1 How does an existential or spiritual process arise and unfold?

#### Question

How does an existential or spiritual process typically arise and unfold?

Method: evidence-based

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#### Recommendations

Given the nature of the question, no recommendations have been made.

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#### Summary of the literature

Where a spiritual process is understood as a process of searching for meaning ('meaning making'), various components can be distinguished in the course of the process [Park 2010]:

- 1 **Initial appraisal of the event.** Every situation in which humans find themselves involves interpretation: meaning is always sought but is generally automatic and implicit. ('I should go to see the lung specialist because I've been coughing for such a long time, but I'm bound to live to 100 because I've always been healthy.')
- 2 **Discrepancies between initial appraisal and personal global beliefs.** Where a perceived discrepancy arises between the current situation and the personal world view, this can give rise to a form of distress. ('The lung specialist says I have an incurable illness and will not recover, yet I've always led a healthy life and have never smoked. It can't be true. Why is this happening to me?')
- 3 **Meaning-making processes.** Meaning-making processes are directed toward reducing the discrepancy between the current situation and the personal world view. According to Park [2010], 'Various categorical schemes have been proposed to understand this process of meaning making, focusing on different dimensions.' These distinctions are overlapping rather than mutually exclusive. Four of the most common distinctions drawn are:
  - a **Automatic versus deliberate processes.** Meaning-making processes take place in both unconscious and effortful ways. ('I notice that the question of why this had to happen to me is no longer preoccupying me so much.')
  - b **Assimilation versus accommodation processes.** The initial appraisal of the situation can shift in the direction of the personal world view (assimilation), or the personal world view may be adjusted as a result of the current situation (accommodation). These processes co-occur to some extent. ('I probably won't live to be 100, but somehow that doesn't matter anymore.')
  - c **Searching for comprehensibility versus searching for significance.** Meaning making is not only about making sense of an event within a system of accepted rules or theories (comprehensibility) but also about determining the significance of this for one's own life from that moment on (value or worth of an event). ('It's really clear to me now that I need to use whatever time I have left to do things I consider truly important.')
  - d **Cognitive versus emotional processing.** Some literature focuses more on the emotional dimension (experiencing and exploring one's emotions) of the process; other literature focuses more on the cognitive (reworking of one's beliefs) dimension. Park points out that 'these differ in emphasis rather than in essential underlying mechanisms'. ('I can increasingly accept the thought that I won't live to see next Christmas.')
- 4 **Meanings made.** Many different meanings can be made as a result of meaning-making processes. It is not a matter of right or wrong, healthy or unhealthy. There are many different ways in which a (new) balance may be arrived at between personal meaning and the spiritual process:
  - a Feeling of having 'made sense' ('I feel my life is complete: it is enough now, I have done my part.')
  - b Acceptance ('There's a time for everything. A time to be born and a time to die.')

- c Reattributions and causal understanding ('Life's a gamble. Healthy living is no guarantee.')
  - d Perceptions of growth or positive life changes ('I notice I have a deep sense of calm; I can face the future without fear.')
  - e Integration of the stressful experience into changed identity ('I've now begun the final phase of my life.')
  - f Reappraised meaning of the stressor ('Being terminally ill helps me to make choices about what I still want and what is no longer important to me.')
  - g Changed personal beliefs ('Religion never meant much to me, but more and more I think there must be something after this life.')
  - h Changed personal goals ('I always wanted to travel after I'd retired, but now I'm happy enjoying my garden.')
  - i Restored or changed sense of meaning in life ('I can enjoy the small things much more now.')
- 5 **Meaning making and adjustment.** Generally speaking, the process of meaning making settles down as the discrepancies decrease sufficiently for the particular person. ('I've stopped working and only want to see people I care about deeply.')

Not every patient will go through all of these phases.

### Conclusions

- When a person's world view no longer matches the current situation this can lead to a form of distress.
- Meaning-making processes are directed toward reducing the discrepancy between the current situation and a person's world view.
- The outcomes of meaning-making processes can be diverse. It is not a matter of right or wrong, healthy or unhealthy. The newly found balance may manifest itself in various ways.
- Five phases can be distinguished in a spiritual process (initial appraisal, discrepancy, process, meanings made, adjustment), but not all patients go through all phases.

### References

Park, C.L. Making sense of the meaning literature: an integrative review of meaning making and its effects on adjustment to stressful life events. *Psychological Bulletin*; [2010]; 136 (2), 257-301.



## 2.2 How does one recognise a spiritual crisis?

### Question

How does one recognise a spiritual crisis?

Method: consensus-based

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### Recommendations

- Signs to watch for that may indicate a spiritual crisis include:
    - Profound questioning about the meaning or purpose of the person's own life
    - Mourning or loss of connection with self, others or a higher power (God)
    - A profound change in the person
    - A circular process in which balance is sought but not found
  - Where a spiritual crisis has been identified or is suspected, it is best to make a referral.
- 

### Summary of the literature

There is no one clear consensus in the literature on the definition of a spiritual crisis. Based on articles by Agrimson [2009], Balk [1999] and Yang [2010], we have formulated the following definition of spiritual crisis:

'An acute disruption in the understanding of oneself, the world and/or the transcendent as a result of external stressors, whereby the individual arrives at a turning point or schism that results in a significant change in the way in which one makes sense of oneself and the world.'

A spiritual crisis may be masked by symptoms of a physical and psychosocial nature. Signs of a spiritual crisis [Agrimson 2009, Balk 1999, Yang 2010] are:

- Profound questioning and/or doubts about the meaning of a person's own life
- Mourning or a feeling of deep loss, often as a result of a disruption in a person's attachment or in a person's connection with self, others or a higher power (God)
- A critical moment or turning point at which a person is changed as a result of the crisis
- A circular process in which balance is sought but not found

### Conclusions

- A spiritual crisis may be masked by symptoms of a physical and psychosocial nature. A patient who is undergoing a spiritual crisis will generally display one or more of the following signs:
  - Profound questioning about the meaning of the patient's own life
  - Mourning or loss of connection with self, others or a higher power (God)
  - A profound change in the person
  - A circular process in which balance is sought but not found
- A spiritual crisis may be precipitated by an acute situation (such as a great loss, terminal disease, or sudden prospect of a longer life after having already said goodbyes because of a previous estimate of life expectancy). These can threaten a person's self-understanding or result in a worsening in various domains.
- A spiritual crisis may have positive as well as negative consequences.

### Considerations

A spiritual crisis may be precipitated by an acute situation (such as deep loss, terminal illness, or sudden prospect of a longer life after having already said goodbyes because of a previous estimate of life

expectancy). These can threaten a person's self-understanding or result in a worsening in one of the following domains:

- Feeling of faith in (or belonging to) God and the world ('Has God deserted me now?')
- Feeling of purpose or meaning ('What is the point of suffering like this?')
- Feeling of inner peace ('How can I find peace within myself?')
- Hope for the future ('What do I hope to still experience?')
- Being in touch with reality ('How do I escape this nightmare?')
- Feelings of connection, security, safety ('I feel so alone.')
- Sense of value ('What's it all for?')
- Ability to rise above oneself ('I have lost my sense of self.')
- Creativity ('I feel completely stuck.')
- Need for forgiveness/feelings of guilt ('I'll no longer be able to make amends.')
- Feeling of continuity with the past ('I no longer recognise myself.')
- Connection with significant people, places (home, nature), relationships, roles etc.

A spiritual crisis may have negative or positive outcomes, depending on personal and other factors.

- Negative outcomes:
  - Physical symptoms such as loss of energy, anxiety, depression, chest or abdominal pain, sensitivity to noise or light, anorexia
  - Psychological symptoms such as anger, resistance or depression
  - Lack of direction
  - Social withdrawal
  - Frequent bouts of crying
  - Decreased attention span
  - Loss of control over emotions or thoughts
  - Suicidal ideation
  - Feelings of abandonment
  - Existential loneliness
- Positive consequences:
  - A sense of renewal or spiritual awakening
  - Spiritual resilience
  - Renewal of hope
  - Self-reorganisation
  - Post-traumatic growth
  - Renewal or growth in relationships

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## 2.3 How does one address hope with patients receiving palliative care?

### Question

How does one address hope with patients receiving palliative care?

Method: consensus-based

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### Recommendation

- Consider which perspective on hope is most helpful for the patient and the family, and where necessary combine perspectives:
  - hope as expectation: expecting that something really will happen
  - hope as coping: deriving comfort from the thought that the future is still open
  - hope as meaning: seeing something as very meaningful

Use these approaches when talking to the patient and family, according to their needs.

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### Summary of the literature

Hope plays an important role in people's lives, and this is also true for patients receiving palliative care and for their families [Olsman 2014b]. However, hope is difficult to define. It is a vital force that may vary during the course of an individual's illness. At the same time, it may take several (sometimes conflicting) forms. Hope is therefore sometimes referred to in the literature as a 'multi-voiced' process [Olsman 2015a]. For example, hope may be the hope of being cured, held simultaneously or alternating with the hope that death will come quickly and painlessly. Some forms of hope may prevail for a time but then fade in prominence without disappearing completely.

Generally speaking, there are three ways in which hope can be construed [Olsman 2014a]:

a Expectation

This expectation may be realistic or unrealistic. Sometimes 'hoping against hope' may weigh heavily on a patient and this burden may need to be discussed.

b Coping

Hope in this case is conceived of as functional, as a strength that helps people to endure their illness, regardless of whether their hope is realistic.

c Significance or meaning giving

People try to discover meaning in their current situation by linking it to the future. One's life story becomes complete, as it were, by weaving past, present and future into a meaningful whole that offers solace because it is consistent with the current situation.

These three perspectives on hope are not mutually exclusive; they can all be used to offer support to patients. In contact with patients and/or their family it will be necessary to explore which approach is most supportive. Where needed, a shift of perspective can be made during an interaction.

### Conclusions

- Hope can be construed in three ways:
  - 1 as expectation
  - 2 as coping
  - 3 as significance or meaning giving.[Olsman 2014a]

## Considerations

The working group believes that the way in which a care giver should address hope depends on the perspective on hope [Olsman 2015b; Olsman 2016].

From the perspective of hope as expectation, care givers sometimes see it as their task to adjust a patient's expectations to be more realistic. This can be useful, giving the patient a realistic idea of the time available to arrange affairs. But telling a patient that their expectations are not realistic will not be appreciated by all patients or in all cultures.

From the perspective of hope as a way of coping, the care giver may find it important not to take away hope, and to offer support or affirmation so that the patient is better able to cope with the present situation.

From the perspective of hope as significance or meaning giving, the care giver can support the value of this vision of the future, and affirm it as an expression of a wish that can help make the current situation bearable.

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## 3 Module 3 Assessment, attention and accompaniment, referral and reporting

### 3.1 How do I talk to patients about existential/spiritual matters?

#### Question

How do I talk to patients about existential/spiritual matters?

Method: consensus-based

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#### Recommendations

- Always be on the lookout for patients and their family using metaphors and images in their communication. These may be a sign of questions about life/existential matters or meaning-giving processes, and often have several layers of meaning ('listen in layers'); make sure to probe gently to learn more.
  - Be alert to life/existential questions or spiritual needs underlying problems that present as physical, mental or social symptoms.
  - Notice meaningful symbols in the immediate surroundings, or in a person's clothing or appearance, and show interest.
  - Check if the patient would like to talk about what the situation means to them.
  - Make sure that you will not be disturbed during a talk.
  - During a talk, create an atmosphere of calm, space and non-judgemental attentiveness.
  - Listen with an attuned ear and be aware that what people say may have several layers of meaning – factual, emotional, biographical – which can be indications of existential/spiritual matters.
  - During the talk, ask open questions, point out and verify non-verbal signals, and do not offer answers yourself.
  - Address patients with an attitude of respect, openness and non-judgement.
  - Evaluate on the basis of the talk about existential/spiritual dimensions whether a patient should be referred to a specialised spiritual care giver.
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#### Summary of the literature

No systematic literature research was undertaken. The considerations are based on Weiher (2004, 2007, 2009).

#### Considerations

##### Attitude

One characteristic of spiritual questions is that they are questions to which there is often no answer or solution. Questions such as 'What did I do to deserve this?' or 'Why must I suffer so much?' are expressions of a process of searching for existential meaning and purpose. Where there is no solution, answers may still be possible. But if there is an answer to these questions, it will not be one from a book. Ultimately the answer can only come from the patient themselves, and the patient can be offered support and help in their search for an answer. This requires care givers to adopt a less familiar attitude. Care givers are primarily trained to help solve problems. When offering spiritual support, however, the main priority is to be present and listen. Then help does not come from outside; rather the aim is to mobilise the patient's own inner strength through presence, commitment, and 'being' rather than 'doing'. When patients' philosophy of life or religious beliefs are different from one's own, and/or they come from a different cultural background, it may require extra effort to engage with them in a respectful, open and non-judgemental way.

### Layers of meaning

Statements that patients make rarely mean just one thing; they often contain several layers of meaning. The layer of meaning pertaining to the existential/spiritual dimension often underlies an expression that on the surface appears to be of a physical or psychosocial nature. An example clarifies this.

#### *Example: four layers of meaning*

A woman, 60 years old, is in hospital and says, 'At night I often lie there and think of my husband.' What does this statement mean? What layers of meaning may be concealed within this single sentence? What question might lie behind this utterance?

This statement can be understood in various ways (Weiher 2004, 2007, 2009):

- Factually (here the meaning is about a factual and objectively verifiable state of affairs): 'Patient lies awake at night'. A focus on the physical aspect prompts questions such as: Is she suffering from insomnia? Should something be done?
- Emotionally (here the meaning is related to thoughts, images, feelings and emotions that are embedded in the statement): 'Patient is thinking about her husband'. Questions that arise from a focus on the psychological/emotional dimension might include: Is the patient worried? Does she miss her husband? Is she perhaps experiencing sadness or longing? How intense are her feelings? What care/support might be needed?
- Biographical (here the meaning is about a person's social context and says something about their identity): 'the patient is (or has been) a wife'. Questions that arise from a focus on this layer include: What kind of bond is there between the two? How is the communication between them? Does her husband have care needs? Is the woman perhaps a widow?
  - (here it is about what moves people most deeply, what inspires them and gives their life meaning; this is often connected with ordinary everyday things in life). Consideration of this layer prompts questions such as: What does it mean for her to think about her husband? What feelings does the memory of her husband evoke? Does it make her feel melancholy/wistful or does she (also) derive strength from his memory? How does the quiet of the night affect her?

All these layers of meaning are interrelated. They can be made manageable by discerning them.

Developing sensitivity to the existential/spiritual dimension involves learning to listen to the layer of meaning about purpose and inspiration, which may lie hidden beneath more superficial expressions. 'How do you feel when you think of your husband at night?' the spiritual counsellor asked this woman. She answered: 'I feel comforted. He passed away two years ago, and especially at night I feel his presence and his comfort during this difficult time.'

Her answer is surprising and shows that one should never be too quick to fill in the meaning that might be implicit in a statement. Each time it is about discovering what a particular statement means for each unique patient. Asking open questions, verifying non-verbal signals and reflecting what you hear can create space for patients to tell about what gives them meaning and strength. As they talk they also become aware of this themselves. Creating space for relating meaningful stories is an important kind of spiritual care. Acknowledging pain that cannot be alleviated but that does demand attention is also an important form of spiritual support that all care givers can provide.

Naturally, one essential condition for a talk about the meaning of life and spirituality is that you create time and calm, and will not be disturbed by phone calls or other matters (see also Module 4). At the same time, devoting attention to existential and spiritual matters while carrying out everyday care is of great significance: showing that you are paying attention, during daily care activities, to people's non-verbal signals and the offhand remarks that patients sometimes make, or showing interest in the meaning that a

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patient attaches to what happens to them. As a patient with advanced multiple sclerosis put it: 'One day I feel like a piece of meat hanging in a hoist, another I am helped like a human being into my wheelchair. One day I am cleaned and another day I am washed.'

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### 3.2 How does the role of a doctor or nurse differ from the role of a care giver who is specialised in providing existential and spiritual support?

#### Question

How does the role of a doctor or nurse differ from the role of a care giver who is specialised in providing existential and spiritual support?

Method: consensus-based

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#### Recommendations

- Assess whether as a doctor or nurse you are capable of giving the required attention and, where necessary, support concerning existential and spiritual matters. Refer the patient to a specialised care giver (spiritual counsellor, medical social worker or psychologist) if the patient has indicated a need for this and you have neither the time nor capacity, and/or a spiritual crisis has arisen.
- For all care givers the following recommendations apply:
  - Bear in mind the following prerequisites for the provision of spiritual care:
    - Be open to your own spiritual dimension.
    - Every so often, really take your time with the patient (a patient will not ask more profound questions if the care giver seems to be in a hurry).
    - Make the patient's goals and needs the priority.
    - Respect your own professional and personal boundaries.
    - Show respect for the patient's culture, beliefs or philosophy of life.
  - Create an atmosphere conducive to the provision of spiritual support:
    - Ensure your manner is calm.
    - Offer a safe environment; create an atmosphere of trust and compassion.
    - Be present in the here and now without imposing.
    - Strike the right tone: not too light and not too heavy.
    - Be yourself and talk as one human being to another.
  - Apply the following points relevant to the process of providing spiritual care:
    - Take into account the wishes and needs of the patient and their family; adjust as necessary in each phase.
    - Show sincere interest in and concern for what the patient is going through; let genuine interest guide you in asking questions.
    - Listen and observe attentively; and ask open questions.
    - Adopt an open attitude; respond with empathy.
    - Suspend all judgement: give the other person the space to search or struggle in their own way.
    - Be prepared to look beyond your own horizons (be open to new experiences regarding other beliefs and cultures).
    - Choose the right moment to suggest your own advice or solutions; nobody wants to be rescued. The point is for a person to connect with their inner strength.
    - Do not take expressions of anger or reproach personally; they may arise from anger and grief.
    - Remain available to patients and family, even if nothing more can be 'done' or if care is refused.

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#### Summary of the literature

No systematic literature research was undertaken for this question, because the working group did not expect to find any studies that provided answers to the question that were relevant to the Dutch context. Therefore, no conclusions are drawn either. The recommendations are based solely on considerations



made by the working group members on the basis of their professional experience, and where possible confirmed by a (non-systematic) review of the literature.

### **Considerations**

A useful model for distinguishing between the role of a doctor or nurse and that of a specialised care giver (spiritual counsellor, medical social worker or psychologist) is the ABC model (see also Table 1) [LKNG 2001] described below.

### **A Attention**

Devoting attention to spiritual needs and concerns requires care givers to adopt an attitude of attentive presence. Patients are vulnerable and dependent on assistance; they have to reveal so much to care givers. It is therefore important to create an atmosphere in which they can feel safe. Primarily, of course, good care by doctors and nurses is based on medical and nursing competencies. But spiritual care also requires the engagement of human capacities. Good care requires a receptive, caring approach that shows openness and sensitivity to what people are feeling and experiencing. Only then is it possible to observe clearly patients' own interpretations or layers of meaning (see 3.1 'How do I talk to patients about existential/spiritual matters?').

As with patients, each care giver has their own past and idiosyncrasies. Self-observation and self-reflection can help a care giver to become aware of their own reactions and the consequences these have for interactions with the patient, which can help prevent misinterpretation of signals from the patient. The extent to which a care giver can feel and deal with their own powerlessness or fear has consequences for their ability to be present with the powerlessness or fear of the patient. Regular self-observation and self-reflection, for example through supervision or peer supervision, are therefore recommended.

It is not only important for care givers to explore and be aware of and work with their own emotions; to be able to address spirituality you also have to be open to it personally. Before care givers are able to listen well to others, they first need to be able to hear what is going on inside themselves. Talking about spiritual matters can affect people very deeply. Patients often know intuitively who they can or cannot discuss these matters with. How much a patient opens up depends on the person offering the spiritual care – more than is the case in other dimensions of care. When a patient senses that a care giver has no antennae for this dimension, the patient is unlikely to share their spiritual feelings. Care givers who take everything extremely seriously are likely to strike the wrong note. In this context the term 'diluted seriousness' ('verdunde ernst') has been coined: the art of addressing of deep issues by weaving these topics into the minutiae of everyday life. This 'dilution' with the everyday makes it easier to raise serious topics. Humour is also a fantastic way to help lighten the mood by breaking the intensity of the dying process. Note, however, that humour needs to be used skilfully and as mildly as possible!

### *Everyday sources of inspiration or philosophy of life as an interpretive framework.*

When a care giver encounters a patient's life/existential questions it is important to be able to understand the context in which these are being asked. Context will assist the care giver and make communication and handing over to other care givers simpler. The most obvious context of meaning giving is the roles one fulfils in everyday life (partner, father, mother, child, professional, member of a football club, churchgoer).

Everyday sources of inspiration and strength are referred to as 'everyday spirituality'. In addition, religious and other wisdom traditions have long offered important frameworks within which to interpret and understand spiritual concerns. It is important to be aware that many different orientations can be distinguished within all systems of belief (see Appendix 11). Moreover, there are differences in the extent

to which followers are 'practising'. Philosophies of life such as atheism, agnosticism and humanism are also of relevance to the experience of meaning and purpose in the last phase of life. Furthermore, people who are seriously ill often rediscover/reconnect with the values of the philosophy of life or beliefs that they grew up with.

Spirituality is a dynamic concept and encompasses myriad processes. Whatever the process taking place, an attitude of acceptance and respect for a person's beliefs is important for everyone. People appreciate such an attitude, and it is more important than knowledge of matters such as rituals associated with a particular belief system. The art is to cultivate being a concerned, interested but very modest visitor. It is very important not to express your opinions about religious or spiritual customs; rather, offer support. However, if a patient is open to it, a personal conversation does not have to be avoided. Be aware, though, that in the process of seeking a new balance a patient may shock others, be rebellious, or say the opposite to what they are thinking (in anger, despair, fear, etc.). Although, for many, religious traditions still fulfil the role of providing a framework of meaning, an increasing number of patients have no connection with a particular religion. There are also more and more patients who combine elements from various life wisdom traditions to construct their own life philosophy.

## **B Accompaniment**

There is no clear demarcation between the categories of Attention and Accompaniment. The big difference between the two, however, is that attention is important in every situation and for every care giver, whereas accompaniment goes a step further and only takes place when a patient indicates they would like this. In other words: attention to the dimension of life/existential questions and offering accompaniment are both part of good care, but accompaniment must never be imposed on someone.

The experience of existential struggle is an important step toward finding a renewed psychological and spiritual equilibrium that enables the patient to face their approaching death. Existential struggle should therefore not be avoided or suppressed. Because this process is very personal and unique to each patient, it is important for patients themselves to be able to determine when they are ready to confront the reality of impending death. Careful posing of the right questions by the care giver can help a patient to progress toward that moment. It is also important that the patient have time and space to process the struggle in their own way.

All care givers can play a role in the provision of spiritual care as part of their professional duties. To be able to do this competently requires a certain amount of training. This guideline is not a substitute for that training, yet it does give an indication of the issues that need to be taken into account.

Spiritual care accompaniment consists of talking with the patient about issues that are of concern to them as they relate to the care giver's medical or nursing activities. The general recommendations made under A (A: attention) also apply to the provision of spiritual care. It is important that doctors and nurses have an understanding of the spiritual process that a patient may be experiencing or wrestling with. In this context the patient's search or struggle can be monitored and issues identified. Where necessary a patient can be referred to a spiritual counsellor who is specially trained in matters of meaning giving and spirituality: if a care giver, the patient or family deems this appropriate. Although the frame of reference of psychologists and social workers is primarily the psychosocial sphere, their discipline provides many opportunities for spiritual care.

Some patients may have a need for support in the form of talking or texts, or for non-verbal forms of communication such as rituals, music and making use of objects with a symbolic or special meaning, to be

able to express what words cannot convey. Spiritual care givers are able to respond to these needs. They may also make use of other techniques such as meditation or visualisation, as may some psychologists.

### C Crisis intervention

See Module 3.6 about how to respond in the event of a suspected spiritual/existential crisis.

Tabel 3.1 THE ABC MODEL

Please note that the sections indicated in this overview as distinct from each other are not always clearly separated.

	Doctor and nurse	Medical social worker, psychologist	Spiritual counsellor
<i>Primary focus, path of access and frame of reference</i>	<i>Somatic</i>	<i>Psychological Social</i>	<i>Spiritual</i>
<b>A Attention</b> (always)	Listen, support, recognise, screen*	Listen, support, recognise, screen*	Listen, support, recognise, screen*, interpret <b>(represent)</b> <b>and connect</b>
<b>B Accompaniment</b> (with patient's permission)	Follow patient's search process, explore, refer, assess*	Follow patient's search process, explore, refer (→), assess*	Follow patient's search process (←) refer, explore, assess, interpret and appraise*
<b>C Crisis intervention</b> (if indicated)	Detect, refer	Recognise, counsel, treat, refer (→)	Recognise, counsel, sometimes: treat, (←) refer, interpret and appraise*

\* See (diagnostic) instruments under Assessment

Table 1: Kinds of spiritual care [Based on LKNG publication: Kun je uit de hemel vallen? (Can you fall out of heaven?) December 2001]

Comments/explanation regarding Table 1:

- Primary focus, path of access and frame of reference are not referred to for the purpose of separating work domains, but simply to indicate a distinction. This implies a care dimension for which a particular discipline bears ultimate responsibility and possesses particular expertise. Within the field of palliative care, multidisciplinary practice (with reciprocal consultation) – and preferably interdisciplinary practice – is always indicated.
- Each discipline evokes its own reality, which will also have its own effect on the patient. A patient may therefore say different things depending on whether they are talking to a nurse, doctor, psychologist or spiritual counsellor.
- Each discipline also has its own particular manner of accompaniment: its own repertoire and role with respect to the patient.
- Spiritual counsellors elicit a different response than doctors or nurses, simply through their presence. They represent a dimension of reflection on meaning. In the context of (religious) belief, spiritual counsellors can also represent other realities, such as a particular faith community or God. A characteristic of spiritual counsellors' work is also the dimension of connection (connecting a person's unique life story with

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appropriate images, symbols, rituals, stories, poems). This requires specific competencies in addition to the 'listening, supporting, recognising, counselling, treating' shared with other disciplines.

- Listening and recognising (see A in Table 1) are always indicated because they are intrinsically valuable, and they may help to prevent a crisis.
- Volunteers who provide palliative care in the terminal phase and the coordinators of this kind of care are not mentioned in the table. Nevertheless, they can also play an important role in the provision of spiritual care. Volunteers are there for the dying person and the family, contributing time, attention and support during the final phase of life. They are less affected by time constraints and the pressures of the professional care system. As a result, they can sometimes be a valuable source of information for professional care givers.

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### 3.3 What assessment tools can be helpful for exploring the spiritual dimension?

#### Question

What assessment tools can be helpful for exploring the spiritual dimension?

Method: consensus-based

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#### Recommendations

- Where a spiritual crisis is not suspected, when devoting attention and offering accompaniment it is advisable to use assessment tools such as the questions provided by the Mount Vernon Cancer Network, FICA and the Ars Moriendi model.
  - Use existing instruments and methods to identify the spiritual dimension of palliative care needs. Dutch examples include the 'Lastmeter' (Distress Thermometer), the IKNL's 'Signalering in de palliatieve fase' and the 'Utrechts Symptoom Dagboek' (Utrecht Symptom Diary).
  - If you suspect a spiritual crisis or that a patient's suffering has a predominantly spiritual component, make a referral.
  - For substantiating a referral, validated spiritual assessment tools are available in English that can be used with people who have sufficient command of English. These include the PRISM, HAI, HHI and FACIT-SP.
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#### Summary of the literature

Three assessment tools are available to aid the appraisal of patients' existential/spiritual state:

- a the questions in the Mount Vernon Cancer Network assessment tool [MVCN 2007] (see Appendix 8)
- b the Ars Moriendi (Art of Dying) model (see Appendix 9)
- c the FICA Spiritual History Tool © (see Appendix 10)

The MVCN cue questions provide an opportunity for the patient to talk about their everyday sources of strength or deeper existential/spiritual dimensions:

Brief assessment:

- How do you make sense of what is happening to you?
- What sources of strength do you look to when life is difficult? (Family? Your faith? Music?)
- Who would you like to have with you? Who would be able to offer you support?

Depending on the answers to the above questions, an assessment can be made of whether a patient's existential/spiritual requirements will be met through careful attention, or whether counselling (by a spiritual counsellor, social worker or psychologist) or crisis intervention (by the spiritual counsellor) is needed (see also the ABC model in Module 3.2).

The Ars Moriendi (Art of Dying) model was developed in Dutch; it is more dynamic and contains more detail. The Ars Moriendi model is included in the Utrechts Symptoom Dagboek (USD: Utrecht Symptom Diary) in order to integrate the spiritual dimension into the assessment of complaints and symptoms of patients receiving palliative care.

The FICA Spiritual History Tool © is brief and addresses this dimension of palliative care in several concise areas of concern [Borneman et al 2010]. FICA has been translated into Dutch but has not yet been validated; this is also the case for the Mount Vernon Cancer Network assessment tool.

Research carried out in the Netherlands and Belgium has shown that the Ars Moriendi model [Voskuilen 2012, Vermandere 2015] and the FICA Spiritual History Tool © [Vermandere 2012] can best be used as

general guides for talking about spiritual concerns with patients, as an aid for including all aspects of spirituality in the conversation.

Guides are available for psychosocial care givers ([www.pallialine.nl/hulp-bij-helpen](http://www.pallialine.nl/hulp-bij-helpen)) and nursing staff [van Leeuwen 2006]; for doctors a recommendation has been made that the subject should be made an integral part of the medical school curriculum [Gijssberts 2015]. For volunteers the key concept of 'Er Zijn' ('Being There') has been developed and this forms basis of the support they provide. 'Being There' is about offering warm, affirming relationships and is based on various social presence theories [Goossensen 2014].

At present there are no specific spiritual assessment tools that have been validated for use in the Netherlands. The Distress Thermometer is a multi-dimensional instrument that includes the spiritual dimension; it is suitable for identifying a patient's current problems, complaints and/or needs. See also the Netherlands Quality Framework for Palliative Care, specifically Domain 6, the Spiritual Dimension/Measurement instruments.

#### Assessment tools

The instruments below are used to assess the existential/spiritual well-being of a patient. They have been developed and validated for the palliative population, but they have not been validated for patients in the Dutch context [Gijssberts 2011].

Three of the instruments have specific questions about existential and spiritual well-being. Best et al. [2015] evaluated tools that are good for measuring spiritual suffering.

To measure hopelessness and demoralisation they advise:

- Pictorial Representation of Illness and Self Measurement (PRISM) [Büchi 2002]
- Hopelessness Assessment in Illness (HAI) [Rosenfeld 2011, 2017]
- Demoralization Scale [Kissane 2004]

To measure hope:

- Herth Hope Index -HHI [Nowotny 1989]

To measure spiritual well-being:

- Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being (FACIT-SP) [Canada 2008]. The FACIT-SP has been tested in the Netherlands to evaluate whether it is a useful tool for nurses to assess the extent of a patient's spiritual well-being. The study revealed that when the FACIT-SP is used patients are referred more frequently to a spiritual counsellor [Vlasblom 2015].

In addition, there are a number of other assessment tools that have been specifically developed and validated for the palliative population. These have not yet been translated into Dutch [Gijssberts 2011] but are regularly used in other countries to assess the existential and spiritual needs of palliative patients. They include:

- Spiritual Needs Inventory (SNI) [Hermann 2006]
- JAREL Spiritual Well-being Scale [Hungelmann 1996]
- Item assessment: 'Are you at peace?' [Steinhauser 2006]

There are also assessment tools that measure quality of life and have a specific section on existential/spiritual matters. These include:

- Quality of Life at the End of Life Measure (QUAL-E) [Steinhauser 2004]

- Hospice Quality of Life Index [McMillan 1998]
  - Missoula-VITAS QOL (MVQOL) [Byock 1998]
  - McGill Quality of Life Questionnaire [Cohen 1996]
- These tools are not yet used in the Netherlands.

### Considerations

Module 3.2 describes three levels of end-of-life spiritual care: attention, accompaniment and crisis intervention (in Dutch: ABC). Attention and accompaniment are aspects of spiritual care that can be provided by care givers from all disciplines. Crisis intervention requires specialist expertise, such as that of spiritual counsellors.

Questions concerning existential and spiritual matters are often not asked outright and are implicit (see also Module 1.2). Because of this, it can be helpful to use tools to identify these questions and to evaluate whether attention, accompaniment and/or crisis intervention is likely to help reduce a person's existential/spiritual suffering and improve their quality of life.

- Tools are available to identify and assess spiritual needs in palliative care. These include the Mount Vernon Cancer Network questionnaire, the Ars Moriendi model and the FICA.
- These tools can also be used when devoting attention to existential/spiritual matters with patients or providing accompaniment, provided no spiritual crisis is suspected.
- The Distress Thermometer, the IKNL 'Signalering in de palliatieve fase' and the Utrecht Symptom Diary also include the spiritual dimension.
- Palliative care volunteers can use the observation method 'dorst of doodangst' ('thirst or fear of death') to identify signs of spiritual suffering in patients.
- If you suspect that a patient is in a spiritual crisis or that a patient's suffering has a predominantly spiritual component, make a referral.
- Very few validated assessment tools are used in the Netherlands. These are meaningful tools for substantiating a referral, and also for evaluating the effect of a spiritual intervention. A review of the international research literature reveals that there are validated assessment tools for use by and/or with palliative patients. These include tools designed to elicit information about existential and spiritual matters, and tools designed to assess quality of life that include a special section on existential and spiritual matters. Dutch research on nurses using the FACIT-SP revealed that its use resulted in more patients being referred to a spiritual counsellor.

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### 3.4 What is the effect of interventions for existential/spiritual support on the quality of life of patients receiving palliative care?

#### Question

What is the effect of interventions for existential/spiritual support on the quality of life of patients receiving palliative care?

Method: evidence-based

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#### Recommendations

Given the nature of the question, no recommendations have been made.

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#### Summary of the literature

##### *Systematic reviews*

The literature search identified three systematic reviews that studied the effect of spiritual care on patients receiving palliative care.

Candy's Cochrane review evaluated the effect of spiritual interventions on patients in the terminal phase of a chronic and progressive life-threatening condition [Candy 2012]. This included five Randomised Controlled Trials (RCTs), two of which evaluated the effect of meditation [Downey 2009, Williams 2005] and three the effect of intervention by a multidisciplinary palliative care team [Brumley 2007, Gade 2008, Rabow 2004]. As it was not possible to separately evaluate the spiritual care aspect in the latter three RCTs, they were not included in this overview.

Martinez evaluated the effect of dignity therapy in patients with advanced life-threatening diseases [Martinez 2016]. This study included five RCTs. One of these did not evaluate the effect on quality of life [Juliao 2014] and was therefore not included in this overview. A second RCT evaluated the effect of dignity therapy in a population of elderly people who were not necessarily in palliative care [Hall 2012]. The other three RCTs are discussed in more detail below [Chochinov 2011, Hall 2011, Rudilla 2016].

Piderman evaluated the effect of interventions to promote spiritual well-being in patients with metastasised cancer [Piderman 2015]. This study included three RCTs. One RCT evaluated the effect of a multidisciplinary intervention in which it was not possible to assess the effect of the spiritual care separately [Piderman 2014]. Another RCT evaluated the effect of an intervention that did not have a clear spiritual component [Zimmerman 2014]. The third RCT did not report on quality of life [Lloyd-Williams 2013]. These RCTs were therefore not included in this overview.

##### *RCTs*

The search identified another two RCTs that were not included in one of the previously mentioned reviews.

Vermandere conducted a cluster RCT among 18 Flemish palliative home care teams which were randomised into an intervention group and a control group. Twenty-five patients received an intervention that included a structured spiritual history and 24 patients received standard care [Vermandere 2016]. All patients had a progressive life-threatening disease.

In a Chinese study, Xiao randomised 80 patients with advanced cancer into an individual life review programme (N=40) or conventional care (N=40) [Xiao 2013]. The intervention was carried out individually by a nurse.

### Quality of the evidence

The quality of the Cochrane review is good [Candy 2012]. This review was based on an extensive search for studies and included explicit reporting on the methodology used and results obtained. A meta-analysis was rightly not carried out because of the heterogeneity of the result reporting. The two other reviews were of low quality, primarily because of the inadequate reporting on the search strategy and the quality evaluation [Martinez 2016, Piderman 2015].

The seven RCTs included here have a high risk of bias due to the inevitable absence of blinding of patients and practitioners [Downey 2009, Williams 2005, Chochinov 2011, Hall 2011, Rudilla 2016, Vermandere 2016, Xiao 2013]. In two studies the randomisation method was unclear [Downey 2009, Xiao 2013] and a third study was classified as a pseudo RCT [Rudilla 2016]. In three studies there was no clear allocation concealment [Downey 2009, Vermandere 2016, Xiao 2013]. In only one study was the person who evaluated the effect blinded [Williams 2005]. In four studies there was either no intention-to-treat analysis or the analysis was unclear [Chochinov 2011, Downey 2009, Rudilla 2016, Vermandere 2016]. Selective reporting of results was found in one study [Downey 2009].

### Effect on quality of life critical outcome measurement

#### *Meditation*

Two RCTs evaluated the effect of meditation: one study in a population of palliative care patients (69% with cancer) [Downey 2009] and one study in a population with end-stage AIDS [Williams 2005]. No significant effect on quality of life was observed in comparison with standard care. Downey reported a corrected average difference of -0.269 ( $p=0.261$ ) after 10 weeks, measured on a scale of 0 to 10 [Downey 2009]. Using the Missoula-VITAS Quality of Life Index (with a maximum score of 30), Williams reported a change in total score after 8 weeks of -0.18 for meditation and -0.56 for standard care ( $p>0.05$ ) [Williams 2005]. After 68 weeks the change was +0.84 for meditation compared with +0.29 for standard care ( $p>0.05$ ).

Both studies also compared the effect of meditation with that of massage and again found no significant effect on quality of life. Downey reported a corrected average difference of -0.33 ( $p=0.41$ ) after 10 weeks [Downey 2009]. Williams reported a change in total score after 8 weeks of -0.18 for meditation and +0.33 for massage ( $p>0.05$ ) [Williams 2005]. After 68 weeks the change was +0.84 for meditation compared with +0.49 for massage ( $p>0.05$ ).

Williams also compared meditation with a combination of meditation and massage [Williams 2005]. After 8 weeks a significant improvement in quality of life was observed in the combination group (meditation alone -0.18 compared with combination +3.75;  $p<0.05$ ); after 68 weeks the difference was no longer statistically significant (+0.84 compared with +4.05;  $p<0.05$ ).

#### *Dignity therapy*

Three RCTs evaluated the effect of dignity therapy, two of which compared this to standard palliative care [Chochinov 2011, Hall 2011] and one of which compared it to counselling [Rudilla 2016]. None of the studies recorded a significant effect on quality of life. Chochinov assessed quality of life using two 10-point Likert scales (scores after intervention reported as Quality of Life rating 6.39 vs 6.34 and Quality of Life satisfaction 6.04 vs 6.05) [Chochinov 2011]. Hall combined these two scales into one score and reported an average difference of 1.56 (95% BI -4.47 to 1.35) after 1 week and an average difference of 0.83 (95% BI -2.96 to 4.61) after 4 weeks [Hall 2011]. They also scored quality of life using the EQ-5D instrument and reported an average difference of 0.10 (95% BI -0.30 to 0.09) after one week and an average difference of

0.01 (95% BI -0.35 to 0.37) after 4 weeks. Rudilla reported an average difference of -0.03 ( $p=0.919$ ) after three months, as measured using two items from the EORTC QLQ-C30 tool [Rudilla 2016].

#### *Spiritual history*

Vermandere found that taking a structured spiritual history from patients with progressive life-threatening diseases had no significant effect on quality of life when measured using the EORTC QLQ-C15-PAL instrument (average difference 1.07;  $p=0.45$ ) [Vermandere 2016].

#### *Life review programme*

Xiao found that a life review programme had a significant effect on the quality of life of patients with advanced cancer, measured on a scale of 0 to 10 (6.31 compared with 4.05 after programme [ $p<0.01$ ]; 5.13 compared with 2.60 after 3 weeks [ $p<0.01$ ]) [Xiao 2013].

#### Effect of other patient-related outcome measurements

##### *Meditation*

Downey reported no significant effect on pain-related distress after 10 weeks, measured on a score of 0 to 5 [Downey 2009].

##### *Dignity therapy*

None of the three RCTs found a significant effect when using the Patient Dignity Inventory or the Hospital Anxiety and Depression Scale. Furthermore, Chochinov found no significant effect when the following tools were used: the Structured Interview for Symptoms and Concerns, the Edmonton Symptom Assessment Scale and the Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being [Chochinov 2011]. Hall found no significant effect on the Herth Hope Index either [Hall 2011]. Nor did Rudilla find any significant effect using the following instruments: the Brief Resilient Coping Scale (dealing with stress), the GES questionnaire (on spirituality) and the Duke-UNC-11 Functional Social Support Questionnaire [Rudilla 2016].

##### *Spiritual history*

Vermandere found no significant effect with the FACIT-Sp-12 scale for spiritual well-being, nor for the Health Care Relationship Trust Scale (HCRTS, which measures the degree of trust between patients and care givers) or a 4-point pain scale [Vermandere 2016].

##### *Life review programme*

Xiao found that there was a significant effect on the following domains of the Quality-of-Life Concerns in the End-of-Life Questionnaire: concern about health care, negative emotions, feeling of alienation, existential distress and value of life [Xiao 2013]. There was no significant effect in the following domains: physical discomfort, nutrition-related worries and support.

#### **Conclusions**

- There is low-quality evidence that meditation has no effect on quality of life compared with standard care or massage among a palliative care population [Downey 2009, Williams 2005].
- There is low-quality evidence that the combination of meditation and massage has a greater effect on quality of life than meditation alone in a population with end-stage AIDS [Williams 2005].
- There is low-quality evidence that dignity therapy has no effect on quality of life compared with standard care or counselling among a palliative care population [Chochinov 2011, Hall 2011, Rudilla 2016].

- There is low-quality evidence that taking a structural spiritual history has no effect on quality of life compared with standard care among a palliative care population [Vermandere 2016].
- There is low-quality evidence that a life review programme has a positive effect on quality of life compared with standard care among a palliative care population [Xiao 2013].

### Considerations

In 2016, after the literature study had been completed, Kruijzinga published a systematic review of the effect of spiritual interventions [Kruijzinga et al. 2016]. The conclusion was that a number of interventions resulted in short-term improvement of quality of life, but that after 3 to 6 months this effect was no longer present.

Although quantitative research has produced little to no evidence that interventions with a spiritual component result in improved quality of life for palliative patients, some qualitative research does make clear the importance of devoting attention to the spiritual dimension at the end of life [Gijssberts 2015, van de Geer 2017]. Promising psychosocial interventions are also being developed in this domain, such as CALM (Managing Cancer and Living Meaningfully) [An 2017].

A systematic review of dignity therapy research showed that this form of support scores high for patient and close family satisfaction and results in an increase in their feeling of meaning and purpose in life. The effects of dignity therapy on physical and emotional symptoms were inconsistent [Fitchett 2015].

Traditionally, impending death is accompanied by rituals. Various religious traditions provide or have provided rituals, images, stories and symbols that help people to deal with the death of a loved one and to face their own imminent death. Examples include praying and reading from the Bible among Protestants, anointing of the sick among Catholics and reciting Koran texts among Muslims. In this time when religious rituals have lost meaning for many people, new end-of-life rituals are emerging, some of which are conducted by professionals such as spiritual counsellors or celebrants [van der Veen 2018]. It is important to allow space for these rituals.

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### 3.5 When do I refer a patient to a specialised care giver (spiritual counsellor, medical social worker or psychologist)?

#### Question

When do I refer a patient to a specialised care giver (spiritual counsellor, medical social worker or psychologist)?

Method: consensus-based

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#### Recommendations

- Make a referral, with the patient's permission, if you think you cannot provide the (spiritual) care that the patient and/or family has a right to. This decision could be made on the grounds of:
    - content-based factors (spiritual crisis, need for rituals, etc.)
    - personal factors (lack of/insufficient expertise, subject matter that touches on one's own struggles)
    - practical factors (not enough time, professional boundaries).
    - To begin with, refer to a spiritual counsellor or someone from the spiritual tradition of the patient and family – unless special expertise (for example, that of a psychologist or medical social worker) is needed, such as in the case of an existential crisis.
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#### Summary of the literature

No recent literature was found describing research on how patients should be referred. No systematic literature research was done concerning this question, because the working group did not expect to find any studies that provided answers to the question that were relevant to the Dutch context. The recommendations are based solely on considerations made by the working group members on the basis of their professional experience, and where possible confirmed by a (non-systematic) review of the literature.

#### Considerations

The following considerations are based on the opinion of the working group.

Key indications for referral may include:

##### *Content-based factors:*

- when you suspect that more assistance is needed, but you do not know what (or how)
- when the spirituality of the patient and/or family should be explored again (for example when there is a sudden devastating change in the prospects for the patient's life)
- when the patient is experiencing feelings of (actual or existential) powerlessness or guilt
- when the patient and/or those around them feel the need for rituals
- when you suspect an existential crisis
- when a patient is caught in a vicious circle of searching and not achieving an equilibrium
- when a patient and/or near one makes an explicit request for a spiritual counsellor

##### *Personal factors:*

- when you run up against personal boundaries: 'I understand that this is important for you, but I cannot provide support in this instance'
- when you, as a care giver, are grappling with personal (existential) issues, desperation or fear, or are confronted with your own grief, pain or powerlessness





*Practical factors:*

- when you lack the necessary expertise
- when, at that moment, you cannot provide calm and space yourself

Making a referral for spiritual care begins, in many cases, by coordinating with care givers who have already developed a relationship with the patient. ('Do you hear the same [spiritual] theme that I hear, do you recognise the same care needs?') This could be a spiritual counsellor, the treating physician, a psychologist, a specialised nurse, a nurse specialist or a social worker. It could also be a personal counsellor or the nurse or care worker with primary responsibility for the patient. The spiritual counsellor is a specialist in spiritual care, in terms of primary focus and frame of reference, and can explore the relevant theme or a spiritual care need with the patient and, if appropriate, with those surrounding the patient.

People who are active within a particular religious or wisdom tradition often have a marked preference for accompaniment from within their own tradition. In contrast, people who merely have a background including some connection with such a tradition should not be blindly referred to a spiritual representative of that tradition, as the patient's connection with the tradition may be strained or even broken. In the latter case it is important to learn whether this is experienced as liberating or as a loss. In the case of a strained relation with a religious tradition it can be sensible to arrange for a spiritual counsellor who is not an explicit representative of that (religious) community but who is knowledgeable about it. As desired, the spiritual counsellor can help the patient to discover which values from that tradition are helpful for the palliative patient and which can be a source of inspiration to the patient. Spiritual counsellors are trained to be able to understand each existential concern or question of meaning within the patient's own frame of reference, and to provide support in such a way that they find their own answers.

For spiritual counsellors, the primary focus and frame of reference is spiritual care. In addition, psychosocial techniques and theories have a role in these professionals' work, as spiritual processes always have psychological, emotional and social components. Psychologists and medical social workers work with a primary focus and frame of reference oriented toward the psychosocial dimension of care. This does not exclude spirituality as a significant theme in their counselling; by and large, much skill and experience can be found within both professional disciplines. Whether to refer to the one profession or the other can depend on availability, personal engagement or the subject matter involved in the crisis.

#### Referral to a spiritual counsellor

A spiritual counsellor is a professional who is specialised in spiritual care. Spiritual counsellors are usually (but not always) affiliated with a specific religious or wisdom tradition. By virtue of their profession they are able to provide spiritual care to anyone, regardless of religious conviction or philosophy of life (Beroepsstandaard [Professional standards] 2015, VGVZ).

Presently spiritual counsellors are available mainly in hospitals, in nursing homes and in a number of care homes. Sometimes it is possible to arrange for a spiritual counsellor at home or in a hospice via home care or through specifically established support centres or help lines.

In many cases hospices have practice arrangements with local pastors and spiritual counsellors from local organisations. Many competent, authorised spiritual counsellors who do inpatient work can be found via the Stichting Kwaliteits Register Geestelijk Verzorgers (SKGV, an organisation that monitors the quality of spiritual counsellors by keeping a professional registry). Also, in primary care it is possible to arrange for support from independent spiritual counsellors in private practice; the VGVZ has a web page with an overview.

In line with their professional role, spiritual counsellors may take the initiative to contact patients and those nearest the patient; they are however required to explore whether the patient appreciates such contact. Still, in many cases the contact will arise from the fact that the spiritual counsellor is part of the palliative care team.

In nearly all cases it is preferable for the referring care giver to remain involved in the process. The fact that the care giver has seen or heard the other person so well means that a more profound need for care has been perceived. In and of itself, this may be experienced by the patient as significant, and it says something about the caring relationship that has developed between the two. It is not easy to draw a line between where attention to spirituality is fitting to the role of a nurse or physician and where it becomes the responsibility of a spiritual counsellor. It is necessary for nurses and physicians to keep an eye on their own professional and personal boundaries. When, on the night shift, a patient asks a nurse, 'Would you pray with me?', one nurse may respond with heartfelt or careful consent and another would not know what to say or do. Furthermore, if care givers find themselves in an emotionally challenging situation (for instance if the patient is the same age as the care giver, or has children the same age as the care giver's children) it is a sign of professional competence to make a referral. The important thing is to respond with respect and to remain respectfully present.

#### What may be expected from a spiritual counsellor?

First and foremost, a spiritual counsellor is focused primarily on the other person: the patient or, as desired, those close to the patient. Their questions, story and life view are central, not those of the spiritual counsellor. The spiritual counsellor aims to help the other person to find their own answers. How important it might be that the spiritual counsellor have a Catholic, Protestant, Humanist, Muslim, Hindu or Buddhist background, for example, is primarily up to the patient. In some situations it is important for the spiritual counsellor to speak the same religious/philosophical language and to know the associated rituals and customs. In other situations it can be refreshing to talk with someone who sees things from a different life view. One competency of spiritual counsellors is to mention their own religious/philosophical background only when it benefits the patient.

Secondly, a spiritual counsellor is not focused primarily on a problem that must be solved, but on available sources of strength. Because spirituality is an intrinsic part of a person's being, the spiritual counsellor addresses the whole person. This whole person is seen as a unique human being who can never fully know and understand themselves. In the final analysis, the depths of every human being are a mystery. It is in those deepest layers that life/existential questions and spiritual processes operate. These cannot be directly accessed or manipulated. They can however be 'touched', allowing the patient to re-establish contact with their own sources of meaning, purpose, inspiration and strength.

#### Place in organisational policy

Other care givers can enlist the aid of the spiritual counsellor for the following:

- consultation and advice with regard to questions involving spiritual care and ethics
- training in the areas of spirituality, religion, world view, meaning giving and ethics (moral consultation)
- adaptation of spiritual care for local versions of philosophies of care as well as national protocols and guidelines
- attention to (care for) the care givers, and fulfilling the role of confidential advisor for other care givers
- contribution to good aftercare, for example in the organisation of memorial gatherings or talking with family after a patient's death

- help in seeking solutions at the policy level as well as drawing attention to the existential and spiritual dimension of patients and care givers
- interagency consultation and advice for GPs and home care professionals within the context of local palliative care networks
- participation in the multidisciplinary team meeting for palliative care

#### Referral to a psychologist, social worker or psychiatrist

When an existential crisis lasts more than a few days and is accompanied by serious psychological symptomatology, referral should also be made to a mental health or psychosocial professional. A description of the help provided by psychologists, medical social workers or psychiatrists is beyond the scope of this guideline, but it is important to realise that it can be very helpful when spiritual counsellors, medical social workers and psychologists work together in such a situation. To give an impression of the kind of care for which care givers on a palliative care team must make a referral, we outline here briefly the specialised treatment of an existential crisis.

#### Possible elements of psychological treatment of an existential crisis

##### *in relation to the past:*

- cognitive restructuring, reappraisal
- review of life

##### *in relation to the present:*

- treatment of reversible physical, psychological and social problems
- maintaining personal grooming, dignity and independence
- cognitive therapy: reappraisal of the present situation
- insight-oriented therapy to rediscover meaning in life

##### *in relation to the future:*

- cognitive therapy
- setting attainable short-term goals
- encouragement to talk about fear of death and learning to deal with feelings and emotions (present, past, future)
- encouragement to talk about religious and world view issues, and/or referral for spiritual counselling

### 3.6 How should one respond when a existential/spiritual crisis is suspected?

#### Question

How should one respond when a existential/spiritual crisis is suspected?

Method: consensus-based

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#### Recommendations

- When an existential/spiritual crisis is suspected, make a referral to a spiritual counsellor, social worker or psychologist. The guiding principles are the nature of the problem, the patient's identification and wishes, and availability of support.
  - Assess whether there is a psychiatric component to an existential/spiritual crisis, and where necessary refer to a psychiatrist. Use Griffith's questions for this [2012].
  - In the case of a spiritual crisis, consider people in the person's own faith or support network, such as a pastor, priest, imam, etc.
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#### Literature study

No systematic literature research was done regarding this question, because the working group did not expect to find any studies that provided answers to the question that were relevant to the Dutch context. Therefore, no conclusions are drawn either. The recommendations are based solely on considerations made by the working group members on the basis of their professional experience, and where possible confirmed by a non-systematic review of the literature.

#### Considerations

When an existential or spiritual crisis is suspected, it is important to ascertain who the person can be referred to. In doing so, take into account the nature of the problem and the match between the identification and wishes of the patient on the one hand and the availability of specialist care providers on the other. The preferred disciplines for a referral are spiritual counsellor, medical social worker and psychologist. Where a spiritual counsellor is sought, consider people in the person's own faith or support network such as a pastor, priest, imam, etc.

Because an existential or spiritual crisis involves acute distress, it is possible that a psychiatric component is also involved. If this is suspected, it is important to find out more so that a patient is not undertreated.

To be able to make a good referral it can be helpful to follow the steps of an assessment process, using the following four main questions [Griffith 2012]:

#### 1 Is the suffering due to a normal syndrome of distress or to a psychiatric disorder?

The following seven questions can help build a 'preponderance of evidence' for how a patient's distress ought to be regarded:

- a Did onset of the distress coincide sharply with a stressful life event? If there was no stressful life event, this may be an indication of a psychiatric disorder.
- b Is the intensity of distress proportionate to the severity of the event?  
Standardised instruments for measuring depression and anxiety [e.g. Hamilton or Beck Depression Scales] usually show high scores for depression and anxiety where a psychiatric disorder is present.
- c Does distress remit when the stressful event remits?  
Distress remaining after the stressor is gone may be a sign of a psychiatric disorder.

- d Are there associated symptoms of a psychiatric disorder? Are there associated features of a normal syndrome of distress? The table below can help to distinguish between normal grief, sadness and demoralisation on the one hand and a psychiatric disorder on the other:

Normal grief, sadness, demoralisation	Depressive disorder
Less pronounced symptoms	Pronounced lack of appetite, lack of energy, disturbed sleep pattern, loss of libido, psychomotor disturbances
Less pronounced symptoms	Pronounced feelings of guilt, loss of self-regard, suicidal thoughts
Comes in waves	Permanent and pervasive depressed mood
Wistful quality to melancholy	-
Feeling of not measuring up to one's own or others' expectations	-

- e Are there identifiable biological or psychosocial risk factors for occurrence of a psychiatric disorder?
- f A family history of psychiatric disorders, emotional neglect or abuse in childhood, alcohol or drug abuse, or treatment with mood-destabilising medications (such as glucocorticoids) can increase the risk of a psychiatric disorder.
- g Is there a past history of a psychiatric disorder? If so, has it shown a pattern of relapse and recurrence?
- h Psychiatric disorders usually have their first onset during teenage years or early adulthood. After that recurrences occur periodically during adulthood in approximately half of patients. Past history of a severe episode of depression lasting longer than a couple of weeks heightens the likelihood that the current episode is a recurrent mood disorder.
- i Has there been a robust response to a psychiatric medication in the past?
- j Where this is the case, it may be an indication of a psychiatric disorder.

## 2 Which practitioners can help relieve the distress?

Where psychiatric disorders are present a general practitioner or a specialist in elderly medicine, where necessary in collaboration with a psychologist, will be the first line of support for the patient. In situations where their expertise is not sufficient, a psychiatrist may play a supportive role. In the absence of a psychiatric component to a patient's distress, a spiritual counsellor, social worker or psychologist can provide care and treatment.

## 3 What is the probable effectiveness of spiritual care, psychotherapy or psychopharmacology, given realistic constraints of treatment setting and resources?

Three scenarios are possible when estimating the effectiveness of interventions:

- All three disciplines (spiritual counsellor, social worker and psychologist) are effective and available; it makes little difference which discipline is chosen.
- Given the problem, one of the three disciplines is more effective and/or more available.
- An integrated plan is needed for two or three disciplines to work together.

## 4 Does the patient want to be referred to a professional with a secular or religious background?

The patient's choice should be respected unless this is likely to increase the risk of harm to self or others.

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### 3.7 How do I report spiritual care?

#### Question

How do I report spiritual care?

Method: consensus-based

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#### Recommendations

- Check with the patient what they consent to have reported (because it is important for other care providers to know) and what should remain confidential.
  - Reach an agreement that all disciplines involved report findings and interventions using: the ABC model (attention, accompaniment, crisis intervention), the Mount Vernon Cancer Network cue questions, and the themes and/or the relevant poles in the Ars Moriendi model (see Appendix 9).
  - Refer to the patient's beliefs and cultural background in the care plan and describe their needs with respect to beliefs and life philosophy.
- 

#### Summary of the literature

No systematic literature research was done concerning this question, because the working group did not expect to find any studies that provided answers to the question that were relevant to the Dutch context. Therefore, no conclusions are drawn either. The recommendations are based solely on considerations made by the working group members on the basis of their professional experience, and where possible confirmed by a non-systematic review of the literature.

#### Considerations

The simplest form of reporting can follow the structure of the ABC model, indicating whether any attention has been paid to the dimension of spirituality/meaning giving, relevant accompaniment, or crisis intervention. Discuss with the patient what can and cannot be disclosed to the team.

A more detailed form of reporting could make use of the Mount Vernon Cancer Network questionnaire (Appendix 8) or the Ars Moriendi model (Appendix 9). The latter distinguishes five themes related to autonomy, suffering, saying goodbye, unfinished business and hope. Indicate for each theme the intervention used:

- a observation and detection
- b accompaniment
- c providing information and advice
- d coordination and discussion

Here too it is important to agree with the patient about confidentiality.

To ensure good continuity of (24-hour) care for the palliative patient, it is best if all disciplines involved report their findings and interventions in the patient's record. It is important to avoid a situation where one discipline has carried out existential/spiritual interventions without informing another discipline.

Privacy can be compromised when problems of a spiritual nature arise. By agreeing with the patient beforehand what can and cannot be reported, their privacy can be ensured.

A research project started in January 2018 in which the Ars Moriendi model is being integrated into the Utrecht Symptoom Dagboek (Utrecht Symptom Diary) to create the USD-4D. Once this is available it can also be used for reporting.



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### 3.8 How do I present my observations at a meeting of a multidisciplinary team, a palliative home care group or other collaborative body?

#### Question

How do I present my observations at a meeting of a multidisciplinary team, a palliative home care group or other collaborative body?

Method: consensus-based

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#### Recommendations

- Devote attention to the existential/spiritual dimension in every case.
  - Because each individual care giver may have seen a different layer of meaning when in contact with the patient, consider their observations regarding existential/spiritual matters as significant.
  - Include a spiritual counsellor as a permanent member of the multidisciplinary team, or invite one for the multidisciplinary team meeting, or to join the palliative home care group or other collaborative body.
  - Make use of a clearly defined way of reporting, such as that provided by the MVCN assessment tool or the Ars Moriendi model.
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#### Summary of the literature

No relevant literature was found in which studies were reported of how observations should be presented to a multidisciplinary body.

#### Considerations

Multidisciplinary practice is a means to deliver consistent, high-quality care: together, multiple disciplines spanning all relevant areas provide care and treatment suited to the specific problems of the patient. A variety of professional practitioners may participate in a multidisciplinary team. The composition of the team depends on the problems of the patient. Coordination of treatment and care by various professional practitioners via a multidisciplinary team meeting offers an additional advantage: it makes repetitive documentation of care and treatments unnecessary.

A multidisciplinary team meeting concerns multidisciplinary treatments requiring collaboration and coordination among the disciplines and with the patient and/or the representative of the patient. See also the guide to the multidisciplinary team meeting (in Dutch) from Verenso [professional organisation of elderly care physicians].

The objectives of the multidisciplinary team meeting are:

- periodic evaluation and adjustment of treatments
- coordination of care and treatments among the disciplines involved
- exchange of information about, and with, the patient
- establishment of the strategy and objectives of treatment and care, in consultation with the patient

A valuable by-product of the multidisciplinary team meeting is the sharing of knowledge and learning. This is also true with regard to existential/spiritual matters, which in itself is a reason to discuss them in every case. As we know, attention devoted to existential/spiritual matters means that each individual care giver – depending on their situation and personality – may have seen a different layer of meaning in their contact with the patient, and this can result in differences in observations [Steggerda 2016]. In the hospital, holding a multidisciplinary palliative care meeting is also one of the requirements for invoicing using the palliative care diagnosis-treatment combination.

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In primary care, palliative home care groups ([www.patz.nu](http://www.patz.nu)) are composed of GPs and district nurses who, supported by a palliative care advisor, try to identify at an early stage who will need what kind of palliative care; they also utilise their expertise to provide that palliative care in the home. Where professional spiritual counsellors practise in primary care (whether or not as part of an care facility) collaboration can be sought in the area of spiritual care, for instance by inviting such a professional to a multidisciplinary team meeting or a palliative home care group. A collaborative experiment with a spiritual counsellor in a palliative home care group was shown to result in a reduction of GP burden and an increase in attention devoted to meaning giving as well as more acceptance by the patient of their own situation [Molenaar 2018, Mowat 2012].

The Ars Moriendi model by Leget [2008] (see Appendix 9) offers care professionals a framework for encouraging the patient to talk about their life questions, and for reporting such exchanges.

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Booklet: Handreiking multidisciplinair overleg, Verenso

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## 4 Module 4 Prerequisites

### 4.1 What are the prerequisites for facilitating the provision of existential/spiritual support?

#### Question

What are the prerequisites for facilitating the provision of existential/spiritual support?

Method: consensus-based

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#### Recommendations

##### *Attitude*

- See the patient as a human being who, besides requiring somatic and psychosocial care, may also need support in the area of life/existential questions which are coming up now that the patient is aware of being terminally ill.
- Assume an open, non-judgemental attitude and be alert to both verbal and non-verbal signals.
- Reflect on which questions might come up for you if you were in a terminally ill patient's situation, and what this would be like.
- Familiarise yourself with the cultures, religions and philosophies of life that are most widely represented in your practice setting.

##### *Communication*

- View life/existential questions as questions that both matter and are very normal.
- Arrange for a professional interpreter for the palliative patient who does not speak Dutch fluently, even if the family is willing to interpret.
- Gather information – if necessary, from the family and other near ones – about the patient's value system, existential/spiritual views and beliefs.

##### *Self-care for the care giver*

- Share your experiences as a care giver with a colleague if you notice that you cannot stop thinking about a patient situation, or that it has a big effect on you.
- Take part in peer supervision with other care givers in order to voice your experiences and concerns.
- Arrange for care-giver supervision if you notice that you are losing resilience in your contact with patients.

##### *Training*

- Develop basic skills for providing spiritual care for palliative patients.
- Develop those same skills as a team, department or medical group, and increase recognition by speaking the same language when identifying spiritual needs as when providing spiritual care.
- Take part in training as a team, department or medical group, in order to gain more understanding of spiritual care, and of the specific cultural and religious demographic in your practice.
- Talk to spiritual care specialists – often spiritual counsellors and psychologists – about organising such training.
- Develop basic skills for identifying and reporting spiritual needs. The method 'Dorst of Doodsangst' ('Thirst or Fear of Death', in Dutch) was developed to increase the sensitivity of volunteers in palliative care to signals that may indicate spiritual needs. This method is also suitable for professionals.

##### *Organisation*

- Create space in your region or facility for the discussion about spiritual care in the organisation of care. In many cases this discussion will involve spiritual counsellors and psychologists, for example in a multidisciplinary team meeting.

- See to it that patients and families are aware of the availability of the spiritual counsellor for confidential, non-judgemental support.
  - Create the opportunity for care givers to engage in peer supervision or peer evaluation with regard to the provision of existential/spiritual support.
  - Name the spiritual dimension explicitly, in addition to the somatic, psychological and social dimensions, in strategic and (multi-)year plans, as an essential topic in the provision of palliative care to patients.
  - Devote attention, in the training of care givers, to the recognition of spiritual concerns among patients; provide tools relevant to this task; devote attention to the development of attitudes and communication techniques.
  - Appoint someone as the designated expert (Dutch: aandachtsvelder) on existential/spiritual care to promote understanding and organisation of existential/spiritual care.
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### **Introduction**

Attending to the existential/spiritual dimension and exploring existential/spiritual needs is possible only when a number of essential prerequisites are in place.

### **Summary of the literature**

No systematic literature research was done concerning this question, because the working group did not expect to find any studies that provided answers to the question that were relevant to the Dutch context. The recommendations are based solely on considerations made by the working group members on the basis of their professional experience, and where possible confirmed by a (non-systematic) review of the literature.

### **Considerations**

In the practice setting, the patient encounters certain care givers the most: the care workers, nurses, nurse specialists and the treating physician. Open and thoughtful communication, and an attitude in keeping with this, is essential in such an encounter. Providing good patient care also requires good self-care.

The following factors have a bearing on the ability of a care giver to implement spiritual care:

- a the attitude and frame of reference of the care giver
- b communication about spiritual topics that are on a patient's mind
- c self-care on the part of the care giver
- d training on the spiritual dimension and on providing spiritual care
- e an organisation that provides time and financial means for the above

#### **a Attitude and frame of reference of the care giver**

Patients who hear that they are terminally ill sustain a direct hit to their existence. As death approaches people often become more aware of life itself. Bad news triggers a range of emotions, including sadness, anger, fear and powerlessness, and patients often 'wonder why'. Attentiveness for this process by the care giver, by being alert to verbal and non-verbal signals and by talking about them, can normalise these emotions and create space, both internally and externally, for the patient to find a way to handle them. The care giver should also devote attention to near ones and to those caring for the patient.

This all requires an adjustment in care giver attitude. Sometimes it is necessary to let go of the familiar way and order of going about one's work. Responding to and exploring the experience of patients who have just heard that they are terminally ill requires different skills than does taking a systematic history. Compassion is the virtue required here.

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Care givers need to tune in empathically and open up in order to enter into dialogue. They must themselves have enough (inner) space for this, and also have an eye and an ear for it. They must be prepared to attune to patients and to be there for them; to listen, not to problem-solve, but to talk with these patients about the themes they have been thinking about or struggling with [Selby, 2017]. Patients indicate that a nurse's attitude should be sensitive, human, warm, caring, well informed and involved. Nurses themselves find it important to show respect, to refrain from overstepping someone's personal boundaries and to be non-judgemental about religion and religious views [Leeuwen, van, 2006].

In day-to-day practice patients come from a variety of philosophical and cultural backgrounds, and speaking about illness and death is specific to both culture and life philosophy (see Appendix 11). The care giver must take this diversity into account, and also the frame of reference within which palliative patients experience their situation. When a patient's experience and choices concerning end-of-life care are influenced by a background other than traditional local religion and culture, care givers should consult, in addition to this guideline, sources that provide supplemental information about this patient's cultural context.

The care giver also needs to take into account the various aspects tied to specific life phases and living arrangements. An older married couple whose children have left the home will be facing different questions and problems than a family with young children. A nurse or doctor can recognise diverse aspects in a patient's spiritual functioning, such as: religion or life philosophy (see Appendix 11), life goals, life review, experience and/or emotions. As well, courage, hope, growth, religious customs and practices, relations and social ties, frame of reference and guiding motive can be recognised as some of these aspects. The fact is: care givers do run into life/existential questions, which may also be referred to as questions of meaning or existential questions, in their contact with patients [Geer, J. van de, 2017]. Among patients with a terminal illness, 77 per cent expect their physician to talk with them about spiritual topics. McCord [2004] and Taylor [2003] report that many patients discuss their spiritual needs with nurses because the patients trust their nurses.

Care givers in palliative care need a number of extra competencies when faced with difficult issues such as final goodbyes, the meaning of life, the search for sources of strength, fear, guilt, intimacy, death and the dying process. These topics require the care giver to be open to getting a sense of the patient's needs, being willing to talk about these needs and to engage in discussion about them. This also requires a certain degree of courage, of sensing intuitively whether or not someone is open to this, and the creativity to help someone to put certain thoughts and experiences into words. This must occur regardless of the care giver's own convictions. A prerequisite is that care givers know their own responses to death, serious illness and grief in (their own) life. Especially in the case of these sensitive topics, it is essential to strike a balance between detachment and concern, and care givers should be aware of this. Nurses regard providing strength, encouraging, giving trust, being understanding and the willingness to help as a nursing attitude. Other aspects important to nurses are being open to the whole person, wishing to bear responsibility and showing respect for the integrity of the patient. Employing empathy, being sensitive and listening to what lies behind the words of the patient are also characteristics of a good care giver. Finally, nurses find it important to be aware of the ethical aspects of the patient-nurse relationship [Koslander, 2005]. Questions about life, suffering and dying are seen as spiritual issues. Nurses have a responsibility in carrying out interventions for spiritual needs. People express these needs in diverse ways and forms [Jochemsen, 2002].

## **b Communication**

Talking with palliative patients about the spiritual experience of their situation involves normal life/existential questions. It is essential to assume an attitude of exploration, rather than being directive. It is not the care giver's role to answer patients' life/existential questions – only the patients themselves can do this.

Within the framework of spiritual care, discussion is focused on what it means to the patient to be terminally ill. Issues that may arise include maintaining autonomy or consciously transferring or letting (some of) it go; finding a new equilibrium in the specific situation; exploring sources of strength; or, where necessary, helping to structure the chaos. The objective is to analyse what is going on and thus help patients retain, or where necessary increase, their control.

Arranging for a professional interpreter (on-site, through the Tolkenlinefoon or with a video link) is highly important for palliative patients who speak little or no Dutch. This is true even when family is willing to translate. Patients must be able to speak in confidence with the care giver, including about issues they do not wish to share with family members. Furthermore, experience has shown that family members may translate selectively, for example to soften the patient's or care giver's message or to protect their dear ones from bad news. The use of a professional interpreter ensures both the care giver and the patient of a correct translation, and the patient is able to speak freely. Interpreters can be found via TVcN (Tolk- en Vertaalcentrum Nederland – the Netherlands Centre for Interpretation and Translation).

Active listening is very important in the provision of palliative care. This means being open to verbal as well as non-verbal signals from the patient, who may at times find it difficult to broach delicate issues. Responding to these signals, naming and verifying them with an unconditional and open attitude can be supportive. Feelings surrounding fear of decline, death, loneliness, powerlessness and despair are not always easily put into words, yet they are allowed to be present. It is best to reflect back to the patient what has been heard, without judgement, without assigning value. When patients have a sense of being acknowledged in how they experience the present situation, they feel heard and supported. Care givers with an open attitude, who not only display professional legitimacy but can also show something of themselves in their contact with patients, facilitate communication. Listening without judgement, daring to ask questions and to probe more deeply, exploration of the question behind the patient's question, and the ability to summarise are prerequisites for good communication.

## **c Self-care on the part of the care giver**

Caring for others, and especially caring for palliative patients, is a source of great satisfaction, yet it also requires a great deal of the care giver. Care givers begin this work full of ideals. Work pressures, market forces, a focus on solving concrete problems or realising concrete objectives can eclipse human encounters with the patient. Care givers who do enter into these encounters are sometimes warned, 'Be careful of your boundaries!'

A genuine encounter with the patient can indeed be confronting, such as in the helplessness of not being able to do something about the patient's suffering, and needing to bear it, alone or together. This always presents an appeal to the emotions and experience of the care giver.

Caring for others requires that care givers take good care of themselves, in order to be able to retain their resilience in this intensive work. Acknowledging and making room for their own feelings and emotions is important, through awareness of these processes. An organisation or medical group/department can

provide supervision or peer supervision for this. Other important items they must attend to are watching their own boundaries, receiving and giving feedback, and having clarity about tasks and responsibilities.

Activities supportive to care givers include finding out what relaxes or nourishes them; humour; and curiosity about their own history and resources.

#### **d Training**

There is a need for training and further elaboration on encouraging open discussion of spiritual themes [Schep, 2017]. Care givers should have, or acquire, adequate competencies for providing spiritual support to palliative patients. In the provision of nursing care, the personal spirituality of the nurse plays a significant role in the attention to spiritual aspects. Other factors are age, experience, spiritual commitment, time available, cultural factors and training. The expectations of patients, nurses and spiritual counsellors vary with regard to the role of the nurse in spiritual care. To nurses, presence, listening and demonstrating respect are the most important facets of spiritual care. Lack of training with respect to spirituality is an important reason where nurses do not provide this care on a standard basis [Leeuwen van, 2006].

The goal is for care givers to develop insight into the spiritual experience of patients, to be able to identify spiritual needs, to be able to provide spiritual care (ABC model [Module 3.2], Ars Moriendi model [Appendix 9]) and, where necessary, to be able to make referrals to other practitioners.

Training for care givers can be provided by care givers who are specialised in spiritual care.

#### **e Organisation**

Any organisation wishing to provide high-quality palliative care recognises the importance of good spiritual care. Part of this is creating the necessary conditions for the care givers.

Patients understand – they can see that nurses are busy – that there is little time and attention for talking, but they do believe that time can sometimes be created for it. Nurses confirm that they have little or no time for the patient, and are therefore unable to devote attention to spiritual aspects. They themselves believe it to be a question of priorities. Sometimes ‘not having time’ is used as an excuse, when actually the nurse finds it difficult to talk about spirituality. The commercialisation of health care, the dominance of medical-technical care and the emphasis on evidence-based care all have a negative influence on work floor culture. This has contributed to the impression that the human aspect of care is in danger [Leeuwen van, 2006].

Care workers, nurses, nurse specialists, and physicians should be able to take additional training to explore and discuss the spiritual dimension and also to be able to identify spiritual distress. The organisation should make adequate staff resources and financing available to make this possible.

Practitioners specialised in the spiritual dimension, in many cases spiritual counsellors (the experts), social workers and psychologists, should be given enough staffing capacity for direct and indirect patient care. Examples of indirect patient care include participation in multidisciplinary meetings, deployment for staff expertise development in the organisation, and participation in policy and advisory committees.

The organisation must devote attention to self-care on the part of care givers so that they can retain their psychological resilience.



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# Appendix

# A1 The working group

All members of the working group are representatives of scientific, professional or patient associations and have a mandate from their organisation to contribute. The group was composed taking into account the geographical distribution of those involved, contributions from both teaching and general hospitals/institutions, and representation of the various associations/disciplines.

The following institutions and associations participated in the revision of the guideline:

- Dutch College of General Practitioners (NHG)
- Dutch Association of Elderly Care Physicians and Social Geriatricians (Verenso)
- Dutch Nurses Association (V&VN)
- Palliatief, the Dutch Association for Professional Palliative Care
- Dutch Patients Association (NPV-Care for life)
- Dutch Federation of Cancer Patient Organizations (NFK)
- Netherlands Patients Federation
- National Support Centre for Palliative Terminal Care Volunteers (VPTZ)
- Dutch Association of Psychologists (NIP)
- Dutch Society of Physicians for Pulmonary Diseases and Tuberculosis (NVALT)
- Dutch Association of Spiritual Caregivers (VGVZ)

Members of the working group:

- Cécile van Dierendonck-Ferwerda, expert by experience/patient representative
- Joep van de Geer PhD, healthcare chaplain
- Marie-José Gijssberts MD PhD, elderly care physician
- Anne Goossensen, PhD Professor of informal care and care ethics, University of Humanistic Studies
- Elise van Hoek-Burgerhart, policy and influencing manager
- Hanneke van Laarhoven MD PhD, general internal medicine specialist, clinical oncologist, Professor of Translational Medical Oncology, University of Amsterdam
- Carlo Leget PhD, Professor in Care Ethics and Ethical Questions in Palliative Care, University of Humanistic Studies, Chair of the working group
- Lianne Oortman, psychologist
- Karin Pool MD, pulmonologist
- Bart Schweitzer MD, general practitioner
- Jos Somsen, senior policy advisor
- Jacques Voskuilen, nurse specialist

Support to the working group was provided by:

- Brigitt Borggreve, palliative care advisor (guidelines), IKNL
- Thekla Bluemink-Holkenborg, secretary, IKNL
- Niesje Munneke, secretary, IKNL

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## A2 Declarations of interest

In order to minimise the influence of conflicting interests on the development of the guideline or formulation of the recommendations, the members of the working group were mandated by their respective scientific and professional associations.

All members of the working group signed a declaration of interests statement at the beginning and the end of the guideline development process, in which they state that they acted independently in drawing up the guideline. Potential conflicts of interest were discussed, and the findings were noted in the declaration of interest statement, which can be obtained from [richtlijnen@iknl.nl](mailto:richtlijnen@iknl.nl).

## A3 Methods and methodology

### Background

The first edition of the Spiritual Care Guideline was drawn up in 2010 under the initiative of Agora. In 2015 the PAZORI (Palliative Care Guidelines) platform decided to give priority to revising the Spiritual Care Guideline. PAZORI is composed of mandated members of various professional, scientific and patient associations. The platform advises IKNL on the development, implementation and evaluation of guidelines. PAZORI identifies problems, prioritises guideline topics, and promotes the improvement of guideline methodologies and the integration of palliative care in tumour-specific guidelines. In March 2016 a new working group was formed to undertake the current revision, which was commissioned by the relevant scientific, professional and patient associations (see Appendix 1). The current guideline was finalised by the working group on 31 May 2018 and submitted for authorisation on 4 June 2018.

The guideline working group included care givers from various medical and paramedical disciplines, as well as two patient representatives.

### Approach

The working group met for the first time on 21 March 2016. The members of the working group devised a questionnaire for professionals and patients (or patient representatives) to gather information for a problem analysis. The completed survey, returned by 171 professionals and 103 patients, identified and/or prioritised problems. The most relevant problems identified were used to formulate questions (see Appendix 5).

With the exception of one question, no further systematic literature research was conducted, partly due to the fact that spiritual care may involve experiential processes that are largely unconscious and unseen. Research in this area requires new methodologies, and is still in its infancy in the Dutch context. There is much literature available however, and references are provided in each module.

The working group spent about ten months drafting the guideline text. For the consensus-based modules, the working group members consulted the relevant literature they had gathered. All texts were discussed at plenary meetings, and after the comments had been processed the texts were approved by the working group. The working group advises the owner of this guideline to revise question 3.4, 'What is the effect of interventions for existential/spiritual support on the quality of life of patients receiving palliative care?', after Gijssberts' systematic review of spiritual care in palliative care has been completed. The working group also advises that information on non-verbal communication be enhanced when the guideline is revised.

The guideline was developed in line with the Quality Framework Domain 6 on the spiritual dimension [IKNL 2017].

### Consultation

The draft guideline was submitted on 6 November 2017 for comments to all the scientific, professional and patient associations and the national and regional working groups that had been involved in the problem analysis. This input from the practice setting was intended to improve the quality and relevance of the draft guideline and to generate nationwide support for the guideline. All comments were evaluated and processed by the working group. Those who had provided commentary were informed of action taken on the basis of their contributions. Because the comments resulted in considerable changes in the guideline text and its structure, the guidelines were sent to the authorising organisations for a second brief evaluation.

The content of the guideline was agreed upon on 31 May 2018 and was sent to the relevant associations for authorisation/approval (see Appendix 6: Authorising associations). During the authorisation process, the patient association strongly recommended that information on non-verbal signals and communication be included in the guideline. The working group approved this advice and as a result the guideline was adjusted and submitted to all the relevant associations once again for authorisation. The guideline text was finalised on 30 September 2018.

### **Method development**

Each chapter of the guideline consists of a guideline text. In each section a question is answered using the headings: question and recommendations, literature review, conclusions and considerations. The references are included in each chapter (or section); the evidence tables can be found in Appendix 4. The answers to the questions (the recommendations in this guideline) are, to the extent possible, based on published scientific research.

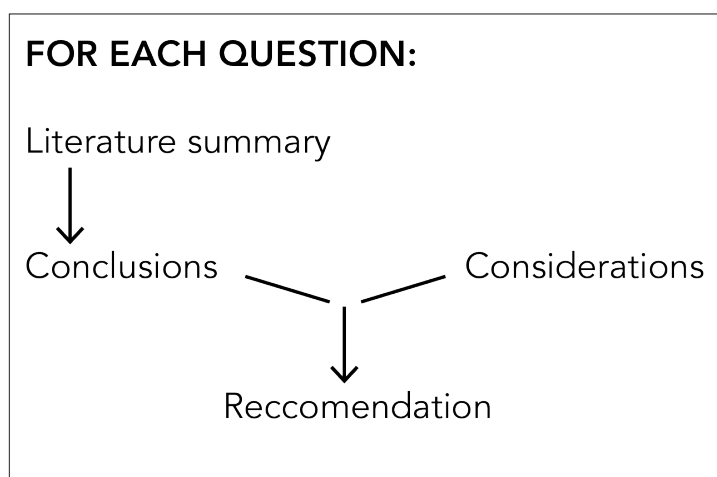
### **Methodology used for the questions for which a systematic literature study**

No systematic literature research was done for any modules except for Module 3.4 (see GRADE methodology), because the working group did not expect to find any studies that provided answers to the question that were relevant to the Dutch context. In addition, no conclusions were mentioned. The texts are based on evidence, but the methodology used in the articles was not evaluated.

The recommendations are based solely on considerations compiled by the working group members on the basis of practical experience, and where possible supported by a (non-systematic) review of the literature.

### **Method used to formulate 'Considerations'**

The considerations are included under a separate heading in the guideline text. In this section the practical context is described and the advantages and disadvantages of the various policy options are evaluated.



In drafting the considerations, the following issues were taken into account:

### **Quality of the evidence**

The higher the overall quality of the evidence, the more likely a strong (positive or negative) recommendation is formulated.

### **Balance of desired and undesired effects**

The greater the difference between the desired and undesired effects, the more likely a strong (positive or negative) recommendation is formulated. The smaller the difference, or the more uncertainty about the size of the difference, the more likely a conditional recommendation.

Explanatory notes:

- Discussion of effectiveness in relation to side effects and complications in the light of the quality of evidence, precision of the size of the effect and perceived minimal clinically relevant advantage.
- Strength of the effect compared to no intervention.
- Presence of comorbidity.
- Clinical irrelevance of the effect.

### **Patients' perspective**

The greater the uniformity of patients' values and preferences in the evaluation of the advantages and disadvantages of an intervention, the more likely a strong (positive or negative) recommendation is formulated.

### **Professional perspective**

The greater the uniformity in professionals' values and preferences concerning the applicability of an intervention, the more likely that a strong (positive or negative) recommendation is formulated.

Explanatory notes:

- Knowledge of and experience with techniques/therapies
- Risks a professional faces when carrying out the intervention
- Expected time savings
- Loss of time as a result of implementing the intervention

*N.B.: the factors below should only be evaluated if a positive recommendation is being considered. A positive recommendation is a recommendation that a particular intervention 'should' take place (strong) or 'might be considered' (weak/conditional). Where this is not the case, a recommendation is termed 'negative'.*

### **Use of resources**

The lower the use of resources (in other words, the lower the costs of an intervention as compared with the alternatives considered and other costs related to the intervention), the more likely that a strong recommendation will be made. The less certainty there is about the claim on resources, the more likely a recommendation will be conditional.

### **Organisation of care**

The more uncertainty about whether the evaluated intervention can feasibly be implemented nationwide, the more likely a recommendation will be conditional.

Explanatory notes:

- The availability/presence of facilities and medicines
- The way in which care is organised/the extent of the change in the organisation of the care process/implementation infrastructure
- Example: specific diagnostic procedures or treatments can only be carried out in certain locations where necessary facilities (e.g. PET scan) are present

### Societal perspective

Legal considerations/ethical considerations/industrial interests/reimbursement by insurers/political and strategic consequences: the less certainty there is on these, the more likely that a conditional recommendation will be made.

Explanatory notes:

Where two treatments are deemed equally effective and one of these is covered by medical insurance, it is possible that the latter will be preferred.

### The GRADE methodology

For submodule 3.4 the evidence-based GRADE methodology was used.

### Selection

In addition to selection on the basis of relevancy, selection was also made on the basis of quality of evidence and strength of recommendations. On this latter basis, the following hierarchy of study design was used:

1. Randomised controlled trials (RCTs)
2. Controlled clinical trials (CCTs)

Where these were not available, comparative cohort research was sought.

### Critical appraisal

Quality of evidence is classified in four categories: high, moderate, low and very low. RCTs start high and observational studies start low. Five factors lower the quality of the evidence (limitations in study design, inconsistency, indirectness, imprecision, publication bias) and three factors can raise the quality of the evidence (strong association, dose-response relationship, plausible [residual] confounding) (See Table 1).

Tabel.1 GRADE methodology for grading evidence

Quality of evidence	Study design	Lower if *	Higher if *
<b>High (4)</b>	<b>Randomised trial</b>	<b>Study limitations</b>	<b>Large effect</b>
<b>Moderate (3)</b>		-1 Serious	+ 1 Large
<b>Low (2)</b>	<b>Observational study</b>	-2 Very serious	+ 2 Very large
<b>Very low (1)</b>		<b>Inconsistency</b>	<b>Dose response</b>
		-1 Serious	+ 1 Evidence of a gradient
		-2 Very serious	<b>All plausible confounding</b>
		<b>Indirectness</b>	+ 1 Would reduce a demonstrated effect, or
		-1 Serious	+ 1 Would suggest a spurious effect when results show no effect
		-2 Very serious	
		<b>Imprecision</b>	
		-1 Serious	
		-2 Very serious	
		<b>Publication bias</b>	
		-1 Likely	
		-2 Very likely	

### Overall quality of evidence

Because the GRADE approach evaluates quality of evidence for each outcome measure, a determination of the overall quality of evidence is necessary. The guideline working group determined which outcome measures were crucial, which important and which not important, both before and after the literature study. In principle, the level of the overall quality of evidence is determined by the crucial outcome measure with



the lowest quality of evidence. However, if there is a difference in the quality of evidence among the various crucial outcome measures, there are two options:

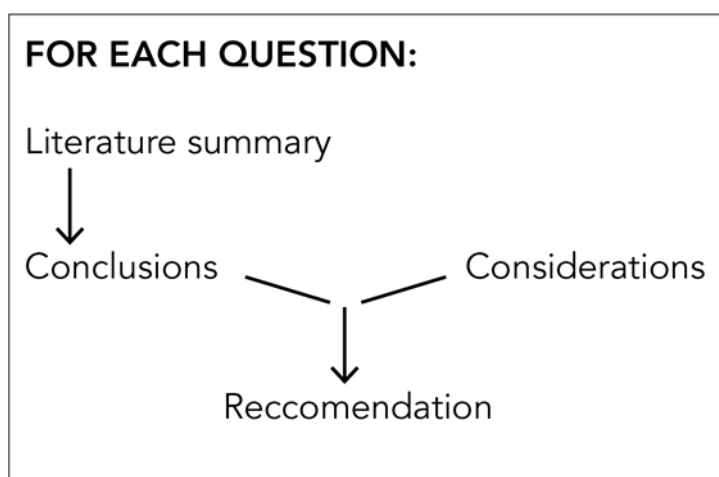
- Where the outcome effects point in different directions (both desired and undesired effects), or where the balance between desired and undesired effects is unclear, the overall quality of evidence is determined by the lowest quality of evidence of the crucial outcome measures.
- Where the outcome effects point in the same direction (all desired or all undesired effects), the overall quality of evidence is determined by the highest quality of evidence of the crucial outcome measure that in and of itself is sufficient to recommend the intervention.

Tabel.2 Formulation of conclusions on the basis of the quality of evidence per outcome measure

Quality of evidence	Interpretation	Formulation of conclusion
<b>High</b>	<b>High confidence</b> that the actual effect lies close to the estimated effect.	There is high-quality evidence that/of... <i>(References)</i>
<b>Moderate</b>	<b>Moderate confidence</b> in the estimate of the effect: the actual effect is likely to be close to the estimate of the effect, but it may diverge substantially	There is moderate-quality evidence that/of... <i>(References)</i>
<b>Low</b>	<b>Limited confidence</b> in the estimate of the effect: the actual effect may diverge substantially from the estimate of the effect.	There is low-quality evidence that/of... <i>(References)</i>
<b>Very low</b>	<b>Little confidence</b> in the estimate of the effect: the true effect is likely to diverge substantially from the estimate of the effect.	There is very low-quality evidence that/of... <i>(References)</i>
<b>Formulation of overall quality of evidence:</b> high/moderate/low/very low		

### Method for formulating 'Considerations'

In addition to the evidence from the literature (conclusions), there are other considerations that are relevant when formulating the recommendations. These are discussed under the heading 'Considerations' in the guideline text. In this section the conclusions (based on the literature) are placed in the context of the practice setting, and the advantages and disadvantages of the different policy options are evaluated. The final recommendation formulated is the result of the conclusion(s) in combination with these considerations.



Figuur 1

From evidence to recommendation

In drafting the considerations, the following issues were taken into account:

#### Quality of the evidence

The higher the quality of the evidence, the more likely a strong (positive or negative) recommendation is formulated.

#### Balance between desired and undesired effects

The greater the difference between the desired and undesired effects, the more likely a strong (positive or negative) recommendation is formulated. The smaller the difference, or the more uncertainty about the size of the difference, the more likely a conditional recommendation.

Explanatory notes:

- Discussion of effectiveness in relation to side effects and complications in the light of the quality of evidence, precision of the size of the effect and perceived minimal clinically relevant advantage
- Strength of the effect compared to no intervention
- Presence of comorbidity
- Clinical irrelevance of the effect

#### Patients' perspective

The greater the uniformity of patients' values and preferences in the evaluation of the advantages and disadvantages of an intervention, the more likely a strong (positive or negative) recommendation is formulated.

#### Professional perspective

The greater the uniformity in professionals' values and preferences concerning the applicability of an intervention, the more likely that a strong (positive or negative) recommendation would be formulated.

Explanatory notes:

- Knowledge of and experience with techniques/therapies
- Risks a professional faces when carrying out the intervention
- Expected time savings
- Loss of time as a result of implementing the intervention

*N.B.: the factors below should only be evaluated if a positive recommendation is being considered. A positive recommendation is a recommendation that a particular intervention 'should' take place (strong) or 'might be considered' (weak/conditional). Where this is not the case, a recommendation is termed 'negative'.*

### **Use of resources**

The lower the use of resources (in other words, the lower the costs of an intervention as compared with the alternatives considered and other costs related to the intervention), the more likely that a strong recommendation will be made. The less certainty there is about the claim on resources, the more likely a recommendation will be conditional.

### **Organisation of care**

The more uncertainty about whether the evaluated intervention can feasibly be implemented nationwide, the more likely a recommendation will be conditional.

Explanatory notes:

- The availability/presence of facilities and medicines
- The way in which care is organised/extent of the change in the organisation of the care process/implementation infrastructure
- Example: specific diagnostic procedures or treatments can only be carried out in certain locations where necessary facilities (e.g. PET scan) are present

### **Societal perspective**

Legal considerations/ethical considerations/industrial interests/insurance reimbursement/political and strategic consequences: the less certainty there is on these, the more likely that a conditional recommendation will be made.

Explanatory notes:

- Where two treatments are deemed equally effective and one of them is covered by medical insurance, it is possible that the latter will be preferred.

### **Method for formulating recommendations**

GRADE incorporates two kinds of recommendations: strong recommendations and conditional (weak) recommendations. The strength of a recommendation reflects the degree of confidence for the desired effects outweighing the undesired effects for the target patient group.

Formulation:

- Strong recommendations: ... should be given/done
- Weak/conditional recommendations: Consider giving/doing...

### **Funding**

The compilation of this guideline was funded by IKNL. The funding body has had no influence over the content of this module.

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### **Process management and responsibility**

IKNL (Netherlands Comprehensive Cancer Organisation) is the knowledge and quality institute for professionals and managers in oncological and palliative care. IKNL develops multidisciplinary guidelines for palliative care. In addition to revising guidelines, IKNL also facilitates the implementation and evaluation of these guidelines. Our aim is the best care for every patient.

IKNL safeguards the quality of evidence-based guidelines (their development, revision, implementation and evaluation) by observing the criteria outlined in the AQUA Quality Standard Guidelines [2014] and the Medical specialist guidelines 2.0.

### **Updating**

The guideline was approved on 30 September 2018 and are valid for a maximum of 5 years. The associations involved and the multidisciplinary working group monitor the extent to which this and other parts of the guideline are still applicable. If necessary, certain parts (modules) of the guideline may be revised.

### **Ownership/Responsibility**

The party responsible for the guideline modules must be able to demonstrate that the modules were formulated with care and the required expertise. The responsible party is defined as the authorising professional association(s) for the module(s) in question. IKNL is responsible for the disclosure and management of the guideline and all modules included.

### **Legal implications of guidelines**

Guidelines consist of recommendations of a general nature. It is possible that these recommendations do not apply in a particular case. Certain facts or circumstances may make it preferable, in terms of interests of the patient, to deviate from the guideline.

In cases where the guideline is not observed the reasons must be documented. Practical implementation of the guideline is the responsibility of the treating physician.

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## A4 Evidence tables

**QUESTION 3.4: What is the effect of interventions for existential/spiritual support on the quality of life of patients receiving palliative care?**

Study ID	Method	Patient characteristics	Intervention(s)	Results	Critical appraisal of review quality
Candy B 2012	<ul style="list-style-type: none"> <li>SR</li> <li>Funding/Col: Marie Curie Palliative Care Research Unit, London, UK; Royal Free and University College Medical School, London, UK; no Col</li> <li>Search date: Nov 2011</li> <li>Databases: CENTRAL, Medline, PsycInfo, Embase, AMED, Cinahl, NHS research register, ATLA Religion database, ASSIA, Anthropology Plus, Social Services Abstracts, Sociological Abstracts</li> <li>Study designs: RCTs, quasi-RCTs, controlled before and after studies and interrupted time series studies</li> <li>N included studies: 5 RCTs</li> </ul>	<ul style="list-style-type: none"> <li>Eligibility criteria: Participants were aged 16 and over, of either sex and:               <ol style="list-style-type: none"> <li>were in the terminal phase of a chronic and progressive life-threatening disease including but not limited to cancers (terminal defined as an estimated life expectancy of less than a year); or 2. had a life-threatening disease with poor prognosis, such as advanced heart failure or dementia, and were receiving palliative care. Participants may or may not have held, or practised, any type of religious or spiritual belief</li> </ol> </li> <li>Patient characteristics:               <ul style="list-style-type: none"> <li>Mean age: 42-74y</li> </ul> </li> </ul>	Spiritual interventions: <ul style="list-style-type: none"> <li>Meditation: Downey 2009, Williams 2005</li> <li>Multidisciplinary palliative care team interventions: Brumley 2007, Gade 2008, Rabow 2004</li> </ul>	See below for individual studies, no meta-analysis performed	<ul style="list-style-type: none"> <li>High-quality review</li> <li>Included RCTs: Downey 2009, Williams 2005, Brumley 2007, Gade 2008, Rabow 2004</li> </ul>

Study ID	Method	Patient characteristics	Intervention(s)	Results	Critical appraisal of review quality
Martinez M 2016	<ul style="list-style-type: none"> <li>SR</li> <li>Funding/Col: no financial support, no Col</li> <li>Search date: Jan 2002 – Jan 2016</li> <li>Databases: PubMed, Cinahl, Cochrane Library, PsycInfo; experts; references</li> <li>Study designs: all</li> <li>N included studies: 28, of which 5 RCTs</li> </ul>	<ul style="list-style-type: none"> <li>Eligibility criteria: patients with advanced life-threatening diseases</li> </ul>	Dignity therapy	See below for individual studies, no meta-analysis performed	<ul style="list-style-type: none"> <li>Review of low quality: broad search, but search strategy unclear, unclear methods for quality appraisal, quality of evidence not taken into account in conclusions</li> <li>Included RCTs: Chochinov 2011, Hall 2011, Hall 2012, Juliao 2013 &amp; 2014 &amp; 2015, Rudilla 2016</li> </ul>
Piderman KM 2015	<ul style="list-style-type: none"> <li>SR</li> <li>Funding/Col: one author received a grant through the Mayo Clinic Cancer Center</li> <li>Search date: Jan 2013 – Jun 2014</li> <li>Databases: Medline, CDSR, Cinahl</li> <li>Study designs: all</li> <li>N included studies: 22, of which 3 RCTs</li> </ul>	<ul style="list-style-type: none"> <li>Eligibility criteria: patients with metastatic cancer</li> </ul>	Interventions to improve spiritual well-being	See below for individual studies, no meta-analysis performed	<ul style="list-style-type: none"> <li>Review of low quality: broad enough search, but simple search strategy, no clear methods for quality appraisal, quality of evidence not taken into account in conclusions</li> <li>Included RCTs: Zimmerman 2014, Piderman 2014, Lloyd-Williams 2013</li> </ul>

## Primaire studies

Study ID	Method	Patient characteristics	Interventions	Results	Critical appraisal of study quality
Chochinov HM 2011	<ul style="list-style-type: none"> <li>Design: RCT</li> <li>Funding/Col: funded by the National Cancer Institute, National Institutes of Health (grant number R01CA102201); the first</li> </ul>	<ul style="list-style-type: none"> <li>Eligibility criteria: patients with terminal prognosis with a life expectancy of 6 months or less, according to their treating physician; receiving palliative care in a hospital or community setting</li> </ul>	<u>Dignity therapy</u> (N=165 randomized, N=108 analyzed): individualised, short-term psychotherapy provided by a psychologist, psychiatrist, or	<u>Quality of life</u> : CRITICAL OUTCOME Two-item Quality of Life Scale (score 1-10): <ul style="list-style-type: none"> <li>Rating: baseline 6.48 vs. 6.27 vs. 6.29, at study completion 6.39 vs. 6.34 vs. 6.64; NS</li> <li>Satisfaction: 6.34 vs. 6.10 vs. 5.83, at study completion 6.04 vs. 6.05 vs. 6.05; NS</li> </ul>	Level of evidence: high risk of bias (subjective outcomes) <ul style="list-style-type: none"> <li>No blinding</li> <li>Incomplete outcome data (no ITT analysis)</li> </ul>

Study ID	Method	Patient characteristics	Intervention(s)	Results	Critical appraisal of review quality
	<p>author is a Canada Research Chair in Palliative Care, funded by the Canadian Institutes for Health Research; no Col</p> <ul style="list-style-type: none"> <li>• Setting: multicentre trial</li> <li>• Sample size: N=441 (randomized)</li> <li>• Duration: recruitment Apr 2005 – Oct 2008; duration of intervention unclear</li> </ul>	<p>(hospice or home) through an affiliated recruitment site in Canada, USA, and Australia; aged 18 years or older; willing to commit to three or four contacts over about 7–10 days; able and willing to provide written informed consent. Patients were excluded if they were delirious or otherwise cognitively impaired (based on clinical consensus and post-randomisation Blessed Orientation Memory Concentration test), 8 too ill to complete the requirements of the protocol, or unable to speak and read English</p> <ul style="list-style-type: none"> <li>• <i>A priori</i> patient characteristics: intervention vs. control <ul style="list-style-type: none"> <li>○ Mean age: 64.2 vs. 66.7 vs. 64.3y</li> <li>○ Male : 52% vs. 45% vs. 51%</li> <li>○ Catholic: 29% vs. 23% vs. 27%</li> </ul> </li> </ul>	<p>experienced palliative-care nurse</p> <p><u>Standard palliative care</u> (N=140 randomized, N=111 analyzed): palliative-care-support services that were available to all study patients, including specialist palliative-care physicians and nurses (ie, experts in the management of pain and symptoms), social workers, chaplains, and psychologists or psychiatrists</p> <p><u>Client-centered care</u> (N=136 randomized, N=107 analyzed): supportive psychotherapeutic approach, in which the research nurse therapist guides the patient through discussions that focus on here-and-now issues</p>	<p>Other outcomes:</p> <p><b>Distress</b> (Patient Dignity Inventory, 25 items, score 1-5): no significant differences</p> <p><b>Structured Interview for Symptoms and Concerns</b> (7 items, score 0-6): no significant differences</p> <p><b>Edmonton Symptom Assessment Scale</b> (8 items, score 1-10): no significant differences</p> <p><b>Functional Assessment of Chronic Illness Therapy</b> (FACIT): no significant differences</p> <p><b>Hospital Anxiety and Depression Scale</b> (HADS): no significant differences</p>	
Downey L 2009	<ul style="list-style-type: none"> <li>• Design: RCT</li> <li>• Funding/Col: Financial support from the National Institutes of Health/National Cancer Institute (grant #5R01-CA106204) and the Lotte &amp; John Hecht Memorial Foundation; Col not reported</li> </ul>	<ul style="list-style-type: none"> <li>• Eligibility criteria: hospice or palliative care patients living in the Seattle, Washington, metropolitan area, who spoke English, were at least 18 years old, were mentally capable of providing reliable responses during a 60-90 minute baseline interview were expected to survive for at least 3 weeks after enrollment, and agreed to</li> </ul>	<p>In all three study arms treatment would last for 35 minutes, but the visit could include up to 10 additional minutes for introductions, information exchange, and paperwork</p> <p><u>Meditation</u> (N=56): Washington-State-licensed naturopathic physicians;</p>	<p><u>Quality of life</u>: CRITICAL OUTCOME Single item (score 0-10), measured at 10w</p> <ul style="list-style-type: none"> <li>• Each of the treatment groups, considered individually, experienced overall decline in the proportion with good-quality life</li> <li>• Linear regression models with adjustment for covariates showed no significant effects of either massage or meditation, when compared with friendly visits</li> <li>• Patient's mean actual QOL rating: adjusted differences from friendly visit -0.269 and -0.146</li> </ul>	<p>Level of evidence: high risk of bias</p> <ul style="list-style-type: none"> <li>• Unclear randomization process and allocation concealment</li> <li>• No blinding</li> <li>• Unclear ITT analysis</li> </ul>



Study ID	Method	Patient characteristics	Intervention(s)	Results	Critical appraisal of review quality
	<ul style="list-style-type: none"> <li>Setting: Seattle-area hospice organizations, cancer and AIDS clinics, physicians' offices, and cancer support groups</li> <li>Sample size: N=167 (randomized)</li> <li>Duration: unclear; follow-up of 9 weeks</li> </ul>	<p>accept assignment to any of the three treatment conditions</p> <ul style="list-style-type: none"> <li><i>A priori</i> patient characteristics: intervention vs. control <ul style="list-style-type: none"> <li>Mean age: 72 vs. 68 vs. 69y</li> <li>Male: 36% vs. 30% vs. 44%</li> </ul> </li> </ul>	<p>meditation providers were to lead the patient in progressive muscle relaxation, mindfulness-based meditation, and guided imagery/visualization</p> <p><u>Massage</u> (N=56): Washington-state-licensed massage therapists; light back-and-neck massage in a position of the patient's choosing, followed by effleurage and goodbye holding. Depending on need, they could spend some time focusing on areas of particular tension or stress</p> <p><u>Friendly visit</u> (N=55): Friendly visitors could spend the allotted time with the patient (e.g., reading to them, engaging in conversation, writing letters, doing light chores, running errands, or just spending time with them); alternatively, they could provide respite or other assistance to caregivers without directly interacting with the patient</p>	<ul style="list-style-type: none"> <li>Patient's expected weeks of good QOL: adjusted differences from friendly visit -0.135 and +0.120</li> <li>Quality of last 7 days of life: adjusted differences from friendly visit +0.515 and +0.546</li> </ul> <p><u>Other outcomes:</u> <b>Pain distress</b> (score 0-5)</p> <ul style="list-style-type: none"> <li>Each of the treatment groups, considered individually, experienced overall decline in the proportion with low pain distress</li> <li>Linear regression models with adjustment for covariates showed no significant effects of either massage or meditation, when compared with friendly visits</li> <li>Patient's expected weeks with low pain distress: adjusted differences from friendly visit -0.036 and +0.179</li> </ul>	
Hall S 2011	<ul style="list-style-type: none"> <li>Design: RCT</li> </ul>	<ul style="list-style-type: none"> <li>Eligibility criteria: patients with advanced cancer aged 18 years or more; excluded: if the palliative</li> </ul>	<p><u>Dignity therapy</u> (N=22 randomized, N=12 analysed at 1w, 8 at 4w):</p>	<p><u>Quality of life:</u> CRITICAL OUTCOME <b>EQ-5D</b></p>	<p>Level of evidence: high risk of bias</p>

Study ID	Method	Patient characteristics	Intervention(s)	Results	Critical appraisal of review quality
	<ul style="list-style-type: none"> <li>Funding/Col: supported by a grant from Dimbleby Cancer Care; no other Col</li> <li>Setting: hospital-based palliative care teams, NHS, UK</li> <li>Sample size: N=45 (randomized)</li> <li>Duration: recruitment Apr 2009 – Jun 2010; 4w follow-up</li> </ul>	<p>care team felt they were unable to take part in a protocol lasting 2 weeks, they were unable to provide informed consent (due to cognitive problems or the severity of their illness) or they were unable to understand English, patients with moderate or severe cognitive impairment</p> <ul style="list-style-type: none"> <li><i>A priori</i> patient characteristics: intervention vs. control <ul style="list-style-type: none"> <li>Mean age: 64.9 vs. 65.3y</li> <li>Male: 41% vs. 57%</li> </ul> </li> </ul>	<p>psychotherapeutic protocol proposed by Chochinov et al.</p> <p><u>Control group</u> (N=23 randomized, N=15 analysed at 1w, 10 at 4w): standard palliative care</p>	<ul style="list-style-type: none"> <li>1w MD=0.10 (95%CI -0.30 to 0.09), effect size = 0.05; 4w MD=0.01 (95%CI -0.35 to 0.37), effect size = 0.00</li> </ul> <p><b>Two 10-point Likert scales assessing current quality of life and satisfaction with quality of life</b></p> <ul style="list-style-type: none"> <li>1w MD=1.56 (95%CI -4.47 to 1.35), effect size = 0.05; 4w MD=0.83 (95%CI -2.96 to 4.61), effect size = 0.01</li> </ul> <p><u>Other outcomes:</u></p> <p><b>Dignity-related stress</b> (Patient Dignity Inventory):</p> <ul style="list-style-type: none"> <li>1w MD=1.21 (95%CI -8.22 to 5.79), effect size = 0.01; 4w MD=2.29 (95%CI -10.11 to 14.68), effect size = 0.01</li> </ul> <p><b>Hope</b> (Herth Hope Index):</p> <ul style="list-style-type: none"> <li>1w MD=2.55 (95%CI -4.73 to -0.36), effect size = 0.20; 4w MD=2.50 (95%CI -5.78 to 0.78), effect size = 0.15</li> </ul> <p><b>Psychological stress</b> (HADS):</p> <ul style="list-style-type: none"> <li>Anxiety: 1w MD=0.39 (95%CI -3.22 to 2.45), effect size = 0.00; 4w MD=0.08 (95%CI -5.21 to 5.04), effect size = 0.00</li> <li>Depression: 1w MD=0.48 (95%CI -2.55 to 1.59), effect size = 0.01; 4w MD=0.59 (95%CI -3.97 to 5.15), effect size = 0.01</li> </ul>	<ul style="list-style-type: none"> <li>Open-label</li> <li>Incomplete outcome data (no ITT analysis, many lost-to-follow-up)</li> </ul>
Rudilla D 2016	<ul style="list-style-type: none"> <li>Design: quasi-RCT</li> <li>Funding/Col: not reported</li> <li>Setting: home care unit, university centre, Spain</li> <li>Sample size: N=75 (randomized)</li> </ul>	<ul style="list-style-type: none"> <li>Eligibility criteria: adult patients with advanced/terminal illness receiving palliative treatment, with knowledge of their diagnosis and prognosis and patients with an interest in dignity. The exclusion</li> </ul>	<p><u>Dignity therapy</u> (N=37 randomized, N=35 analysed): psychotherapeutic protocol proposed by Chochinov et al.</p>	<p><u>Quality of life:</u> CRITICAL OUTCOME Two items of the EORTC-QLQ-C30 Effect size = 0.02, p=0.919 (MD = -0.03)</p> <p><u>Other outcomes:</u></p>	<p>Level of evidence: high risk of bias</p> <ul style="list-style-type: none"> <li>Pseudorandomisation, no allocation concealment</li> <li>No blinding</li> </ul>

Study ID	Method	Patient characteristics	Intervention(s)	Results	Critical appraisal of review quality
	<ul style="list-style-type: none"> <li>Duration: 3 months</li> </ul>	<p>criteria were: (1) less than two weeks of predicted survival; (2) evidence of a conspiracy of silence; and (3) cognitive impairment (comprehension/ expression problems)</p> <ul style="list-style-type: none"> <li><i>A priori</i> patient characteristics: intervention vs. control <ul style="list-style-type: none"> <li>Male: 57% vs. 63%</li> </ul> </li> </ul>	<p><u>Counselling therapy</u> (N=38 randomized, N=35 analysed): based on the guidelines for counseling proposed by Arranz et al.</p>	<p><b>Patients' sense of dignity</b> (Patient Dignity Inventory):</p> <ul style="list-style-type: none"> <li>Symptom distress: effect size = 0.37, p=0.13</li> <li>Existential distress: effect size = 0.34, p=0.16</li> <li>Dependency: effect size = 0.05, p=0.81</li> <li>Peace of mind: effect size = 0.40, p=0.10</li> <li>Social support: effect size = 0.03, p=0.88</li> </ul> <p><b>Hospital Anxiety and Depression Scale</b> (HADS):</p> <ul style="list-style-type: none"> <li>Anxiety: effect size = 0.56, p=0.02</li> <li>Depression: effect size = 0.14, p=0.54</li> </ul> <p><b>Resilience</b> (Brief Resilient Coping Scale): Effect size = 0.17, p=0.48</p> <p><b>Spirituality</b> (GES questionnaire):</p> <ul style="list-style-type: none"> <li>Intrapersonal spirituality: effect size = 0.32, p=0.19</li> <li>Interpersonal spirituality: effect size = 0.20, p=0.40</li> <li>Transpersonal spirituality: effect size = 0.35, p=0.15</li> </ul> <p><b>Social support</b> (Duke–UNC-11 Functional Social Support Questionnaire):</p> <ul style="list-style-type: none"> <li>Confidential support: effect size = 0.14, p=0.56</li> <li>Affective support: effect size = 0.32, p=0.18</li> </ul>	<ul style="list-style-type: none"> <li>Incomplete outcome data (no ITT analysis)</li> </ul>
Vermandere 2016	<ul style="list-style-type: none"> <li>Design: cluster RCT</li> <li>Funding/Col: supported by the Vlaamse Liga tegen Kanker and the Constant Van de Wiel Fund for General Practice (KU Leuven); no other Col</li> </ul>	<ul style="list-style-type: none"> <li>Eligibility criteria: Dutch-speaking patients suffering from a progressive, life-threatening disease, at least 18y old, aware of the palliative diagnosis; patients whose prognosis was estimated (by their treating physician) to be less than 2 months were excluded</li> </ul>	<p><u>Spiritual history taking</u> (N=25): spiritual history taking on the basis of the ars moriendi model</p> <p><u>Usual care</u> (N=24)</p>	<p><b>Quality of life: CRITICAL OUTCOME EORTC QLQ-C15-PAL</b></p> <p>No significant difference:</p> <p>Total score: evolution difference mean 1.07 (95%CI -1.77 to 3.91; p=0.45)</p> <p>Global score: evolution difference mean 0.32 (95%CI -0.57 to 1.21; p=0.47)</p>	<p>Level of evidence: high risk of bias</p> <ul style="list-style-type: none"> <li>Unclear allocation concealment</li> <li>No blinding</li> <li>3 exclusions in each group, no ITT analysis</li> </ul>

Study ID	Method	Patient characteristics	Intervention(s)	Results	Critical appraisal of review quality
	<ul style="list-style-type: none"> <li>Setting: 18 regional nursing offices, Belgium</li> <li>Sample size: N=49 patient-provider dyads that completed the study</li> <li>Duration: inclusion Apr 2013 – Oct 2013</li> </ul>	<ul style="list-style-type: none"> <li><i>A priori</i> patient characteristics: intervention vs. control <ul style="list-style-type: none"> <li>Mean age: 71.9 vs. 72.0y</li> <li>Male: 54% vs. 37%</li> </ul> </li> </ul>	at least one routine home visit between pre- and post-measurements	<p><b>Other outcomes:</b></p> <p><b>Spiritual well-being</b> (FACIT-Sp-12): No significant difference: Evolution difference mean -0.21 (95%CI -3.18 to 2.76; p=0.89)</p> <p><b>Pain</b> (4-point verbal rating scale): No significant difference: Evolution difference mean 0.14 (95%CI -0.33 to 0.61; p=0.55)</p> <p><b>Patient-provider trust</b> (HCRTS): No significant difference: Evolution difference mean -0.37 (95%CI -3.45 to 2.70; p=0.81)</p>	
Williams 2005	<ul style="list-style-type: none"> <li>Design: RCT</li> <li>Funding/Col: The National Institute for Nursing Research, National Institute of Health provided funding for this study through grant NR08093-02. This project is affiliated with the Yale Center for Interdisciplinary Research on AIDS, which is supported by a grant from the National Institute of Mental Health (P30 MH62294); other Col not reported</li> <li>Setting: 40-bed nonprofit, skilled nursing facility dedicated to HIV/AIDS care, US</li> <li>Sample size: N=58</li> </ul>	<ul style="list-style-type: none"> <li>Eligibility criteria: patients with age 18 years or older, a diagnosis of AIDS as defined by the CDC HIV Classification System, in residence at Leeway for a minimum of 1 month (to allow for stabilization of medications and equilibration to the environment), and a life expectancy of at least 2 months; at least one of the following: (1) CD4 T-cell count less than 200 cells/mm<sup>3</sup>; (2) viral load greater than 100,000 copies per milliliter; (3) comorbid diagnosis of cancer, cirrhosis/liver failure, severe congestive heart failure, severe chronic obstructive pulmonary disease, end-stage renal failure; exclusion if cognitive impairment or decompensated mental illness</li> </ul>	<p><u>Meditation</u> (N=13): 90-minute introductory group class on the basic principles of Metta meditation conducted by a meditation teacher; meditation exercise at least once daily for 4 weeks</p> <p><u>Massage</u> (N=16): 30-minute massage, 5 days out of each week throughout the 4-week intervention period</p> <p><u>Meditation + massage</u> (N=13)</p> <p><u>Standard care</u> (N=16): comprehensive assessments by a</p>	<p><b>Quality of life: CRITICAL OUTCOME</b></p> <p><b>15-item Missoula-VITAS Quality of Life Index (MVQOLI)</b> Total score at 8w, change from baseline: Meditation -0.18, massage +0.33, combination +3.75, standard care -0.56; significant difference between combination group and the 3 other groups</p> <p>No significant (p&gt;0.05) change in scores from baseline was seen in any of the five dimensions or the total score at 8 and 68 weeks for the meditation only, massage only, and control groups</p> <p>Significant improvements from baseline were seen in transcendent (+5.92) and function (+19.08) at 8 weeks for the combined meditation and massage group. The combined group improvements were significantly different from the decline in scores seen in standard care</p>	<p>Level of evidence: high risk of bias</p> <ul style="list-style-type: none"> <li>No blinding of participants</li> <li>Otherwise good study</li> </ul>

Study ID	Method	Patient characteristics	Intervention(s)	Results	Critical appraisal of review quality
	<ul style="list-style-type: none"> <li>Duration: Nov 2001 – Sep 2003</li> </ul>	<ul style="list-style-type: none"> <li><i>A priori</i> patient characteristics: intervention vs. control <ul style="list-style-type: none"> <li>Mean age: 45 vs. 43 vs. 47 vs. 46y</li> <li>Male: 54% vs. 50% vs. 69% vs. 63%</li> </ul> </li> </ul>	<p>multidisciplinary health care team consisting of representatives from medicine, nursing, social services, dietary, and recreation departments</p>	<p>(transcendent: -4.13, function: -5.00), massage only (transcendent: -3.69, function: +1.44), as well as the meditation only group for the transcendent score (-3.62)</p>	
Xiao 2013	<ul style="list-style-type: none"> <li>Design: RCT</li> <li>Funding/Col: none to declare</li> <li>Setting: home-based hospice, China</li> <li>Sample size: N=80</li> <li>Duration: unclear</li> </ul>	<ul style="list-style-type: none"> <li>Eligibility criteria: patients (1) being newly admitted to the study hospice; (2) being diagnosed with advanced cancer by a physician; (3) awareness of their diagnosis, prognosis, and therapy; (4) being an adult (at least 18 years old); and (5) having no cognitive or verbal communication impairments. The exclusion criteria were being severely disabled and having a disease that was expected to progress rapidly (Karnofsky Performance Status &lt;40%)</li> <li><i>A priori</i> patient characteristics: intervention vs. control <ul style="list-style-type: none"> <li>Mean age: 59.8 vs. 58.5y</li> <li>Male: 55% vs. 50%</li> <li>Religion: 70% vs. 75%</li> </ul> </li> </ul>	<p><u>Life review program</u> (N=40): Same as routine care, + life review program: reviewing a life (3 sessions) and formulating a life review booklet; individually conducted, registered nurse as facilitator</p> <p><u>Routine care</u> (N=40): home visits and weekly telephone follow-up, focusing on physical symptom management, medical consultations, and health education, whereas psychospiritual support was spontaneous</p>	<p><u>Quality of life: CRITICAL OUTCOME</u>  <b>Overall QOL (single-item scale 0-10)</b>  Significant differences in within-group (F = 32.881, p=0.000), between-group (F = 52.615, p=0.000), and interaction effects (F = 40.555, p=0.000)</p> <p><u>Other outcomes:</u>  <b>QOL concerns (adopted Quality-of-Life Concerns in the End-of-Life Questionnaire, 28 items)</b>  Physical discomfort:  Within-group effect was significant (F = 35.185, p=0.000), but between-group (F = 2.254, p=0.137) and interaction effects (F = 0.518, p=0.596) were not</p> <p>Food-related concerns:  Significant difference in within-group effect (F = 22.650, p=0.000), but none in between-group (F = 3.936, p=0.051) and interaction effects (F = 0.236, p=0.790)</p> <p>Healthcare concerns:  Significant differences in within-group (F = 5.561, p=0.005) and between-group effects (F = 4.766, p=0.032), but not in interaction effect (F = 1.305, p=0.274)</p> <p>Support:</p>	<p>Level of evidence: high risk of bias</p> <ul style="list-style-type: none"> <li>Unclear if adequate randomization process and allocation concealment</li> <li>No blinding</li> </ul>

Study ID	Method	Patient characteristics	Intervention(s)	Results	Critical appraisal of review quality
				<p>Significant differences in interaction effect (F = 6.330, p=0.003), but not in within-group (F = 2.850, p=0.067) and between-group effects (F = 2.707, p=0.104)</p> <p>Negative emotions: Significant differences in within-group (F = 9.987, p=0.000), between-group (F = 8.683, p=0.004), and interaction effects (F = 20.033, p=0.000)</p> <p>Sense of alienation: Significant differences in between-group (F = 9.191, p=0.003) and interaction effects (F = 9.118, p=0.000), but none in within-group effect (F = 0.704, p=0.484)</p> <p>Existential distress: Significant differences in within-group (F = 21.243, p=0.000), between-group (F = 14.301, p=0.000), and interaction effects (F = 17.447, p=0.000)</p> <p>Value of life: Significant differences in within-group (F = 9.344, p=0.000), between-group (F = 68.218, p=0.000), and interaction effects (F = 117.227, p=0.000)</p>	

Abbreviations: 95%CI: 95% confidence interval; Col: conflicts of interest; MA: meta-analysis; MD: mean difference; NS: not significant; QOL: quality of life; RCT: randomized controlled trial; SR: systematic review.



# A5 Problem inventory and questions

## Problem inventory

The results of the problem inventory (in Dutch) can be found by clicking on the links below:

- Results of the problem inventory professionals Zingeving en spiritualiteit
- Results of the problem inventory patients Zingeving en spiritualiteit

## Questions

Module	Methodology	Question
1.1	CB	When is attention to existential/spiritual matters called for?
1.2	CB	How do I recognise and identify questions and/or needs concerning existential/spiritual matters?
2.1	EB	How does an existential or spiritual process arise and unfold?
2.2	CB	How does one recognise a spiritual crisis?
2.3	CB	How does one address hope with patients receiving palliative care?
3.1	CB	How do I talk to patients about existential/spiritual matters?
3.2.	CB	How does the role of a doctor or nurse differ from the role of a care giver who is specialised in providing existential and spiritual support?
3.3	CB	What assessment tools can be helpful for exploring the spiritual dimension?
3.4	EB	What is the effect of interventions for existential/spiritual support on the quality of life of patients receiving palliative care?
3.5	CB	When do I refer a patient to a specialised care giver (spiritual counsellor, medical social worker or psychologist)?
3.6	CB	How should one respond when a existential/spiritual crisis is suspected?
3.7	CB	How do I report spiritual care?
3.8	CB	How do I present my observations at a meeting of a multidisciplinary team, a palliative home care group or other collaborative body?
4.1	CB	What are the prerequisites for facilitating the provision of existential/spiritual support?

CB = consensus-based

EB = evidence-based



## A6 Authorising organisations

The guideline 'Existential and Spiritual Aspects of Palliative Care' was submitted for authorisation to the following organisations:

- Dutch College of General Practitioners (NHG)
- Dutch Association of Elderly Care Physicians and Social Geriatricians (Verenso)
- Dutch Nurses Association (V&VN)
- Palliactief, Dutch Association for Professional Palliative Care
- Dutch Patients Association (NPV-Care for life)
- Dutch Federation of Cancer Patient Organizations (NFK)
- Netherlands Patients Federation
- National Support Centre for Palliative Terminal Care Volunteers (VPTZ)
- Dutch Association of Psychologists (NIP)
- Dutch Society of Physicians for Pulmonary Diseases and Tuberculosis (NVALT)
- Dutch Association of Spiritual Caregivers (VGVZ)

All organisations have authorised the guideline except for the Dutch College of General Practitioners (NHG) and the Dutch Society of Physicians for Pulmonary Diseases and Tuberculosis (NVALT). They have approved the contents.

## A7 Implementation and evaluation

Promoting the implementation of the guideline begins by with widespread publicity and circulation. Further implementation involves specific interventions that help professionals to incorporate newly learned knowledge and skills into their palliative care practice routines; it also involves ensuring that this happens. The working group draws up an implementation plan as part of each guideline. Any activities and interventions for dissemination and implementation can take place at regional as well as national level. Information can be found at [www.iknl.nl](http://www.iknl.nl). The implementation plan for this guideline is an important aid that can help the various disciplines to effectively implement the recommendations in the guideline.

### **Target audience (from the guideline)**

All professionals who provide palliative care to patients:

- General practitioners, specialists in elderly care medicine, other medical specialists, nurses, nurse specialists, physician associates, spiritual counsellors, Netherlands Comprehensive Cancer Organisation advisors, social workers, psychologists and physiotherapists, care providers from other disciplines and voluntary care givers.

### **Current situation**

Spiritual and existential matters currently do not receive the attention they deserve in palliative care. Care givers tend to devote little attention to this dimension, they regard questions of meaning and purpose as being confined to religious belief, and they also find it difficult to broach these issues with patients. Those providing care need practical guidance to help them talk about spiritual and existential matters. Developing awareness of four dimensions is in line with the quality framework.

### **Strategy**

What will it take to move from the current situation to the desired situation? It is advisable to choose several strategies.

Key message of the guideline

**Always be attentive; sometimes offer accompaniment appropriate to your role; in the event of a crisis make a referral.**

### **Objective for implementing the guideline (verify with the working group)**

Care givers are familiar with the content of the existential/spiritual care guideline and put them into practice.

- Care givers have practical tools for offering spiritual/existential support
- Care givers know where they can obtain support and who they can refer to
- Care givers are aware that spiritual and existential matters encompass more than religious beliefs

### **Which enabling factors are present?**

- There is increasing awareness of and interest in a broad range of spiritual matters. The Palliative programme is running a number of projects on the topic of meaning and purpose.

### **Which limiting factors are present?**

- Care givers have limited awareness of spiritual and existential matters
- Spirituality is understood as being synonymous with religious belief
- Care givers find it difficult to discuss the meaning and purpose of life, and are not sure how to do so.

### Communications strategy

The activities listed in the table below will be undertaken to make people aware of the guideline. Specific recommendations are included in the table, with an indication of the relevant target group. Attention is given to whether all target groups are served.

Message	Medium	Target group	When	Who
Key message of existential/spiritual care guideline	IKNL website, IKNL newsletter, Fibula	General care givers	23 October and as soon as possible thereafter	IKNL
Key message of existential/spiritual care guideline, dissemination within own network	Palliative care network coordinators	Care givers within the palliative care network		
Make a short film with key message of the guideline	Short film	General care givers	Late 2018	IKNL
Twitter, news items, LinkedIn IKNL	Twitter, share news items	General and specialised care givers	At the launch and then at every news event	IKNL

### Strategy for motivating and increasing support base

The following activities will be undertaken to encourage people to innovate.

Activity/medium	Target group	When	Who
Launch of the guideline	Working group and key stakeholders in the field	23 October 2018	IKNL
Post e-case	General and specialised care givers	Included in launch news item	IKNL
IKNL newsletters (for Palliative Care and Oncology)			
Fibula newsletter		Published occasionally	
Newsletters of relevant professional associations involved	NHG, VGVZ, NIP, Verenso, V&VN, Palliactief, NPV, VPTZ, NVALT, Actiz, STZ, NVZ (Ned. Ver. van Ziekenhuizen), Vilans, PaTz, EPZ, FMS*		IKNL and relevant organisation
Selected magazines, sites and newsletters			
Workshop on guidelines at National Congress on Palliative Care (NCPZ) 2018	General and specialised care givers	8 November	Carlo Leget, Marie-José Gijssberts, Joep van de Geer

\* See List of Abbreviations, Appendix 12

## Education strategy

The following activities will be undertaken to teach new knowledge and skills

Activity	Target group	Who
Revision of 'Signalering in de palliatieve fase' [Problem identification in palliative care] set	care givers	IKNL
Translation of the guideline summary into English	All target groups for the guideline	Carlo, translator
Multidisciplinary establishment of an (accredited!) educational programme including a core module in which the guideline is explained, but where the focus is on the theme 'Your own spirituality' A second module to include: what words and questions to use, how do you listen? etc. Also, which models can be used (is consistent with the recommendation to decide as an organisation to use one model, so that a foundation can be laid for using the same language across participating disciplines)		
Supplement basic palliative-care training	care givers/providers	IKNL
Regular basic training, subsequent modules and coaching on 'Being There'. This ensures, in principle, the A for attention (in the ABC model). Also guidance to support volunteers themselves.	volunteers	VPTZ
The booklet 'Dorst of Doodsangst' (Thirst or Fear of Death), on the subject of meaning and spirituality, has been available for some time and there is now also an e-learning version. Adapt M.J. Gijsberts' training	volunteers	VPTZ
Train palliative care advisors on new guideline	Palliative care advisors	IKNL

### Facilitation strategy

The following essential steps will be taken to help implement the guideline

Activity	Target group	Who
Make card with examples of sentences care givers can use?		IKNL
Patient summary	Patients and general care givers	IKNL
Approach board/quality officers for accomplishment of these essential steps		

### Proactive (market-oriented) strategy

The following measures will be taken to heighten the sense of urgency.

Activity	Target group	When	Who
Patients' version of the guideline	Patients and their families	Once launched, available on kanker.nl, PalliArts and Pallialine	IKNL

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## A8 Mount Vernon Cancer Network questionnaire

The three cue questions used in the Mount Vernon Cancer Network (England) spirituality assessment tool:

- 1 How do you make sense of what is happening to you?
- 2 What sources of strength do you look to when life is difficult?
- 3 Would you find it helpful to talk to someone who could help you explore the issues of spirituality/faith?

Source: Mount Vernon Cancer Network. (2007). Spiritual support steering group. Final report on spiritual support. Stevenage, UK: Mount Vernon Cancer Network.

# A9 The Ars Moriendi model

## The five themes

### self – other

This concerns the question, 'Is this my illness / death?' Questions relating to authenticity, self-determination, autonomy, loyalties and the role of others in these.

### doing – allowing

This concerns control over pain and suffering. Where should we become more active in physical/psychological/social/spiritual areas? Where should we accept and allow the process to unfold?

### holding on – letting go

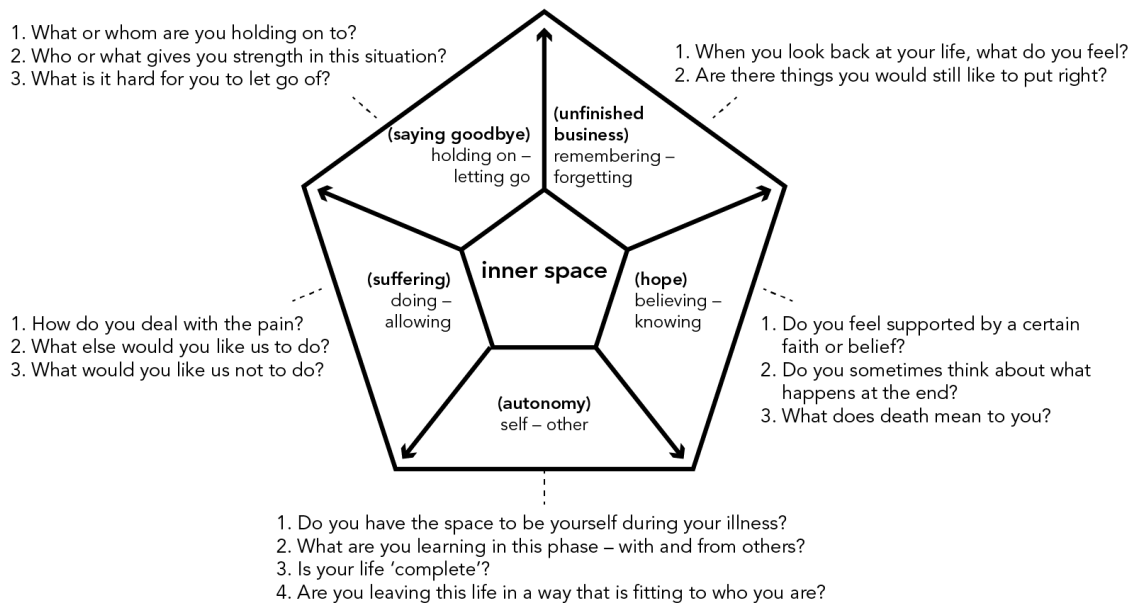
This concerns saying goodbye to people and things we hold dear, and to life. Being ill / dying is not only slowly letting go; it is also holding on to what is essential. What or who is essential?

### remembering – forgetting

This concerns looking back, taking stock, concluding one's life. And possibly forgiveness as an integration of remembering and forgetting, which is also important in the grieving process of the bereaved.

### believing – knowing

This concerns the meaning(s) of suffering and death. The end, a transition, a new beginning? Living on in people, in things? Another life? Can you live with questions to which there are no answers?



Carlo Leget, Ruimte om te sterven. Een weg voor zieken, naasten en zorgverleners (Tielt: Lannoo 2003/2012)

Carlo Leget, Van levenskunst tot stervenskunst. Over spiritualiteit in de palliatieve zorg (Tielt: Lannoo 2008)

Carlo Leget, Art of Living, Art of Dying. Spiritual Care for a Good Death (London/Philadelphia: JKP 2017)

# A10 FICA

The FICA Spiritual History Tool © was developed by Dr Puchalski and a group of primary care physicians to help physicians and other healthcare professionals address spiritual issues with patients. Spiritual histories are usually taken as part of the regular history during an annual exam or new patient visit, though they can also be taken as part of follow-up visits, as appropriate. The FICA tool serves as a guide for communication in the clinical setting.

The acronym FICA can help healthcare professionals structure questions while taking a spiritual history.

## **F - Faith and Belief**

'Do you consider yourself spiritual or religious?' or 'Is spirituality something important to you?' or 'Do you have spiritual beliefs that help you cope with stress/difficult times?' (Contextualize to reason for visit if it is not the routine history). If the patient responds 'No,' the health care provider might ask, 'What gives your life meaning?' Sometimes patients respond with answers such as family, career, or nature. (The question of/about meaning should also be asked even if people answer yes to spirituality)

## **I - Importance**

'What importance does your spirituality have in your life? Has your spirituality influenced how you take care of yourself or your health? Does your spirituality influence you in your healthcare decision making?' (e.g. advance directives, treatment etc.)

## **C - Community**

'Are you part of a spiritual community?' Communities such as churches, temples, and mosques, or a group of like-minded friends, family, or yoga group, can serve as strong support systems for some patients. For further exploration: 'Is this of support to you, and how? Is there a group of people you really love or who are important to you?'

## **A - Address in Care**

'How would you like me, your healthcare provider, to address these issues in your healthcare?' (In the newer models including the diagnosis of spiritual distress, A also refers to the Assessment and Plan of patient spiritual distress or issues within a treatment or care plan.)

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# A11 Religions and philosophies of life

## **Dying and bereavement within various philosophies of life/religions©:**

**This information was compiled by Agora, in Bunnik, [www.agora.nl](http://www.agora.nl), in consultation with VGVZ, the Dutch Association for Spiritual Caregivers [revised 2018].**

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### **Preliminary general remarks**

All the philosophies of life/religions described in this section have many different denominations as well as differences in the degree to which adherents are 'practising': from ultra-orthodox to mainly secular.

It is of the utmost importance to show an attitude of acceptance of and respect for another's beliefs; this is always appreciated and is more important than knowing about rituals. The art is to be a concerned and interested but very discreet visitor. Family or those close to the patient will then usually be able to tell the (professional) care giver what their expectations and preferences are.

It is very important not to immediately express your opinions of religious or spiritual customs, but if the patient shows openness and interest, a personal conversation does not have to be avoided.

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### **Buddhism**

Buddhism is a non-theistic wisdom tradition based on the teachings of the Buddha. The Buddha's vision on suffering forms the basis for the Buddhist philosophy of life. Humans suffer because they do not realise that everything is impermanent. They therefore cling in vain to that which changes constantly, and are thus disappointed again and again. The Buddha described a pathway for transforming the mind and thus overcoming suffering. The practice of meditation forms an integral part of this path.

Death is seen as a great transition and Buddhists adhere to the notion of reincarnation: the continuity of consciousness from one life to the next, in the form of karmic energy. Karma is the driving force that is generated by our actions and intentions. The state of mind at the moment of death has a big influence on the nature of a person's reincarnation.

Good to know

- Create an atmosphere of calm, kindness, simplicity and attention.
- Ask about specific wishes concerning meditation and other practices before, during and after death.
- Ask about the amount of time that needs to have passed before the body can be laid out, so that the last phase of the dying process is not interrupted.

### **Christianity**

Christians believe in one God, and in his son Jesus Christ as the Saviour of mankind. They regard life as a gift from God.

Christianity comprises various branches, including Catholicism, the Eastern Orthodox Church, Protestantism, Evangelicalism such as the Pentecostal church, and others. Each denomination has its own emphasis and there are often wide differences within denominations. A person's spiritual beliefs determine how they deal with sickness and suffering. Some see sickness and suffering as an event where God is a source of support and comfort. Others might experience these as a punishment or lesson from God.

Christians traditionally believe in life after death, though how this is conceptualised may vary, and in resurrection at the 'end of time'. Most Christians – believers, in any case – regard dying as returning to God.

### *Catholicism*

In the daily life of practising Catholics, the Pope and the bishops are important figures whose ideas on how one should live and die are respected. The Roman Catholic Church observes a number of rituals called the sacraments.

#### Good to know

- A Roman Catholic who is gravely ill or dying will receive the 'last rites'. The sick person is anointed (a sacrament) with fragrant holy oil as a symbol that God is near.
- Although the Roman Catholic authorities condemn euthanasia, many Catholics act according to their own views.
- Traditionally Catholics are buried when they die, but that is changing and some now choose cremation. It is customary to hold a wake the evening before the funeral. The funeral service usually includes a celebration of Holy Communion.

### *Protestantism*

In the Protestant tradition the Bible is seen as the Word of God, although certain contemporary denominations tend to emphasise its human character. The spectrum of differences in Bible interpretation is considerable: from the word of God to the opinions of people. This influences believers' views on death and bereavement.

#### Good to know

- Protestants observe no religious rituals for the sick and dying, but there are Church customs. It is not unusual, and is often explicitly requested, that a pastor or elder visit; the Bible is often read and prayers are said. Some may become anxious about the judgement that they believe they will face after death.
- In some orthodox Protestant denominations illness and health are a matter of divine providence. This is a reason for some not to have health insurance and to refuse vaccinations.
- The traditional Protestant view of euthanasia (and abortion) is that God gives life and humans may not end it themselves. In contemporary Protestantism there is some acceptance of euthanasia.
- A burial or cremation is usually preceded by a funeral service and before that an opportunity to pay respects and offer condolences.
- Very conservative Protestants do not speak of a 'funeral service'. Sometimes a devotional meeting is held. Flowers are not an accepted part of the funeral.

### *Eastern Orthodox Christianity*

Eastern Orthodox Christianity comprises a large group of denominations, many of which stem from Eastern Europe (Russia, Romania, Greece, Armenia and Serbia) and other areas including Syria, Turkey and Ethiopia. The Eastern Orthodox Church consists of the Christian communities that split away from the Roman Catholic Church in 1054. Since there is a union between the church community on earth and that in heaven in Orthodox Christianity, members of the congregation live in two worlds at the same time: this earthly world and that of the spirit. The Orthodox Church has no specific rituals for the terminal phase of life, but like the Roman Catholic Church it carries out last rites, which are the sacraments of anointing the sick, confession and Holy Communion. Anointing the sick is not only performed when the end of life is near, but throughout life when there is sickness and sin ('sickness of the soul').

Orthodox Christians have a duty to live; this is the reason they are on earth. As death nears, Orthodox Christians are aware that the purpose of life is not limited to being here on earth. They place their faith in God's will and this earthly existence is regarded more and more as preparation for eternal life.

Good to know

- When death nears it is important to contact an Orthodox priest, as having one present when death comes is valued. In the Netherlands this is not always likely to be possible.
- As far as is practicable, the deceased is washed, dressed and placed in the coffin by family or close friends, or by a professional.
- A candle is burnt near the deceased's head and the priest says a prayer while burning incense. The latter is an essential part of the ritual, but one that others need to be aware of beforehand, as it is not permitted in all funeral homes.
- It is customary for a watch to be kept over the deceased (a wake) and it is important that the coffin remain open until the moment of burial or cremation.

### **Hinduism**

According to Hindu belief the purpose of human life is moksha, a Sanskrit word meaning enlightenment, liberation, and release from the cycle of death and reincarnation to be united with the Supreme Being, Brahman. Until this happens humans are bound through their karma – the sum of actions in their present and previous lives – to the cycle of death and reincarnation. Hindus observe certain rites of passage (samskaras), including the funeral rites performed when someone dies.

Some Hindus believe (as do some Muslims) that certain diseases are caused by 'the evil eye'. Many Hindus wear an 'ogri ai' bead to protect them from evil spells. When a person is dying the family gathers and a priest (pandit) is summoned, who will first pray to try to heal the dying person. If it becomes clear that the person is dying, specific rituals are carried out. These vary among different Hindu communities.

Good to know

- As death nears the dying person is placed with their head toward the east, if possible in their own room or near the entrance to the house. A lamp is lit near the person's head.
- The family and pandit need to be able to play a prominent role while a person is dying and after their death.
- For practical reasons the deceased is usually laid out and placed in the coffin in a funeral home, where there is more space and the body can be kept cool. Mourners usually visit every day, often in large numbers (expect dozens of visitors).
- Many rituals are involved, including arranging the person's hair, their clothes, a drop of water on the lips and sacrificial offerings. If you are involved, be guided by the family and members of the community.
- The body may under no circumstances be embalmed. No organs may be removed for use by others. Cremation is strongly preferred, but if the deceased has indicated a wish to be buried this will be respected.
- Most Hindus are vegetarian, and during the mourning period this is strictly observed. For example, biscuits will not be eaten as they may contain eggs, gelatine or animal fat. To avoid offence it is better not to serve biscuits with any tea or coffee.

### **Humanism**

Humanism is a philosophy of life that emphasises the value and agency of human beings, without theism or other supernatural beliefs. One hallmark of humanism is that people are the ones who, as individuals or together, time and again determine the meaning and of life and its quality. Humanists usually have a positive view of humanity and focus on life itself. It is considered important to bring this life to a good end in a way that is fitting for the particular person, and with dignity.

#### Good to know

There are no specific requirements or rituals for the end-of-life phase. Core values include, as much as possible, self-direction and dying with dignity.

- The fact that the law leaves room for euthanasia does not mean that humanists necessarily want to make use of it, but they may wish to discuss it as an option with family and carers.
- Great value is attached to saying one's final farewells. It is possible to arrange a funeral with an independent humanist celebrant (see <https://humanistischeuitvaart.nl/>).

#### *Islam*

For Muslims everything comes from God: health, sickness and death. To Muslims, undergoing exhaustion, sickness, sorrow, pain, suffering and fear are paths to God forgiving some of their sins. Illness is therefore seen as a means for forgiving sins. In Islam it is a religious duty to comfort the sick, for example by mentioning only positive subjects in conversation.

Muslims believe that God determines the time at which each person will die. Intervening in life by way of euthanasia is forbidden and will be punished in the afterlife. Death is not the end, but a transition to another life.

#### Good to know

- If required, make sure meals are available that have been prepared in accordance with the dietary laws of the particular person. In this case they should be halal.
- Be cautious in giving a patient 'bad news'. Unless patients ask, doctors are not required to tell them that their illness is life-threatening.
- Visiting the sick is a religious duty for Muslims, so bear in mind that there may be many visitors, even when the person is very close to death. Do not assume that men and women who do not belong to the same family will automatically be present together in the same space. Care facilities with mixed wards and nurses of both sexes may pose problems.
- As long as it is not harmful, the dying person is placed on their right side with the face toward Mecca, or on their back with the feet facing Mecca. If this is too difficult or painful, the person is laid with their head slightly raised in order to be able to look toward Mecca.
- Euthanasia is regarded as the equivalent of suicide, which Islam forbids. Palliative sedation is permitted in some situations. Necessity knows no law.
- The duties that need to be performed by the Islamic community upon the death of a person, if possible led by an imam, must be accommodated. These include reciting a declaration of faith, reading from the Koran at the deathbed, ritual bathing of the body and wrapping it in a shroud, and an appropriate burial.
- The deceased must be buried intact (or in the same grave with any amputated body parts). Interpretations within Islam regarding organ donation vary. In the final declaration of the Contactorgaan Moslims en Overheid and the Sjiitische Islamitische Raad Nederland (February 2006) it is noted that organ donation is permissible.
- Public display of excessive grief is frowned upon (which is why women are not allowed to attend funerals.) Outwardly lavish displays are forbidden, as is music. Everything is to be kept simple.
- Separate space for men and women mourners needs to be arranged where possible.

#### *Judaism*

In the Jewish faith the soul is immortal. It is believed that one day God will bring the dead back to life.

According to Jewish law, a dying person (goses) is someone who shows the signs of the start of the dying process, such as a dropped jaw during breathing, death rattle, etc. A dying person should no longer be given unnecessary medical treatment, or be touched or washed. According to Jewish tradition, a person has the right to live and also the right to die.

#### Good to know

- If required, make sure meals are available that have been prepared in accordance with the dietary laws of the particular person. In this case they should be kosher.
- A dying person should no longer be given unnecessary medical treatment, or be touched or washed.
- Jewish law does not permit euthanasia; sedation may be permitted when a person is dying but external factors are hindering the process. A person has the right to die.
- Rituals that need to be accommodated may include recitation of the Viddui, a prayer that is a declaration of faith and confession, ritual washing and wrapping the body in a shroud after death, and burial in accordance with the faith.
- Only when the soul has left the body may the eyes and mouth of the deceased be closed. This is traditionally done by the children of the deceased. The person who has died is then immediately covered with a sheet (so they are concealed from the world) and a candle or lamp is lit.
- The mourners are not comforted before the burial takes place. It is not customary to visit the family of the deceased or pay your last respects to the deceased.
- Cremation is not permitted according to Jewish tradition (as then it would not be possible to rise from the dead).
- The burial takes place as soon as possible. This is often so quickly that there is no time to send a card (rouwkaart) announcing the person's death. Even if the deceased was not someone you knew personally, attendance at the funeral is expected; this is regarded as a religious duty. Flowers are not part of Jewish custom but are not forbidden.
- Men are usually expected to wear a kippah/yarmulke/skullcap at a funeral.

#### *Winti*

Winti is regarded as a nature religion and is mainly observed by Afro-Surinamese in the Netherlands. The spirits of ancestors and one's own spirit are revered. The Wintis can influence a person's life both physically and mentally. There are different Winti denominations, but they all share a belief in the importance of the deceased's soul finding peace. Many rituals are performed to propitiate the soul of the deceased: these include rituals during which people go into trance and sometimes speak with the voice of the dead person. In Winti belief, the soul of the deceased returns to the creator, but first 'wanders'. Group rituals ensure that the wandering soul can leave earth peacefully and will not remain to haunt the relatives.

#### Good to know

- Be aware that the rituals may involve large numbers of people.
- It is very important that the correct rituals be performed in the prescribed way.
- During the farewell ritual that is done before the body is laid out, family members touch the deceased. Be aware that this is often accompanied by displays of intense emotions.
- The body is usually laid out by the Surinamese dinari (a group entrusted with these responsibilities) in a funeral home.
- On the morning of the funeral a short farewell ceremony is also held in the funeral home for the immediate family.
- The dead are usually buried.
- A short prayer service is usually held in the auditorium; at the end the coffin is opened again so that mourners can say their farewells. The family are encouraged to express their emotions freely.

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## A12 List of Organisations mentioned in this publication

Abbreviation	Dutch name	English name
Actiz	Actiz	Actiz
EPZ	Expertise Centrum Palliatieve Zorg, UMC	Expertise Centre for Palliative Care, UMC
FMS	Federatie Medisch Specialisten	Dutch Association of Medical Specialists
KWF	KWF Kankerbestrijding	Dutch Cancer Society
NFK	Nederlandse Federatie van Kankerpatiëntenorganisaties	Dutch Federation of Cancer Patient Organizations
NHG	Nederlands Huisartsen Genootschap	Dutch College of General Practitioners
NIP	Nederlandse Instituut van Psychologen	Dutch Association of Psychologists
NPV-Care for Life	Nederlandse Patiëntenvereniging	Dutch Patients Association
NVALT	Nederlandse Vereniging van Artsen voor Longziekten en Tuberculose	Dutch Society of Physicians for Pulmonary Diseases and Tuberculosis
NVZ	Nederlandse Vereniging van Ziekenhuizen	Dutch Hospital Association
Palliactief	Palliactief	Dutch Association for Professional Palliative Care
Patiëntenfederatie	Patiëntenfederatie Nederland	Netherlands Patients Federation
PaTz	Palliatieve Thuiszorg	PaTz groups for primary palliative care (PaTz stands for Palliative care at home)
SKGV	Stichting Kwaliteitsregister Geestelijk Verzorgers	
STZ	Samenwerkende Topklinische opleidingsZiekenhuizen	
TVcN	Tolk- en Vertaalcentrum Nederland	Netherlands Centre for Interpretation and Translation
V&VN	Verpleegkundigen en Verzorgenden Nederland	Dutch Nurses Association
Verenso	Vereniging van specialisten ouderengeneeskunde en sociale gerieters	Dutch Association of Elderly Care Physicians and Social Geriatricians
VGZ	Vereniging van Geestelijk Verzorgers	Dutch Association of Spiritual Caregivers
Vilans	Vilans	National Centre of Expertise for Long-term Care in the Netherlands
VPTZ	Vrijwilligers Palliatieve Terminale Zorg Nederland	National Support Centre for Palliative Terminal Care Volunteers

Integraal Kankercentrum  
Nederland  
info@iknl.nl  
www.iknl.nl

