

# Spiritual care

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# Colophon

Version 1.0 of the Spiritual care guideline was written by the Agora *Spiritual care guideline* working group between 2006 and 2010.

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# Introduction

Many people who are confronted with illness begin to ask themselves questions. When the disease is life threatening, the questions can be life size. 'What did I do to deserve this?' 'What did I do wrong?' 'Why do I have to suffer?' 'Why should I go on living?' 'Am I not just a burden for others?' Such life issues or vital questions can be called **spiritual** or **existential questions**. They represent the big questions in life to which many people seek answers in their life view or religion. Anyone who works in palliative care will sooner or later encounter such questions. Sometimes the questions are posed literally; sometimes a person's search for meaning and purpose will appear in stories or in subtle comments. How can one respond? What can one do by oneself and when is it wise to call upon colleagues from other disciplines?

The present guideline has been written primarily for doctors and nurses, without the intention of excluding care providers from other disciplines or volunteers. All those involved with the physical and psychosocial welfare of patients need to know about the existential questions that are involved. To determine appropriate care and treatment, it is important to know what it is that lends meaning and purpose to the lives of the persons concerned.

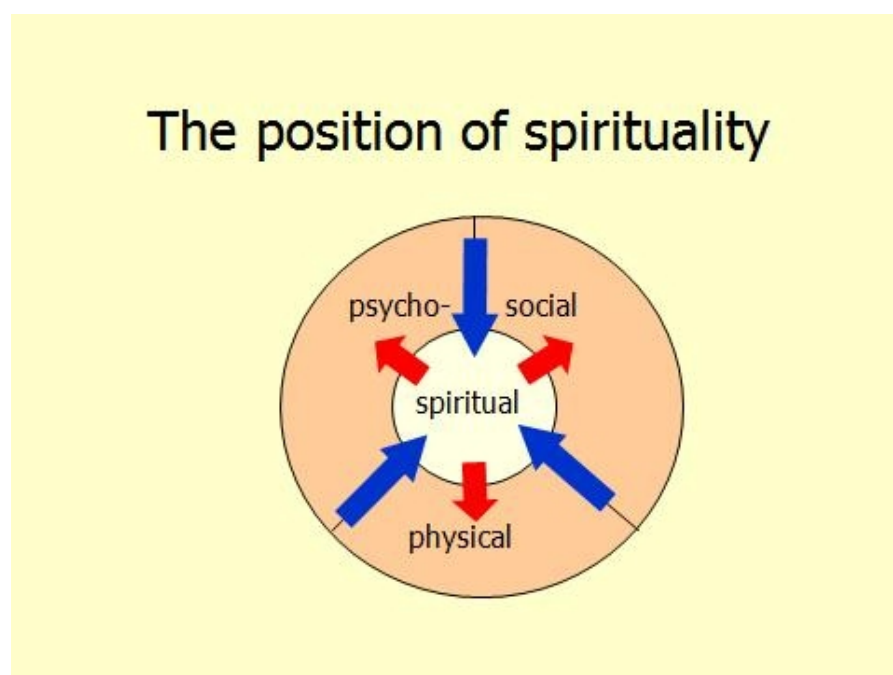
First of all the guideline provides assistance by enabling one to distinguish between:

- A. situations in which *ordinary attention* to life issues is sufficient,
- B. situations in which patients need *counseling* on life issues or experience normal struggles for which counseling by an expert may be beneficial, and
- C. situations where the struggle with life issues leads to an existential crisis requiring a *crisis intervention* by a healthcare chaplain<sup>1</sup>, a medical social worker, or a psychologist.

In the second place the guideline offers some practical directives for providing good care in the various situations.

The guideline is structured as follows. First, an explanation is provided of characteristic features of life issues<sup>2</sup> and of the terminology that is employed in such matters. Secondly an indication is given of how often such questions, struggle and crisis occur. Then recommendations follow for diagnostics, providing advice and treatment. The threefold distinction between normal care, special needs and crisis situations is employed throughout the guideline.

We chose the term 'spirituality' in the name of the guideline to refer to the field of life issues. In that way the guideline is in accordance with the definition of the World Health Organization (WHO) for palliative care, which speaks of attention for needs of a physical, psychosocial, and spiritual nature.



**Fig. 1. The position of spirituality**

Visual representation of the relation between the spiritual dimension and the physical, psychological, and social dimensions of human existence. The spiritual dimension is depicted as the most intimate and concealed dimension: less measurable than the other three, but continually in a relationship of reciprocal influence with them.

Spiritual care as a component of palliative care is also important for those near to the patient. The approaching death of a loved one can evoke spiritual questions for them as well. In addition the spiritual process of those near to the patient can be connected to (anticipatory) grief.

<sup>1</sup>*Translator's note:* A more or less literal translation of the Dutch 'geestelijk verzorger' would be 'spiritual caregiver'. In Dutch the term refers only to a spiritual care specialist (chaplain) to be distinguished from other professionals who might be spiritual care providers (Dutch: 'zorgverleners'). In accordance with recent English literature on palliative care, the authors prefer 'healthcare chaplain' as a translation for 'geestelijk verzorger'. (Handzo, 2011, page 266).

<sup>2</sup>*Translator's note:* 'Life issues' is a translation of the Dutch 'levensvragen' (literally: life questions) which in this context bears the connotation of questions about life and death.

## Terminology

The term 'spirituality' is difficult to define. Along with attention for physical and psychosocial problems, the WHO definition (2002) mentions 'spiritual' in an unassuming way. When the term is literally translated into Dutch, it evokes not only recognition, but also questioning and resistance.

On the one hand spirituality is often associated with life views of which there is a broad diversity in the Netherlands. For people with a Roman Catholic background, the term 'spirituality' is traditionally synonymous with a connotation of 'religious life'. Protestant believers often associate the term with monasteries and Catholic customs. Protestants prefer to speak of personal devotion or a life of faith. Since the rise of the 'new age' movement in the 1960s, spirituality has become a vogue term that can refer to a multitude of movements, including those inspired by Eastern religions and worldviews. On the other hand, spirituality is associated with notions of the search for and experience of meaning in life. In a negative sense, spirituality is associated with vagueness or wrongly confused with the term spiritualism (contact with the deceased). Partly for that reason, some care providers prefer to employ the terms 'existential' or 'worldview'<sup>3</sup>.

For the present guideline the term spirituality is employed in accordance with international literature on the subject. The domain of the guideline is pre-eminently a domain in which close attention to language is essential because it deals with values and faith, with the existential meaning or purpose of things, people and ultimately with life as a whole. In this guideline<sup>4</sup> the term spirituality is defined as follows:

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

The spiritual field is multidimensional:

1. 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).
2. 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).
3. Religious considerations and foundations (faith, beliefs and practices, the relationship with God or the ultimate).'

<sup>3</sup>*Translator's note:* 'Worldview' is a translation of the Dutch word 'levensbeschouwing' (literally: 'life views') and is a generic term for religious, humanistic and philosophical views on life, whether on a practical level or a more developed, traditional sense.

<sup>4</sup>*Translator's note:* On the approval date of the guideline 6-6-2010 spirituality was defined as 'the functioning of people with regard to worldviews, including issues related to the search for and experience of meaning'. Spirituality includes a wide range of sources of inspiration - varying from religious to the ordinary. For some people the emphasis lies on emotional experience (e.g. prayer, enjoyment of nature, literature, music, art) or on activities (meditation, performance of rituals, or commitment to a good cause); others experience spirituality more intellectually (contemplation or study). Spirituality affects one's entire existence. It is dynamic and has more to do with the source of an attitude towards life than it does with a distinguishable realm of life. Four months later, the authors were working towards the EAPC Taskforce on Spiritual Care in Werkhoven. For the purpose of international debate the EAPC Definition is used here.

## Characteristic features of spiritual care

From the outset it is important to keep three matters in mind when spiritual care is involved. They are applicable throughout the entire guideline.

### **1. Pay attention to the spiritual process from the very beginning of the palliative phase**

In the palliative phase of illness the end of life approaches. As soon as one becomes aware of this, it is a normal human response that life issues arise. This may be connected to daily matters or to more religious themes. In order to provide an impression of the range of issues, a several clusters of predominant themes are listed without attempting to be exhaustive:

- Search for meaning (experience or loss of meaning)  
Does my life still have meaning? Questions on the experience of darkness, or of fate. Why me? Matters concerning: enrichment in the remainder of one's life, increased depth, connectedness, transcendence, death wish, request for euthanasia, feeling finished with life.
- Loss of control  
Feelings of powerlessness, doubt, autonomy, dependence, neediness, coping, manipulability, sense of dignity.
- Time perspective  
Reduction of the future, living day by day, awareness of death, acceptance, resignation, denial, learning to deal with a situation, personal transformation, integration. Is it really over now? What is there after this life? Focusing on the near future in order to make the present bearable. How should I use the time I still have? Who do I still want to see, and who do I not want to see?
- Connectedness and isolation  
Being struck, facing things alone, feeling cut off, healing, integration in a spiritual community, feeling connected (with a greater whole), kindred spiritness.
- Hope and despair  
Despondency, hopelessness, unrealistic hope, What are my sources of strength and inspiration? What provides me with trust, hope, and growth? What keeps me going? What really matters now?
- Life balance  
Guilt, making amends, punishment, seeking new balance, 'bringing to closure', acceptance, reconciliation. What have I done wrong? What am I leaving behind? What was I able to give? But also: celebrating life, blessings, the good life, putting things into perspective, and humour.
- Religious conviction  
'What does God have in store for me?' 'May I entrust myself to my Creator?' 'How do I become reconciled with God?' 'Will I be punished after this life?'

In general it is important not to wait until the terminal phase to pay attention to the spiritual process. It is better to pay attention to spiritual care as soon as the diagnosis of a life-threatening disease has been made. As the disease progresses, energy levels diminish, while physical discomfort, pain and/or drowsiness may increase. The patient may no longer be able to deal with 'spiritual maintenance'.

### **2. Develop sensitivity for detecting signals on spiritual issues; these are often not immediately apparent**

Spirituality is intertwined with a patient's entire life. It plays a part in everything a patient undergoes. That does not mean, however, that patients are always able to clearly express themselves in spiritual matters. Spiritual questions are often questions left unasked, questions that are not yet completely clear for the patient. Hence, the patients themselves do not always recognize them. Neither do care providers always recognize spiritual questions. As a result the questions are overlooked, postponed and often neglected. Because spiritual questions are intertwined with one's entire life, they have an intimate and personal

character. Patients do not easily talk about them with just any care provider. There are also patients who do not want to deal with such questions.

For all such reasons, spiritual care is inadequate if only provided when the patient requests it. In an attentive conversation matters can be clarified for both parties. In the process of conversation a patient can suddenly discover what is on his<sup>5</sup> mind, and while listening a care provider can detect signals that pertain to spiritual care.

How can one be trained to be sensitive to those signals? A first step is to realize that statements made by patients seldom have a singular meaning, but usually contain layers of meanings. Spiritual questions are inextricably connected with the three other dimensions of palliative care (physical, psychological and social), and sometimes the spiritual layer of meaning is concealed under an expression that seems to be mainly of a physical or psychosocial nature. An example can help clarify this.

*Example of four layers of meaning*

A 60-year-old woman is a patient in a hospital and says, 'I lie awake at night a lot thinking about my husband'. What does this utterance mean? What layers of meaning can lie concealed within this one sentence? How should we interpret the sentence? From the perspective of the fourfold focus of palliative care the question can be understood in different ways.

- **Physically** (in regard to a factual, objective, and verifiable account of the current status): 'The woman lies awake at night'. Focusing on the physical domain evokes questions such as: Is this insomnia? Should something be done about this?
- **Psychologically** (in regard to thoughts, images, feelings, and emotions that lie concealed in the statement): 'The woman thinks about her husband'. Examples of questions that focus on the psychological/emotional aspect are: Is the woman worried? Does she miss her husband? Is it from sorrow or from longing? How severe is it? What type of care may be needed?
- **Socially** (in regard to the social environment to which someone is connected and in relation to which he shares something about his identity): 'The woman is (was) married'. Questions that arise by focusing on this layer are: What kind of relationship do/did they have? How do they communicate with each other? Is her husband needy? Is the woman a widow?
- **Spiritually** (in regard to what moves people most deeply, inspires them and gives their lives meaning, which in many cases may be connected to ordinary things in life). Focus of attention on this dimension evokes questions such as: What does it mean for her to think about her husband? How does she experience her memories of her husband? Does it make her sad, or does she derive strength from it, or both? How does the silence of the night affect her?

All of the layers of meaning are interconnected with each other. Distinguishing them makes them potentially manageable. Becoming sensitive to the spiritual dimension of palliative care means: learning to listen to the layers of meaning, purpose and inspiration that can lie concealed under more superficial details. '*How do you feel when you think about your husband at night?*' the healthcare chaplain asked the woman. Her answer was, '*It consoles me. He passed away two years ago and particularly at night I have the feeling that he's with me and supports me in this difficult time.*'

What is surprising about her answer is that it shows that the meaning of a statement should never be assumed too quickly. Each time again, the task is to discover what the statement uniquely means for the individual patient. By posing open questions and summarizing what you hear, you can create space for patients to tell where they derive purpose and strength from. They become aware of it themselves while they are speaking. Providing time and space for stories that have meaning to a patient is thus an essential aspect of spiritual care. But also taking time to focus on pain that cannot be alleviated but does require attention is an important aspect of spiritual care that every care provider can provide.

**3. Develop a 'refraining mode'**

Another characteristic of spiritual questions is that they involve issues for which there may be no available solution. Questions such as, 'What did I do to deserve this?' or 'Why do I have to suffer like this?' are expressions of a search for existential meaning and purpose. Just because there is no solution at hand, does not mean that there is nothing to say in response. However, if an answer to such questions is ever to be found, it will not come from a book, nor from this guideline. Ultimately it can only come from the patient, who can be supported or assisted in his search for an answer. That requires the care provider to take a

less familiar approach.

Care providers are primarily equipped to help solve a problem. However, in the context of spiritual care 'presence' is the primary concern. Presence is a way of acting that lays emphasis on attentive listening. Instead of providing help from outside, attempts are made to mobilize the inner strengths of the patient by being present and faithful and by emphasizing 'letting be', rather than 'doing', as a 'refraining mode' of action.

Awareness of the different layers of meaning and a 'refraining mode' are important for all forms of spiritual care. Both are basic equipment for every good care provider.

<sup>5</sup>*Translator's note:* The Dutch guideline uses 'he' or 'his' generically and is translated in that manner, but 'she' and 'hers' is also intended.



## Prevalence

Everyday attention to life issues is always important. According to a recent American study, 88% of the patients with an advanced stage of cancer consider attention to religiosity and spirituality to be of some or great importance. 72% think that too little attention is paid to their needs in this area.

At first sight Dutch patients in the palliative phase seem to have few spiritual concerns. An analysis of the consultation questions that are posed to the various palliative care teams in the Netherlands shows that spiritual concerns play a role in only 8.4% of the consultations. In most cases it is the consultant who reports that there is or may be some concern in the spiritual dimension.

In a patient study conducted by Staps and Yang all respondents (n = 82) report that they appreciate it when the doctor providing treatment takes the time for questions regarding how a life threatening illness affects them and what it means to them. When a doctor does not pay attention to the life issues that arise, the patient often feels that he is being treated impersonally.

Nevertheless questions in the area of spirituality are often disregarded and not even recognised by the clinician. Among the causes for that are: a lack of knowledge about what spirituality is; underrating the importance of spirituality for patient care and the effect it has on the patient's physical and psychosocial well-being; and ignorance on how to deal with life issues and spiritual concerns. It has not yet been ascertained how often palliative patients in the Netherlands have gone through an existential crisis so severe that it requires intervention by a healthcare chaplain or psychologist.

Much of spiritual care also remains partially or completely out of the sight of care providers (and researchers) because representatives of worldview or religious communities attend to it. In large parts of the Netherlands spiritual support by clergymen, priests and pastoral workers, for example, plays a large role without ever being documented.

# Origins and developments

Research on spiritual processes in the health care sector has been primarily carried out for and with patients with cancer. Descriptions of those processes are, generally speaking, also applicable to patients who face other life-threatening illnesses.

Fundamental to understanding the spiritual process is the observation that people find their way in life by attributing purpose or meaning to practically everything. Attributing purpose to something gives people a sense of stability and it bestows a certain degree of intimacy to their existence. In the uncertainty of existence no person can live without meaning.

Every person knows that death is unavoidable. Nevertheless, we have a strong tendency to suppress the fact that this applies to each and every one of us. For ourselves we easily assume that the future either will not end or that the end is remotely distant. That reduces a sense of finiteness to theoretical knowledge that has no further influence on personal thoughts or feelings. That works well, as long as the end is not looming nearby.

When that is the case, for example when a loved one dies or when someone enters the palliative or terminal phase of a disease, a process of searching or struggle can develop. That is a normal response.

## The natural course of a spiritual process

In that natural process a number of themes can be distinguished that often succeed each other in phases.

- Awareness of finiteness  
The awareness of finiteness arises at the moment that the existential threat impresses itself upon the patient. That awareness overcomes many patients as soon as they hear that they have been diagnosed for cancer or the message that they can not be cured. Some people panic. Such awareness may also cause profound loneliness in the experience of patients. The awareness of finiteness can also come to the foreground as the consequences of illness and treatment have increased impact on a patient. During a stable period of the disease process, the awareness of finiteness may arise when the patient has more time to consider all that has befallen him and where it all may lead to.
- Loss of grip on life  
The awareness of finiteness causes the patient to feel as if he has lost all grip on life. The constructs of meaning relied upon no longer suffice for dealing with the threat, because death on short term had no place in those constructs. The struggle that occurs is often characterized by negative emotions such as anxiety, panic and a depressed mood. Everything is perceived as negative. When the patient isolates himself, the social environment is unable to provide support. Patients will experience such aspects of the spiritual struggle in various degrees and intensity. While anxiety and panic may be predominant for one patient, for another it may be a sense of powerlessness or existential loneliness that prevails.
- Loss of meaning  
When death approaches, a sense of future is lost. What the patient experiences is often perceived as unreasonable and meaningless. Everything that is dear to the patient is in danger of falling away. It makes no sense to make plans. Following up on previous plans is no longer realistic. Normally time plays an important role in how the struggle progresses. After a few days the emotional impact of the first shock will usually diminish. The doctor will have given information about the current situation, the possible course of events and the alternatives for alleviating the symptoms. While the disease still holds its threatening character, the patient experiences physically that that does not mean that he will immediately die.
- Bereavement process  
When the initial reaction of shock diminishes, the awareness of all the things one must let go of, such as loved ones and plans, becomes greater. A bereavement process begins.
- Experience of connectedness  
In times when former ways of attributing meaning to life fall short, the patient may unexpectedly have an experience of connectedness to or of being part of a greater whole. The experience arises suddenly and cannot be called up consciously. We reserve the term '*experience of connectedness*'<sup>6</sup> for that experience in order to distinguish it from prior *ways of searching for and finding meaning* that have come under pressure. Many times the experience occurs when the patient has dared to confront the threatening implications of his situation. Such an experience of

connectedness may be new for the patient, and therefore difficult to verbalize. Moreover, the patient may think this experience is strange or crazy. He may be afraid that other people will think the same if he were to talk about it with them. In general, he will only talk about it with others if he feels safe with them and taken seriously. The conscious experience of connectedness results in a reduction of anxiety.

- Integration of meaning and experience of connectedness

When the search for meaning and the experience of connectedness are again integrated, new constructs are created that allow for the reality of death. That which the patient is undergoing and which isolates him from others is situated within a broader frame of reference (humanity, nature, worldview, religion). It may be an experience of deep connectedness with nature or with a transcendent dimension such as infinity or God. That can make it easier to accept the limits of life. When the short life expectancy has been integrated into a system of meaning, the patient will focus more on the here and now. He will also experience a sense of changing. The short life expectancy will lead to setting other priorities. He will let himself be led more by what he himself deems important, or by what he personally needs and less by social expectations. Due to those changes he can attain a new sense of balance. As a person he may feel stronger or more self-assured, and more aware of the connectedness with a greater whole. That may lead to a feeling of confidence or hope, although anxiety and resistance may also continue to play a major role.

*Case example: Spiritual care by a doctor*

An example of a common search for factors that could have a positive effect on a disturbed balance is related by a doctor in the following.

Ms. M., a 46-year-old married woman with three children, has been admitted to a hospice due to a lung carcinoma with bone and liver metastases. Ms. M. is always cheerful and seems in a certain sense to be at ease with her disease process. There are relatively few symptoms. Fatigue, however, is rapidly increasing. At a certain moment, I was urgently requested to go to her. I met her together with her husband and she appeared deeply despondent, exhausted and desperate. Immediately she said: 'You have to give me an injection to end my life. I'm completely worn out. I can't go on any more. I just can't. I can't.' I sat next to her, took her hand, and let her tell me how impossible it felt to continue living in that way. In what she told me I sensed an underlying problem. She wanted so much to appear strong up until the end, especially for her children. And now she felt that she could no longer uphold that image of herself. That made her feel hopeless. She felt like she could no longer face herself or her children and she just wanted to get out, literally! I said that I also thought that she could no longer go on like this. I said that she was too tired and sick to keep upholding such an image of herself in her sickbed, while at the same time continuing to take care of the ups and downs of others. I also said that it was no longer necessary. I told her that she had already earned all the medals she could possibly achieve by caring for others. I also mentioned that she could now put that phase behind her, give in to her fatigue and discover that she would be loved just as much. She then looked to her husband who repeated exactly the same message in his own words. She began to cry and surrendered in a certain way. A bit later she asked for a glass of water, and it was remarkable how all her despair had disappeared in such a short time. Due to the acknowledgement by others she could now let go of an unbearable weight that she could hardly bear. Her last week took on a totally different character. She was able to die in peace after a moving farewell from her husband and children.

From: Van Leeuwen PW. *Ondraaglijk of bijna niet alleen te dragen?* [Unbearable or almost not to be borne alone?] *Pallium* 2003; 4: 6-11.

When those near to the patient cannot go along with the shift of priorities and the accompanying behavioural changes, the result may sometimes be the arousal of tensions or alienation, while other contacts may become more significant.

Living in the here and now

Living with a sense of connectedness with a greater whole may increase the appreciation of the patient of the blessings and enjoyments of the moment. The patient will live more in the here and now. By living in a new balance, he may get the feeling that his life has something deeper to offer. Many patients say that a

life-threatening illness has enriched their lives. We should, however, be careful about romanticizing such a statement. And we should certainly not apply it to other patients. The awareness of one's own finiteness is the ultimate confrontation with 'life as it is', which is always different than what one thought, expected or hoped it would be. It is often an unpredictable process in which the patient oscillates back and forth between extremes, between hope and anxiety, resistance and surrender. When the discomfort increases and the body gets weaker, a time may arrive when the fight to preserve life becomes futile and death is experienced as liberating. That may result in a longing to die or a request for euthanasia.

### 'Spiritual maintenance'

Patients in the palliative phase react differently to their situation. Not all patients experience spiritual searching or struggle (see below). Such spiritual needs may, however, be present even without struggle. Often there will then be a need for 'spiritual maintenance'. There may be spiritual needs that people would like to share and for which they would sometimes want to receive counselling<sup>7</sup>. Those needs may be of importance in the very last phase of life, or during the transition from curative treatment to palliative care and what follows.

<sup>6</sup>*Translator's note:* The Dutch guideline distinguishes literally between an 'experience of meaning' or 'purpose' ('zinervaring') and ascription or giving of meaning ('zingeven'), the latter of which has been generally rendered with the more common English phrase 'search for meaning'. Following the explanation in the text of the experience of meaning in terms of 'connectedness', the translator chose the phrase 'experience of connectedness in order to more clearly distinguish the experiential act and the act of ascription. Both, however, have to do with meaning and purpose.

<sup>7</sup>*Translator's note:* The term 'counselling' is here a translation of the Dutch term 'begeleiding' (literally: accompaniment). Although the term 'counselling' need not refer here to a formal technical skill, it is chosen as a translation because the term 'begeleiding' bears more a professional sense than would the more generic translation 'help'.

## **Phases of struggle or searching in the spiritual process**

Some patients go through struggle in phases. The course they run may be similar to the pattern sketched above. There is, however, one difference. When the patient becomes aware of his finiteness, he briefly experiences anxiety or panic, but at the same time, he considers it 'too much' or 'too intense' to experience. He withholds his emotions before they have the chance to overwhelm him. One patient reported that it was as if she had turned off a switch. The threat of death is banished to the subconscious so that one is able to act as seems appropriate. There may be an expression of emotions, but only briefly. In this way the patient maintains a certain amount of control. This makes it possible to let the reality of the threat and the accompanying emotions gradually enter into one's consciousness, a process that can take weeks or months. Once that stage has been reached, a patient can face the threat without hindrance and let the emotions come to surface and subsequently focus his attention on other matters later. The further course of the spiritual process (including experiences of meaning and connectedness) will correspond with the way things go with patients for whom the threat was inescapable from the very beginning. Enduring the existential struggle is an important step in finding a new psychological and spiritual balance that enables the patient to deal with the approaching end of life.

### The absence of spiritual distress

A spiritual searching or struggle does not arise for all patients in the palliative phase. As long as the purpose of the medical treatment is curative, most patients focus on being cured and they banish the threat of approaching death to the subconscious. Even when medical treatment does not have the intention to cure, many patients will focus primarily on dealing with the treatment and its effects. This postponement of facing the threat can be seen as an effective coping strategy to deal with the burden of the treatment, or as an inability to recognize the threat and all the questions that go along with it.

The confrontation with the end of life, and hence the struggle with it as well, will not come to the forefront if a patient continues to deny the severity of his situation. Such denial may at that time be the most feasible way of dealing with the threatening situation. It is therefore not advisable to break through that mechanism if a patient does not indicate readiness to do so. The person will first have to develop a different coping strategy.

The absence of struggle, however, does not always indicate denial of the situation. When people have already had a clear awareness of the relativity of life prior to being severely ill, the awareness of their approaching death need not necessarily lead to a spiritual struggle. That can be understandable considering:

- the advanced age of the patient which has gradually confronted him with limitations throughout the years. That gives him the ability to develop an attitude toward life (a framework of meaning) within which his own finiteness already been allotted a place.
- the prior history of the patient. If he has previously been confronted with death and loss in an intensive and direct way, it is possible that he has already developed a framework of meaning which accounts for his own finiteness.
- a realistic, pragmatic attitude of the patient due to which the approach of death is not perceived on an emotional level to be a threat. When confronted with his own finiteness, the patient may immediately be able to face the new reality and deal with it effectively.
- a strong framework of meaning, specifically a well-defined worldview, through which one's own mortality and death can naturally be incorporated. The perspective on life and death may be deeply rooted in the patient's worldview, which has taught him, for example, to accept 'whatever comes from God's hand'.

## An existential crisis; stagnation in the spiritual process

Sometimes the course of the spiritual process runs less naturally because the confrontation with the end of life is so severe that a patient becomes anxious, has panic attacks or shows signs of depression. In this guideline we then speak of an **existential crisis**. Characteristic of such a process is that the patient experiences feelings of anxiety and panic, powerlessness and meaninglessness.

In the face of an existential crisis, a patient needs more specialised counselling by a healthcare chaplain and/or psychologist. In this guideline we reserve the word *crisis* for situations in which the care providers deem intervention to be necessary. That does not always concur with a spiritual searching or struggle that the patient himself describes as a crisis.

The spiritual searching or struggle may stagnate and lead to an existential crisis if the patient continues to be resistant to the fact of his illness and cling to one or more of the aspects of his situation prior to being ill, such as:

- being physically healthy (in the present). The patient stays focussed on the discrepancy between the capacities that he previously possessed and now no longer has, or on his altered body image. Sorrow, anger, and resistance continue to predominate.
- having particular expectations (future). The patient is obsessed by the threats that await him in the future. He has the tendency to assume the most negative scenarios. Unreasonableness and feelings of anxiety predominate. The anxiety may also be related to what a patient fears about what will happen after dying.
- 'security' of the familiar and cherished (past). The patient is preoccupied with what he has to let go of. That obviously evokes a lot of sorrow. It is, however, also possible that the patient is preoccupied with certain occurrences and events in his life with which he is not satisfied, or with regard to which he has feelings of guilt.
- or more generally. The patient is stuck in an conception of life (religious or otherwise) within which the things that he undergoes cannot be incorporated in a meaningful manner.

Characteristic of the existential crisis is that the preoccupations mentioned above and the accompanying feelings persist for a longer period of time (weeks), and continue to dominate the behaviour and/or the communication. If the existential crisis persists for a long time, it can lead to anxiety or mood disorders, and/or to a death wish.

# Diagnostics

This chapter is divided into the following parts:

- Detecting signals and encouraging open discussion
- Diagnostics for an existential crisis
- Predisposing factors
- Diagnostic instruments for doctors and nurses
- Instruments for healthcare chaplains

## Detecting signals and encouraging open discussion

Detecting signals is a matter of carefully observing and listening. What is someone's posture? What is the expression on his face? What might that mean exactly? If someone is apathetic, despondent, or cynical, does that indicate a need for contact? Along with attentive observation, listening is also important. We indicated above how statements can contain different layers of meaning. In order to detect spiritual issues it is necessary to be attentive to the various layers. Talking about spiritual questions can best be encouraged by asking open questions. If and how a conversation takes place depends largely on the attitude of the care provider (see item A, Table 1 in [Policy](#)).

### The absence of signals

If a patient does not give off any signals in a situation in which experience has shown that many people suffer existentially, it may be appropriate to sound out the need. An example of how to do that would be a question like, 'You give me the impression that you are very relaxed. Is that how you feel?' If it is not so, the patient would probably answer 'No,' and a basis of trust would have been laid. That could become an opening for conversation. If the answer is 'Yes,' the patient may indeed feel tranquil. He may, however, answer 'Yes' even if he is not feeling relaxed but does not want to talk about it with the person asking about it, at least not yet. In both cases conversation will need to follow about the meaning of 'Yes' or 'No'. By inquiring the care provider should make it clear that he is willing to talk about the matter if the patient so desires. It is important that the care provider realizes that sometimes the patient may be so consumed by physical suffering, that it is too difficult to express existential suffering.

## Diagnostics for an existential crisis

The patient or his social environment may provide verbal or behavioural signals that indicate an (imminent) existential crisis.

### Signals of the patient and the social environment

- The patient reports it himself. He will not call it an existential crisis, but rather he will use expressions such as: 'I can't deal with this anymore.', 'Why should I go on living?', 'I feel lost'.
- Changes in the patient's usual behaviour. This is the case when the patient is in a somber, depressive mood, is difficult to motivate to do something, or no longer makes any plans, not even on a short term. When the patient has a chronic bad mood, and is always grouchy and angry, that also may be an indication of an existential crisis.
- The patient somaticizes to a great degree. Existential problems are often expressed in physical symptoms or in behaviour. In general somatization is more common among men than women. Somatization is also more common in some cultures than others.
- The patient isolates himself.
- The patient says in a manner of despair that he wants to die. That despair is distinguishable from situations in which a patient states that he has lived long enough and expresses acceptance.
- Those around the patient report that the patient is despondent or that they do not know what is wrong with him.

## Predisposing factors

There are two types of factors that make it more difficult for the patient to deal with the imminent end of life and that can lead to searching, struggle or existential crisis:

### Patient-related factors

- Prior history with one or several depressive episodes.
- Prior history with several psychological traumas that have been insufficiently dealt with.
- A suicide attempt.
- Intense anxiety with regard to personal judgement after death.
- High objectives in life along with the feeling that little has been accomplished.
- A situation in which the patient is aware of the threat of death, but does not permit himself to have the corresponding emotions.
- A strong discrepancy between an idealized image of reality and the hard reality in which the patient now finds himself.

### Situational factors

- The patient is pressured by the social environment to face his imminent end. In many cases, this happens out of justifiable concern for the patient. The care provider or those near to the patient are of the opinion that the patient has been denying the situation for too long, or is showing an insufficient awareness of the severity of the situation.
- The patient does not receive sufficient opportunity to undergo his struggle. That can occur due to rapid progression of the disease, or a result of too many visitors, so that the patient has insufficient time. It may also be that the situation is too threatening for the care provider or those near to the patient. People are afraid that the patient will no longer be able to deal with his situation if he surrenders to it. They may try to limit the struggle by suggesting what they believe to be solutions, by playing down the severity of the situation, or by completely avoiding talking about the matter. Sometimes the social environment itself does not know how to deal with the situation and therefore avoids any type of substantial conversation.
- The patient experiences the manner of care as an infringement upon his autonomy, independence and dignity. This is more common in a clinical setting than in a home.
- The patient has insufficient social support.
- The patient's partner or child has a disease or a severe limitation. This can give the patient a feeling that he is unable to fulfil his task in life.

## Diagnostic instruments for doctors and nurses

### Screening

Along with general attention to the spiritual dimension, which is always important, there is the option of briefly checking the spiritual situation of every patient as a standard. The American consensus document (Puchalski 2009) speaks of 'screening'. Based on a few simple questions, the patient's situation is screened to establish any need for more extensive spiritual care. The benefit of such a standard approach is that attention for spiritual care is placed on the agenda at an early stage. The need can be made explicit in the patient's medical file. Screening cannot replace more general attention to the spiritual dimension, but it can be done by all care providers. No special training is necessary. A possible form of screening might consist of the following three questions:

- Is there at this time anything in particular that you are concerned about?
- Where did you previously find support in difficult situations? (Family? Worldview? Music?)
- Who would you like to have near you? From whom would you like to have support?

Depending on the answers an assessment can be made whether it is necessary to immediately provide counselling or whether it can be left to the patient to manage his own searching or struggle.

### Assessment ('spiritual history')

In order to assess the extent to which a patient needs counselling, and if so, who would be the best to provide it, the patient's situation with regard to spiritual care can be assessed. The American consensus document refers to that as 'spiritual history'. In principle, it can be done by every professional who has followed a brief training.

Assessing a spiritual history is intended to provide insight into matters of meaning and purpose that are important to the patient. Assessment is broader and more thorough than a screening and also requires some training. A care provider should not feel uneasy about the topic and has to know how to respond should a patient take the opportunity to tell his life story. A spiritual history implies a more thorough inquiry into someone's concerns, sources of help and hope. It can be built into an existing interview format, along with the mapping of physical and psychosocial care dimensions. It can then be allotted a fixed place in the patient's file.

Especially in the United States, various instruments have been developed such as FICA and SPIRIT, for assessing the patient's potential need for spiritual care. The American models function in a society in which 96% of population considers itself to be religious, and 92% are members of a religious or worldview association. These models have not yet been applied in the Netherlands. They would have to be adapted to the Dutch culture for implementation. The two models are presented here for illustration.

### **FICA**

**F: Faith** and beliefs

**I: Importance** of spirituality in the patient's life

**C: Spiritual community** and support

**A: How** does the patient wish spiritual issues to be **addressed** in his or her care?

### **SPIRIT**

**S: Spiritual** belief system

**P: Personal** spirituality

**I: Integration** with a spiritual community

**R: Ritualised** practices and restrictions

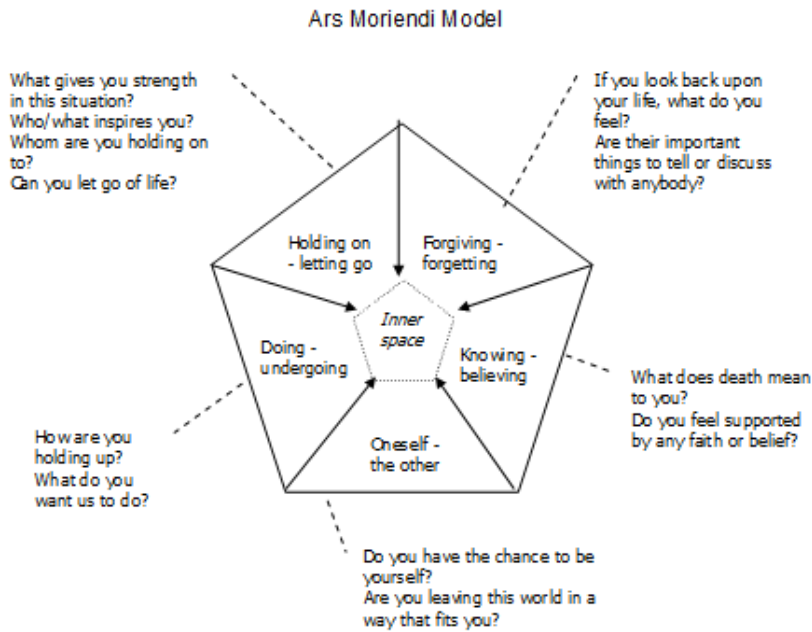
**I: Implications** for medical care

**T: Terminal** events planning

In various places in the Netherlands and Flanders, the '*ars moriendi*' model (the '*art of dying*' model) by Leget is used as an instrument to assess a patient's spiritual situation (see Figure 2). The model goes back to the medieval *art of dying*. The core concept of this model is the term '*inward space*'. Spiritual care focuses on recovery or enlargement of the inward space as a 'disposition by which someone can peacefully and freely relate to the emotions that are evoked by a situation'. The idea is that when someone possesses inward space, life issues can be regarded and considered from various vantage points. In order to help enlarge the inward space of patients it is important that care providers themselves possess an inward space. That fosters in patients the trust that they can turn to a care provider with their spiritual questions. In addition, it may help the care provider distinguish the various layers found in a patient's expressions, as discussed above.

The *ars moriendi* model distinguishes five major themes that may express themselves in the form of tensions or polarities in the face of imminent death. In each polarity the patient can feel himself being pulled back and forth between two extremes. Repeatedly it is the task (art) to find the right balance between both extremes. For each person that is a unique process.





**Fig. 2. Art of dying model**

## Instruments for healthcare chaplains

### Interpretation and appraisal

Besides the instruments for screening and for assessing spiritual history, healthcare chaplains have instruments for interpretation and appraisal of spiritual needs. (The American consensus document uses the term 'spiritual assessment'). That can provide an indication of the patient's questions, wants, wishes, needs, and spiritual resources. That is not done with a structured questionnaire, but with an interpretative framework that requires more extensive training. That goes beyond the professional competencies of doctors and nurses. The healthcare chaplain initiates an open conversation with the patient. With the aid of the interpretive framework the healthcare chaplain gradually develops a notion of the spiritual situation of the patient and the themes that are central to it. Interpretative models that healthcare chaplains can use are familiar to the profession and make up part of their professional competence. One can think of authors such as Fitchett, Leget, and Weiher.

# Policy

Palliative care is by definition multidisciplinary. Close multidisciplinary cooperation is of fundamental importance for spiritual care, but the various disciplines each have their own role and task. The following section of the guideline is structured according to a graduating scale (A, B, C) depending on the severity of the situation and the positioning of the roles of various care providers (see Table 1 - Types of spiritual care per discipline). It should be noted that in actual practice distinctions in this schematic framework can not always be clearly drawn.

**Table 1 - Types of spiritual care per discipline**

		<b>Doctors and nurses</b>	<b>Medical social workers, psychologists</b>	<b>Healthcare chaplains</b>	
	<i>Primary focus, access, and frame of reference</i>	<i>Somatic</i>	<i>Psychosocial</i>	<i>Spiritual</i>	
<b>A</b>	<b>Attention</b> (always)	Listening supporting, recognizing and screening*	Listening supporting, recognizing and screening *	Listening supporting, recognizing screening * and interpreting	Representing and connecting
<b>B</b>	<b>Counselling</b> (upon request of the patient)	Following the search process, referring, and assessing*	Following the search process, referring, ( ), and assessing*	Following the search process, ( ) referring, assessing*, interpreting and appraising*	
<b>C</b>	<b>Crisis intervention</b> (if indicated)	Detecting, referring	Recognizing counselling, treating and referring ( )	Recognizing counselling, (sometimes) treating, ( ) referring interpreting and appraising*	

\* See (diagnostic) instruments in [Diagnostics](#)

Comments on the table:

- In indicating primary focus, access and frame of reference the intention is not to exclusively separate professional domains, but merely to distinguish them. The distinctions point to the dimension of care for which a discipline bears final responsibility and possesses specialized expertise. In palliative care multidisciplinary cooperation (with mutual consultation) or (preferably) interdisciplinary collaboration is always desirable.
- Every discipline evokes its own reality ('world') that has a different effect on the patient. That influences what a patient tells a nurse, doctor, psychologist, or healthcare chaplain, respectively.
- Each discipline also has its own discipline-bound manner of helping or counselling, its own repertoire and role with regard to the patient.
- By their presence, healthcare chaplains evoke a different response than do doctors or nurses. They represent a dimension of meaning in life. Coming from a specific worldview traditions, healthcare chaplains can also represent other realities, such as a religious community or God. What is also characteristic of the work of healthcare chaplains is the dimension of connectedness (linking the unique life story with appropriate images, symbols, rituals, stories, and poems). That requires its own set of competencies along with those shared with other disciplines such as listening, supporting, recognizing, counselling, and treating.
- Listening and recognizing (see A in the Table) are always meaningful in themselves, but they also serve to prevent crisis.

- Volunteers in terminal palliative care are not included in this table. Nevertheless, they also can play an important role in the provision of spiritual care. Volunteers are present for the dying and those near to the patient in contributing time, attention, and support during the patient's last phase of life. Volunteers are less pressed for time and do not have the pressure of the professional healthcare system. Therefore, they sometimes have valuable information for professional care providers at their disposal.

## Attention

This guideline assumes that *attention* to the spiritual dimension of palliative care is always present. That attention can take two forms:

- an open, listening attitude
- a brief spiritual screening through which the spiritual dimension is allotted a place in the patient's file and is put on the agenda (see [Diagnostics](#))

### Open, listening attitude

Being attentive to spiritual matters and needs requires care providers to assume an attentive attitude of being present. Patients are vulnerable and in need of assistance. They have to expose themselves to care providers in many ways. For that reason it is important to create a safe atmosphere. Of course, proper care by doctors and nurses rests upon medical and nursing expertise, respectively. Spiritual care, however, also requires active commitment as a human being. Good care requires a receptive, caring attitude that shows openness and sensitivity for what people experience. Only then is it possible to properly observe the expressions and the layers of meaning that patients themselves provide.

Just like the patient, the care provider is also a person with his own past and peculiarities. By means of self-observation and self-reflection a care provider can become aware of his own responses and their consequences in his interactions with patients. That can help avoid erroneous interpretations of the patient's signals. The degree to which a care provider is able to acknowledge and deal with his own powerlessness or anxiety influences his ability to exercise presence when the patient feels powerless or anxious. Regular self-observation and self-reflection, for example in the form of (peer) supervision, are therefore recommended.

It is not only important for the care provider to acknowledge and deal with his own emotions. In order to be able to take time for spirituality, he has to open himself to it. Before care providers can listen to others effectively, they first have to be able to listen to what is going on in their own inner self. Conversations on spirituality can touch one deeply. Patients often well sense with which persons they can or cannot talk about something. More so than in other dimensions of care, the person of the care provider determines what the patient shares. When a patient senses that a care provider does not have an antenna for the spiritual dimension of care, the chance is great that the patient will not express himself on the matter. However, care providers who take everything too seriously may be inadequately attuned to the patient's needs. Andries Baart speaks in this respect of the importance of *diluted severity*: the art of talking about serious matters casually and with ease while feeding or washing. Diluting serious matters with daily affairs makes it easier to talk about them. Humour can also be a fantastic way of lightening up the atmosphere because it breaks through the intensity of the dying process. But do employ humour skilfully and as mildly as possible!

### General recommendations with regard to providing spiritual care

#### *Conditions*

- Be open to your own inward spiritual dimension.
- Take some time (The patient will withhold more profound questions if the care provider appears to be in a rush).
- Put the patient's aims and wants at the forefront.
- Respect your professional and personal limitations.

#### *Atmosphere*

- Radiate peacefulness and quiet.
- Provide safety and a trusting relationship (compassion).

- Be present in the here and now, without imposing yourself.
- Do not make things too light or too heavy.
- Just be yourself and talk person to person.

### *Process*

- Tune yourself in to the desires and needs of the patient and those near him, in every phase again.
- Show genuine interest and attention for the patient's feelings. Ask things with sincere interest.
- Listen and observe attentively. Pose open questions.
- Assume an open attitude. Respond with empathy.
- Suspend any judgment. Give the other the opportunity to work through his searching or struggle in his own way.
- Offer advice and solutions at the right moment. No one is looking to be saved. Important is that a person makes contact with his own strengths.
- Do not take anger or blame personally. They are often an expression of anxiety or sorrow.
- Remain available for the patient and those near to him, even if nothing else can be 'done' or if care is refused.

### Everyday resources or worldview as a context for interpretation

When a care provider is confronted with the life and death issues of a patient, it is important to be able to relate those questions to a broader frame of reference. A frame of reference provides support for the care provider and makes communication with and referral to colleagues easier. The most obvious context for existential meaning consists of the roles that a person fulfils in daily life (partner, father, mother, child, professional, member of a football club, churchgoer). In relation to everyday sources of inspiration and strength one can speak of 'every-day spirituality'.

From time immemorial religious and worldview traditions have also provided significant frameworks for understanding and interpreting spiritual issues. It is important to realize that there are many denominations within every worldview or religion. In addition there is a difference in the manner in which followers practice their religion. People may be orthodox or quite liberal. Additionally, it is not uncommon that persons who have become thoroughly secular rediscover religious values from their upbringing.

Spirituality is a dynamic concept and many different processes can be involved. Whatever process one goes through, an attitude of acceptance and respect for someone's convictions on life is important for everyone and for their wellbeing. Such an attitude precedes any specific knowledge on the rituals of the worldview involved.

The challenge for the care provider is to be a concerned, interested but discrete visitor. It is of great importance never to voice an opinion about various customs but to provide support. However, if a patient provides an opening, a personal conversation need not be avoided.

Even though for many people religious traditions still fulfil the role of lending meaning to life, an increasing number of patients has no connection to religion. And increasingly there are patients who draw upon elements from various traditions in order to compile their own worldview.

## **Counseling**

The aspects of *attention* and *counseling* somewhat overlap each other. The major difference between them is, however, that attention is a task for care providers in every situation, whereas counseling goes a step further, and only is provided when the patient wants it. In other words, general attentiveness to life issues and the provision of counseling are both part of good care. But counselling may never be imposed upon a patient.

Undergoing existential struggle is an important step in finding a new psychological and spiritual balance that enables the patient to deal with the imminence of the end of life. For that reason an essential struggle should not be avoided or suppressed. Because it involves a patient's very personal and unique process, it is important that the patient himself can determine when he is able to confront the threat of death. A care provider who asks the right questions can help the patient move towards that moment. Similarly, it is important that the patient has the time and the space to deal with the struggle in his own way.

All care providers, including doctors and nurses, can play a role in spiritual counselling on the basis of their own profession. There is a certain degree of training needed in order to do it skilfully. This guideline cannot be a substitute for proper training, but does address issues that one needs to take into consideration.

Counselling in spiritual care entails conversation with a patient on the issues that concern him in relation to the medical or nursing treatment. The general recommendations for providing spiritual care in category A

are applicable. With regard to counselling it is important for doctors and nurses to have knowledge of the spiritual process a patient goes through or in which he is caught up. In that light one can observe the searching or struggle of the patient and detect what is going on. If needed, the patient may be referred to another professional (dependent upon one's own judgement or that of the patient or those near to him). Some patients may need support in the form of conversation, texts, or rituals. Healthcare chaplains are equipped to meet those needs. In addition, they may, just as some psychologists, employ other techniques such as meditation or visualization.

## Crisis intervention

With regard to counselling it is the patient who indicates if it is desired or not. In crisis intervention, the care provider can take the initiative. Depending on the severity of the situation and the patient's capacity to cope, the existential searching or struggle generally could last for a few days or a few weeks. If it lasts longer, the patient needs to be referred to a healthcare chaplain or psychologist, especially if the patient can barely function, or when the caregiver senses a severe need and does not know how to deal with it himself. A medical social worker may also provide help in that case. Because palliative care is anticipatory, contact with those disciplines will ideally already have been made at an earlier stage in the disease process.

## Referral

Referral for spiritual care begins in many cases with consent among care providers who have built up a significant relationship with the patient. ('Do you hear the same (spiritual) theme that I hear? Do you recognize the same need?') The other professional to whom referral is made may be a healthcare chaplain, but it may also be the treating doctor, a psychologist, a nurse specialist or nurse practitioner, or a social worker who is already involved in the case for other reasons. It may also be a personal counsellor or the case nurse who has primary responsibility. The healthcare chaplain is as far as his primary focus and frame of reference is concerned a specialist in this area. He can also explore the theme or the spiritual need with the patient, and if necessary, with those near to the patient.

People who are active in a worldview tradition often have a clear preference for counselling from that tradition. With regard to persons who at one time had a relation with a specific tradition, it is not always a good idea to blindly refer them to a representative from that tradition. In some cases, the relationship with tradition has become tattered or broken. It is then important to know if the break is viewed as a liberation or as a loss. In the event of a relationship to a tradition that has become tattered, it may be advisable to call in a healthcare chaplain who has knowledge of the tradition, but who does not explicitly represent the (religious) community. If the relationship with a religious tradition has been broken, restoration of contact with the religious community through an official representative of the community may well be a good option. Disappointment cannot, however, be ruled out, because what one left behind in a church can often no longer be found there. The community will have changed, as the person in question has changed. Sometimes the patient's hesitation (or that of those near to him) is so great that a healthcare chaplain is needed bridge the gap. (To the comment, '*They'll look strange at my coming back after so many years,*' a response could be, '*I think they'll be happy to see you again, and they'll be happy to be able to be of some help to you in this situation.*') It may be that the hesitation is so great that it would be better not to make any attempts to recover the broken relationship with the tradition. The focus should then lie on appealing to the patient's personal sources of inspiration.

Healthcare chaplains have spiritual care as their primary focus and frame of reference. In addition, psychosocial techniques and theories play a role in their work. Spiritual processes invariably involve psychological, emotional, and social components. The primary focus and frame of reference of psychologists and medical social workers is related to the psychosocial dimension of care. That does not mean that spirituality cannot be an important theme in their counselling. A good deal of expertise and experience is found in both fields of specialisation. Depending on the availability, personal involvement or the theme of a crisis, a patient can be referred to one professional or another.

## Referral to a healthcare chaplain

A healthcare chaplain is a professional specialised in spiritual care. Healthcare chaplains are usually, but not always affiliated with a religious or worldview tradition. However, by virtue of their professionalism, they can also provide spiritual care to patients from other religious or worldview traditions.

Currently, healthcare chaplains are mainly available in hospitals, nursing homes and in a number of convalescent homes. In exceptional cases a request can be done for a healthcare chaplain via home or telephone support services. The funding and the policies of hospices do not always allow for a healthcare chaplain to be affiliated with the hospice. In many cases working arrangements have been made with local pastors/clergy and healthcare chaplains from organizations in the vicinity. In addition there are independent healthcare chaplains with their own private practice who may be called upon.

Within his scope of practice a healthcare chaplain can take the initiative to contact patients and those near to them. However, in many cases the contact will arise because the healthcare chaplain is already part of the palliative care team. Another care provider can also refer a patient to a healthcare chaplain.

Referral to a healthcare chaplain is desired when:

- A patient or those near to him explicitly request a healthcare chaplain.
- There is an impression that a person would benefit from some support, but cannot express that himself. The need can be clarified by checking if 'there is need to talk about it with someone' and making a referral if necessary.
- There is an impression that there is an implicit need for support, but that a straightforward offer would lead to denial. A healthcare chaplain may be requested to casually come by and make acquaintance.

In almost all cases, it is advisable that the referring care provider also remains involved in the process. The fact that the care provider has observed and listened to the patient means that a deeper lying need has been detected. The patient can experience that involvement as significant. That reflects the quality of the care relationship that has developed. It is not easy to define where the attention for spirituality belongs to the role of nurse or doctor, and where it should be transferred to the responsibility of the healthcare chaplain.

It is important for nurses and doctors to keep their professional and personal limits in view. A patient asking a night-shift nurse 'Would you pray with me?' may be met with cordial or tactful consent by one nurse, while another nurse might not know how to respond. But also in situations in which a care provider is confronted with his own emotional limits (e.g., the patient is of the same age as the care provider, or has children of like age as those of the care provider), referral is a sign of professional action. Respectful presence and response is important.

### Important indications for referral:

#### *Intrinsic reasons:*

- when you suspect that something more is needed, but you do not know what (or how).
- when the spirituality of the other person must be reassessed (e.g., when life expectancy suddenly and dramatically changes).
- when experiences of powerlessness and (actual and existential) guilt arise in the patient.
- when the patient and/or loved ones have a need for rituals.
- when you suspect an existential crisis.

#### *Personal reasons:*

- when you are confronted with personal limitations: '*I understand that this is important for you, but I am unable to be of help.*'
- when you get tangled up in your own life issues or are confronted with your own hopelessness or anxiety, with sorrow, pain or feelings of powerlessness.

#### *Practical reasons:*

- when you run up against your own professional limits.
- when you cannot at a certain moment provide the needed quiet and space.

### What can be expected from a healthcare chaplain?

Healthcare chaplains take various approaches to care. Depending upon his own religious or worldview background, the healthcare chaplain employs a specific conceptual frame of reference with its own rituals, but in a manner appropriate to the support of the patient and to his wishes. Nevertheless, there are a number of general lines to follow.

In the first place, a healthcare chaplain focuses primarily on the other person, the patient. The patient's story and life are the primary focus, not those of the healthcare chaplain. The extent to which it is important to have a healthcare chaplain from, e.g., a Catholic, Protestant or Humanist background, is mostly up to the patient himself. In some situations, it is important that the healthcare chaplain speaks the same religious or worldview language and is familiar with the accompanying rituals and customs. In other situations, it may be refreshing to speak with someone who has another perspective on life.

In the second place, a healthcare chaplain does not focus primarily on a problem that has to be solved. Because spirituality is interwoven with the entire person, the healthcare chaplain focuses primarily on the person as a whole. The whole person is regarded to be a unique human being who can never completely know and understand himself. Ultimately, the deepest layers of every person are a mystery. It is in the deepest layers that issues of life and death and spiritual processes occur. Those layers are not readably accessible or manageable. They can be 'touched upon so that a patient can again make contact with his own sources of meaning, purpose, inspiration and strength.

### Place in organizational policy

Other care providers can enlist the aid of a healthcare chaplain for the following matters:

- consultation and advice with regard to questions about spiritual care.
- training in the area of spirituality, religion, worldviews and meaning.
- translation of spiritual care into local formulations of care policies and national protocols and guidelines.
- attention (care) for care providers and the role of confidant for other care providers.
- contributions to follow up care, e.g. in organizing memorial services or in follow up sessions with family.
- collaboration at policy levels and contributions to the attention paid to issues of meaning and spirituality for patients and care providers.
- consultation and advice for doctors and home care workers in local palliative care networks.

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

When an existential crisis lasts longer than a few days and is accompanied by severe psychological problems, one should also refer the patient to a professional psychologist or psychosocial care provider. This guideline does not address the substantive counselling provided by psychologists or social workers. It is, however, important to keep in mind that it may be valuable to have healthcare chaplains, medical social workers and psychologists work together in such a situation. In order to provide an impression of what type of care might be involved in a referral by care providers from a palliative care team, we briefly address the major aspects of specialised treatment of an existential crisis.

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

*With regard to the past:*

- cognitive restructuring, reappraisal
- drawing up a life balance

*With regard to the present:*

- treatment of reversible physical, psychological, and social problems
- maintaining outward care and appearance, dignity and independence
- cognitive therapy: reappraisal of the current situation
- insight-driven therapy to recover meaning

*With regard to the future:*

- cognitive therapy
- setting attainable short-term goals
- encouragement of conversation on the fear of death and learning to deal with feelings and emotions (current, past, future)
- encouragement conversation on religious and worldview issues and/or referral to a healthcare chaplain.

### **Case history**

#### **An illustration of what a psychologist can do in a (severe) existential crisis**

A psychologist is requested to see Ms. Hendriks, a 45-year-old woman on the oncology ward. The reason for referral is that Ms. H. had a severe emotional reaction to the bad news that she received earlier that day. During that consultation, she was told that the treatment of her colon carcinoma was unsuccessful and that palliative treatment was all that could yet be provided.

Psychological: Previously Ms. Hendriks always expressed a positive attitude and was able to accept her situation. She is shocked that that has now changed and she feels only anger and anxiety. Nevertheless, she thinks that she should come to accept the news and asks for psychological support. There is some haste because she lives far away and will be going home the next morning.

Diagnosis: The care provider is of the opinion that there is existential distress. That is how the patient experiences her crisis and she requests an intervention. Although the emotions are very intense, the expectation is that the coping process can proceed in a normal fashion. That is discussed with her. However, because her emotions are very intense and she does not dare to go home, she asks if there is something that can be done.

Advice: Help is possible by administering *flooding* in combination with a variant of *thought stopping*. Flooding is exposure to the anger and anxiety-provoking reality, that allows the feelings to be extinguished. Thought stopping is the interruption of the stream of unpleasant thoughts and feelings so that the patient can learn to channel her emotions.

Implementation: The techniques are explained and a taxation is made with the patient of what the new reality is. She states: the approach of death, the permanent character of a stoma, being bed-ridden and increasing dependence. The patient is asked to vocalize these things ('I am going to die of this disease', 'I will never get rid of this stoma', etc.) and to let the accompanying feelings arise freely. Her husband, who is present, is asked to remain at the background and restrain from any comforting action. After fifteen minutes, the subject is changed and pleasant memories from her youth are recalled. This procedure is repeated twice. The intensity of the emotions decreases and the patient expresses confidence that she can manage again.

Follow-up: Three weeks later she is re-admitted due to pain. She says that she was able to accept the situation and that she and her husband had a good period of time together. Even the issues that were first perceived as negative, had taken on a positive meaning. The stoma, for example, is now a blessing, under the current circumstances, it would be agony to have to use a bedpan.



## Summary: the ABCs of spiritual care

Patients requiring palliative care sense, more strongly than before, that life is finite. That confronts most people with enormous questions: issues of life and death, that can also be called questions of meaning or existential questions. Many people seek answers to the big questions of life in their worldview or religion. Those questions affect the physical and psychosocial welfare of patients. Therefore, in order to determine proper care and treatment it is important to know what people consider meaningful in and about life.

In this guideline we chose the term **spirituality** to refer to those issues of life. In that way the guideline is in accordance with the definition of the World Health Organization (WHO) for palliative care, which speaks of attention for needs of a physical, psychosocial, and spiritual nature.

Three issues are characteristic of spiritual care:

- Focus of attention on this care dimension is important from the beginning of the palliative phase so that questions and utterances can be contextualized within the entire spiritual process.
- This care dimension always has different layers of meaning that are interwoven with each other.
- At issue are questions and utterances for which generally no solution can be given, but that do require attention and response.

It is very important for every professional to be aware of these three characteristics and to be able to deal with them appropriately. In addition palliative care is per definition multidisciplinary. Different disciplines have their own role and responsibility also with regard to spiritual care. This guideline is based on a threefold distinction (A, B, C) within a graduating scale of severity, in which the roles of various caregivers can change.

The scale involves:

- A. situations in which *everyday attention* to life issues is sufficient;
- B. situations in which patients need counseling on life issues or in which they experience normal struggles for which counseling by an expert would be beneficial; and
- C. situations where the struggle with life issues leads to an existential crisis requiring *crisis intervention* by a healthcare chaplain, medical social worker, or psychologist.

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