

summary of the guideline  
**existential and  
spiritual aspects of  
palliative care**

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Existential and Spiritual Aspects of  
Palliative Care

It is in your best interest as a care giver  
to be familiar with this guideline.

# introduction

Patients receiving palliative care and their loved ones are confronted by the fact of human mortality. This awareness can have a significant impact on these patients' peace of mind and emotional state, as a result of the effects of illness, awareness of impending death, and perhaps fear of death. The national guideline 'Existential and Spiritual Aspects of Palliative Care' provides insights and tools for recognising and discussing the existential and spiritual questions and needs of patients and their loved ones.

## Existential and spiritual

The terms existential (matters of meaning and purpose) and spiritual are used synonymously in this guideline. We use the European Association for Palliative Care (EAPC) consensus-based definition: 'Spirituality (or: a sense of meaning and purpose) 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.'

## Origins and process

The existential/spiritual dimension always plays a role in human life, yet it is often unconscious and unseen. Unexpected events tend to bring existential concerns to the fore, when what is happening does not match a person's image of themselves and of life. Sometimes this leads a person to struggle for a while. This is normal. Some people find it comforting or useful to receive support when they are struggling; others prefer to be left alone. A small minority requires the help of a specialised care giver.

## Existential and spiritual aspects of palliative care

- Always be alert to the fact that life/existential questions or spiritual needs may underlie problems that present as physical, emotional/psychological or social symptoms.
- To distinguish your own role from the role of specialised care givers, you can make use of the ABC model:

### (A) Attention

Devote attention to existential/spiritual matters with every patient receiving palliative care, and at all times. Show interest and focus your attention on the needs of the patient/friends and family at that particular moment. There are two forms of attention:

- an open attitude of listening, and/or
- a brief diagnostic exploration of the spiritual dimension, which is then recorded in the patient's record and becomes a priority.

### (B) Accompaniment

There is no clear demarcation between Attention and Accompaniment. The big difference between the two 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. 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.

# existential and spiritual

## (C) Crisis intervention

Watch for signs that may indicate a spiritual crisis, such as:

- 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;
- a profound change in the person;
- a circular, sometimes desperate process in which balance is sought but not found.

## Hope in the existential/spiritual process

Consider which perspective on hope is taken by the patient (and loved ones): hope as expectation, hope as coping and/or hope as meaning.

## Talking to patients

- Check if the patient would like to talk about what the situation means to them.
- 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.
- Ask open questions, and point out and verify non-verbal signals.
- Arrange for a professional interpreter for a palliative patient who does not speak Dutch fluently, even if the family is willing to interpret.
- 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.
- Utilise the cue questions of the Mount Vernon Cancer Network (MVCN):
  - how do you make sense of what is happening to you?
  - what sources of strength do you look to when life is difficult?
  - who would you like to have with you? Who would be able to offer you support?
- Alternatively, make use of the sample questions in the diamond model regarding the five themes and their relevant poles (see next page).

# existential and spiritual

## The diamond model

### saying goodbye

holding on - letting go

- 1 What or whom are you holding on to?
- 2 Who or what gives you strength in this situation?
- 3 What is it hard for you to let go of?

### suffering

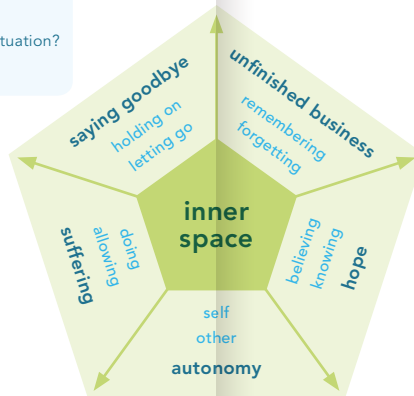
doing - allowing

- 1 How do you deal with the pain?
- 2 What else would you like us to do?
- 3 What would you like us not to do?

### autonomy

self - other

- 1 Do you have the space to be yourself during your illness?
- 2 What are you learning in this phase – with and from others?
- 3 Is your life 'complete'?
- 4 Are you leaving this life in a way that is fitting to who you are?



### unfinished business

remembering - forgetting

- 1 When you look back at your life, what do you feel?
- 2 Are there things you would still like to put right?

### hope

believing - knowing

- 1 Do you feel supported by a certain faith or belief?
- 2 Do you sometimes think about what happens at the end?
- 3 What does death mean to you?

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

Use existing instruments and methods to identify the spiritual dimension of palliative care needs. Dutch examples include the 'Lastmeter' (Distress Thermometer), the IKNL method 'Signalering in de palliatieve fase' and the 'Utrechts Symptoom Dagboek' (Utrecht Symptom Diary).

# existential and spiritual

## Referral

Determine whether referral to a specialised care giver is necessary by evaluating your talk with the patient about existential/spiritual matters. Use the ABC model.

A referral is called for if you identify or suspect an existential/spiritual crisis.

- 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.
- To begin with, refer to a spiritual counsellor or someone from the spiritual tradition of the patient – unless special expertise (that of a psychologist or medical social worker) is needed, such as in the case of an existential crisis.
- Assess whether there is a psychiatric component to an existential/spiritual crisis, and where necessary refer to a psychiatrist.

## Reporting

Refer to the patient's beliefs and /or cultural background in the care plan and describe their needs with respect to beliefs and life philosophy.

Reach an agreement that all disciplines involved report findings and interventions in terms of:

- the ABC model: (A) attention, (B) accompaniment, (C) crisis intervention;
- the Mount Vernon Cancer Network cue questions; and
- the themes and/or relevant poles in the diamond model.

## Self-care

Caring for others – and especially caring for palliative patients and their loved ones – is a source of great satisfaction, yet it also requires a great deal of 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.



Consult the most recent  
version of the guideline.



**Edition**

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