

WISSENSRAUM NO. 19

PALLIATIVE CARE – ILLNESS, SUFFERING, DEATH AND SPIRITUALITY

Religious and worldview-based conceptions at the end of life

“When people reach the limits of life, accompaniment needs more than symptom control.”

AKADEMIE DER WEISHEIT — WISSENSRÄUME

◆ 1. When the Question Changes

In the course of a serious illness there comes a point at which the question itself is transformed.

For a long time it runs: What can we do? Which therapy is possible, how can pain, breathlessness, nausea and restlessness be brought under control? These questions by no means lose their importance in palliative care. Precisely where an illness is no longer curable, the careful treatment of distressing symptoms gains weight. The body remains the place where illness is experienced, and pain, breathlessness and weakness are not philosophical constructions.

And yet, at some point, even very good symptom control no longer suffices to understand what is happening to a person. For a life-limiting illness changes more than a body. It changes time, relationships, and the future that until then stood self-evidently in the background. Roles dissolve, certainties are shaken, and a person comes into contact with questions that for decades needed no room. What remains of my life? What will become of those I leave behind? Is there something I still need to say, to forgive, to ask forgiveness for? Why is this happening to me of all people? Where is God, and what if no one is there? What comes after death, or does anything come at all?

With such questions the landscape of accompaniment changes. Medicine does not end, but it suddenly finds itself in a larger space, the space of the human being. This Wissensraum enters it. It regards palliative care as a multidimensional happening and asks what stance does it justice: a stance that neither interprets nor instructs, but leaves the person room for his or her own search. The ethical questions at the end of life are unfolded in Wissensraum No. 2 — The Ethical Compass in Palliative Care; here the concern is the experience of illness, suffering and dying, and how people live through it with their religious and worldview-based convictions.

“Medicine does not end at this border. It finds itself again in a larger space.”

◆ 2. The Person Behind the Diagnosis

A diagnosis can be named. The person who bears it cannot be fully captured in it.

A tumour can be located, a weak heart classified, an illness described. But the person lives in a story that began long before the illness. He belongs to other people or has lost people, he carries memories, hopes, injuries and convictions within him, he has loved, worked, believed, doubted, decided and neglected. With a life-limiting illness this biography does not vanish behind the diagnosis. On the contrary: some things now emerge more clearly than ever before.

So a person can be well cared for physically and yet deeply disquieted. A patient says she has no pain, and yet lies awake at night because for twelve years she has had no contact with her daughter. Another suffers from pronounced symptoms and nevertheless experiences moments of peace, humour and connection. Both show that illness and suffering are not synonyms. Illness can be read from findings. Suffering arises where a person experiences that something essential to him is threatened or lost: his independence, his role, his dignity, his future. It therefore depends not only on the severity of the illness, but on what it touches in this one person.

This distinction is among the preconditions of palliative accompaniment. Whoever overlooks it may carefully treat what is measurable and fail to notice what is actually keeping the person from sleep. Whoever takes it seriously asks not only where it hurts, but also what hurts right now and for what there is no finding.

“It is not the illness that suffers. It is the person who suffers.”

◆ 3. Total Pain — When Pain Becomes More Than Pain

From the hospice movement comes a language for the experience that suffering at the end of life wears many faces at once.

The concept of total pain describes four dimensions that stand side by side and interpenetrate: the physical, the psychological, the social, and the spiritual or existential. In lived experience they cannot be cleanly separated. A pain can begin physically and become more unbearable through fear. Breathlessness can be a physiological symptom and at the same time trigger fear of death, which in turn intensifies the breathlessness. An unresolved quarrel in the family can heighten inner restlessness so far that symptoms become unendurable which would otherwise be bearable. And the question of the meaning of one's own life can surface in the middle of an apparently purely medical conversation, over a dose adjustment or a question about breakfast.

The concept thus does more than widen the notion of pain. It changes the perception of who is actually suffering: not an organ, not a symptom, but a person who cannot be broken down into mutually independent areas of responsibility. What appears to one profession as a physical problem meets another as a question of relationship and a third as a question of guilt and forgiveness, and it is the same person in whom all of this coincides. No dimension can therefore replace another.

“A person cannot be broken down into mutually independent areas of responsibility.”

◆ 4. From the Outside to the Inside

Dying can be described as a movement in which the outer grows quieter and the inner gains weight.

This image is no staged model and no prescription for how a person ought to die. It describes a direction of view that some companions recognise in practice. Dying often becomes visible first in the body, in weakness, pain and the decline of what a person is still able to do. Beneath it lie breath and strength, restlessness and an exhaustion that sleep can hardly ease any more. Further within lie feeling and thinking, with fear and anger, sadness and defiance, with humour and tenderness. Deeper still, the questions of meaning, guilt and significance meet. And in the innermost, something sometimes shows itself that can hardly be named: peace, wonder, stillness, a moment in which nothing needs to be explained any more.

From this image follows first of all a task of perception, for on each level something different helps: relief and attentive touch for the body, pauses for breath and strength, a hearing for the feelings, room without an answer from outside for the question of meaning, and for stillness that no one fills it. In acute distress, relief always takes precedence: a person who cannot get air cannot ask about meaning, and inviting him to do so would not be spiritual care.

Nor may the image become an expectation. Not every person reaches the innermost stillness, and whoever does not has missed nothing. How this thought can be unfolded into a map of accompaniment is shown by Wissensraum No. 20 — Three Bodies, Five Sheaths.

“With every layer that grows quieter, the significance of what remains grows.”

◆ 5. The Invisible Dimension

The spiritual dimension has one peculiarity: it is often invisible.

Blood pressure can be measured, pain described on scales, a wound observed and a laboratory value compared. Meaning cannot be measured. Hope has no reference range, reconciliation appears on no monitor, and the fear of having lived without significance can be assigned to no parameter. Perhaps that is precisely why there is a danger of overlooking it, or of hastily consigning it to pastoral care.

Yet spirituality and religion are not the same. Spirituality describes the individual search for meaning, significance, connection, hope and support, likewise what a person experiences as sacred or inviolable, and it also includes the possible loss of all this. It can be lived religiously: a

person prays, believes in God and draws strength from a community. Another rejects every religion and experiences connection in nature. One listens to music, another would like to touch her dog once more, someone asks for the anointing of the sick. Yet another says: “After my death everything is over.” This conviction too belongs to the worldview reality of this person and deserves the same respect as prayer. Spirituality is not bound to religious affiliation.

Spiritual care therefore does not begin only when someone asks for a clergyman. It can begin in a very simple question that presupposes neither denomination nor prior knowledge.

| *“What sustains you?”*

◆ 6. No Addendum, No Exaltation

Spiritual care is neither a decorative addition to medicine nor its spiritual exaltation.

The term can give the impression that, beside medical, nursing and psychosocial care, there is yet another area to be added if needed. But where palliative care perceives the person in his wholeness, it inevitably also meets his questions about meaning, relationship, guilt, farewell and finitude. What matters is whether this dimension is perceived, and that means at the same time respecting its limits. Not every restlessness is existential, not every despair calls for work on meaning, not every silence is transcendence. What appears as an existential crisis can just as well be an expression of depression, delirium, untreated fear, insufficiently relieved symptoms or simple exhaustion, and these states are to be clarified professionally before they are interpreted spiritually. The depressive narrowing of one's own possibilities is considered separately in Wissensraum No. 10 — Depression as a Blocked Transition.

An expressed wish to die requires particular care. The wish that dying may come soon, the wish to hasten death, and suicidal thoughts are not the same, even though in language and in experience they can touch one another. A wish to die must therefore be neither hastily understood as suicidality nor classified as a purely existential or spiritual statement. It calls for an open conversation, for the question of what suffering is expressed in it, and for a multiprofessional assessment.

| *“Wholeness means making no dimension the explanation of all the others.”*

◆ 7. The Question of Why

Hardly any question carries more weight at the end of life than this one: Why?

Why me? Why did God allow this, why does my prayer not help? For millennia people have tried to interpret suffering, and the patterns of these interpretations recur in almost all cultures. Suffering can be understood as punishment, accompanied by guilt and shame and the belief of having to atone for earlier actions. It can appear as a test, a trial of endurance, often linked with the idea of a higher plan or a lesson for the soul. And it can count as a basic condition of being human, as part of a life that includes illness and death, without any intention having to lie hidden behind it.

Such interpretations can sustain, and they can burden. Whoever feels punished adds to the suffering a guilt that perhaps no one has imposed on him. None of these interpretations is right or wrong in itself, and none may be imposed on a suffering person from outside or hastily evaluated.

Herein lies an essential limit of professional accompaniment. It may ask about the meaning a person himself gives to his experience, but it may not produce this meaning for him. Whoever explains to a suffering person that his illness is a test, fate, God's will or a necessary experience of his soul crosses this limit, even if the interpretation seems entirely coherent within one's own worldview. For what is comfort to the one explaining can be an additional burden to the one suffering. The dignity of what remains unresolved is the subject of Wissensraum No. 21 — The Right to Suffer.

“*The sufferer has the right to his own interpretation — and equally the right to none.*”

◆ 8. When Faith Sustains — and When It Breaks

Religion can be an extraordinary source of strength at the end of life. Yet it does not always sustain.

Prayers, familiar texts, songs, rituals, blessings, the community of those who pray along, and trust in a reality greater than one's own course can give security when almost everything else has become uncertain. At the same time, research on religious coping indicates that the same religion works differently depending on how it is experienced. Trust, the experience of being held, and the support of a community are frequently associated in studies with better psychological adjustment. The experience of being punished or abandoned by God, by contrast, tends to go with greater distress.

Religion can itself become a place of conflict. “Why does God let me suffer?” — “I believed all my life and prayed so much.” — “Has God abandoned me?” Here a spectrum opens that cannot be arranged in stages. There is lamenting and quarrelling, which is an expression of pain and not a rejection of faith. There is doubting and struggling, the search for control and meaning. And in some there is a form of acceptance and surrender, a yielding to the unavoidable. These movements alternate; none is better than another, and no one has to arrive at acceptance.

Doubt is not necessarily the opposite of faith, lament not the opposite of hope, and anger not the failure of spiritual development. It becomes threatening where a person feels abandoned by God, regards his praying as in vain, or experiences everything as meaningless and sees no way out. One then speaks of spiritual distress. It should not be borne by one person alone but calls for a careful assessment by several professions: pastoral care, psychology, nursing and medicine together.

“*Sometimes the deepest spiritual engagement consists in quarrelling.*”

◆ 9. What Comes After?

Hardly any border of human experience has produced as many images as death.

There is the idea that the person is preserved as a person and rises to a new life with God. There is rebirth, a renewed embodiment in the cycle of births in which a path continues. There is the hope of liberation from the suffering-laden cycle of conditioned existence, of an extinction that is thought of not as annihilation but as the end of suffering. There is dissolving into a greater ground, living on in descendants, work and memory. And there is the conviction that with death consciousness ends for good, and that a life receives its meaning not from a beyond but from itself.

These conceptions are not interchangeable. They stem from different religious, philosophical and worldview traditions and each has its own presuppositions and hopes. Whoever hopes to rise again hopes for something other than one who trusts in a new embodiment, and again something other than one who hopes for liberation. Where one hope is directed at the preservation of the person, another is directed precisely at its dissolving. In everyday nursing, these concepts must therefore not be mixed. The sentence “You’ll be back” can sound, to a person whose hope is resurrection, like a denial of his faith.

Within every tradition, moreover, there are currents of their own, and many people carry conceptions that cannot be assigned clearly to any teaching: brought along from childhood,

changed in life and examined anew in the face of death. These too deserve respect. Culturally sensitive accompaniment therefore requires more than knowing something about religions. Knowledge gives orientation, but a label does not yield a need: not every member of a faith community wishes the same, and not every person without religious affiliation is free of rituals, of hope or of experiences he feels to be transcendent. This applies to prayer and blessing in dying just as to touching the body, care by women or men, and the handling of the deceased. From this follows a principle for the whole of accompaniment: know religion, ask people. An overview of traditions and of dignity beyond death can be found in Wissensraum No. 2 — The Ethical Compass in Palliative Care; what remains of a person in others, even when no afterwards is conceived, is considered in Wissensraum No. 8 — The Echo of Life.

“Whoever replaces another person’s image of death with his own takes from him what he holds on to.”

◆ 10. Grasping Instead of Querying

Spiritual needs cannot be queried like vital signs. They want to be perceived.

Professional care is accustomed to collecting information: Where is the pain, since when, how strong? Spiritual concerns elude this logic, because they seldom appear in question-and-answer form. They show themselves in subordinate clauses, in pauses, in requests that seem trivial at first. “I’d like to go outside” can be a simple wish or touch a memory. “Please put some music on” can mean distraction or the longing for something that has accompanied a whole life. “Why should I go on living at all?” can contain much and calls for careful assessment, as described.

The grasping that takes the place of querying proceeds slowly and allows pauses, for in the pause there often arises what could not be said in the answer. It asks further instead of interpreting: “What do you mean by that?” It attends to breath, voice and non-verbal signals, and it notices its own resonance, the stirring a sentence sets off in the listener which, unexamined, could become an interpretation. Structured conversation guides ask what gives strength, how important it is at present, and whether a sustaining community exists. They give security especially at the beginning, but they are memory aids and not forms. One of the most beautiful open questions for everyday use is also one of the simplest: What is sacred to you? It presupposes no religion, yet leaves room for one.

Perhaps the art of spiritual history-taking therefore lies less in asking as many questions as possible than in hearing when behind an answer another question waits.

“Behind many an answer, another question waits.”

◆ 11. When Words End

Not every experience can be told. Sometimes words are missing, and then actions can carry meaning.

A candle is lit. A window is opened, even after death, so that the room becomes wide. A letter is written that is never sent, photographs are looked at, a memory book is begun, a song sounds, a hand is held. Such symbolic acts need not be religious. They give inner processes an outer, tangible form and make accessible something that evades language. Letting go finds a form in them, reconciliation can be spoken even if the recipient never reads the letter, and thanks and appreciation can take shape in a life review that lets a person experience that a life was more than its last illness.

The value of such acts does not lie in their having to accomplish anything. They can give form to a moment: to farewell, to remembrance, to gratitude, to letting go, or also to what remains unfinished. What holds is that they are offered and not imposed. No ritual is obligatory, and no reconciliation may be demanded where it is not possible or not wanted. Sometimes the simplest gesture, a glass of water or a pillow set straight, is already the form in which attention happens.

“A ritual need not accomplish anything. It can give shape to a moment.”

◆ 12. The Person of the Companion

Whoever accompanies people at the end of life meets his own finitude.

This can hardly be avoided. The other's fear can touch one's own, his hope can speak to a longing of one's own, his conception of death can call forth agreement or resistance. Self-awareness therefore belongs to spiritual care as well. When do I interpret? When do I want to reassure because I can scarcely bear the uncertainty myself? When does compassion become taking over?

Two dangers are particularly near. One is projection: transferring one's own fears to the other, with the thought “I would be so afraid of death” and the unspoken assumption that he must feel the same. The other is proselytising, passing off one's own worldview as universally valid, whether in pious consolation or in an enlightenment that considers the other's faith outdated. Both are rarely meant badly, and both abandon the person at the very moment they want to come close to him.

Professional accompaniment needs closeness and needs boundary. The stance includes a serving without claim: the person one accompanies is not there to fulfil one's own needs. A compassion that exhausts itself becomes a danger, for the one who gives and for the one who receives. Breathing spaces and small transition rituals, such as consciously taking off work clothes at the end of a shift, mark the boundary between service and private life, and self-care is a precondition here and no weakness. The fine border between caring and carrying is considered in Wissensraum No. 23 — Care in the Light of Ayurveda.

“Spiritual care first requires the readiness not to make one's own person the measure of the other.”

◆ 13. A Shared Task

Spiritual care is not the task of one profession. It is the task of all who accompany a person.

Whoever hears a question during a dressing change that does not belong to the dressing change meets the spiritual dimension of a person, whether he wants to or not. Nurses, physicians, psychologists, social workers, therapists, volunteer companions and pastoral carers are all able to perceive it. This does not mean everyone must be able to do everything. It means everyone should be able to notice when more lies behind a request, and should know when and to whom to refer.

For there are situations in which perceiving is not enough: when people fall into spiritual distress, when they ask for ritual acts of their tradition, when questions of guilt become overwhelming or a wish to die appears. Then people are needed who are trained for it: pastoral care and religious accompaniment of the respective community, psychology and psychotherapy, social work, medical expertise. It belongs to the professionalism of all to call in help in good time, and to the professionalism of the specialists not to devalue the perception of others.

In the midst of this structure stand the relatives. They too ask questions of meaning and guilt, of hope and farewell, often more quietly than the patient and often with no one to whom they may put them. Their grief frequently begins long before the death, and their convictions can differ from those of the dying person. How care is structured for this, from outpatient support through palliative ward and hospice to the rights of the individual, is unfolded in Wissensraum No. 4 — Palliative Care 2026: The Architectural Foundation.

“Perceiving is the task of all. Deepening sometimes needs others.”

◆ 14. Conclusion — Presence Instead of Explanation

In the end there remains one of the most difficult demands of palliative accompaniment: that there are questions that cannot be answered.

Why this person? Why this suffering, this end? What comes after? No companion has to solve these questions, and perhaps he should not even try. For some questions are not questions of knowledge. They are the expression of an experience for which a person seeks a counterpart, and a hasty answer can close the space the question has just opened. Presence here means more than physical attendance. It means enduring one's own perplexity without leaving the other alone in it: to listen without immediately explaining, to ask without expecting a particular answer, to be silent without withdrawing. The stance that renounces filling a space with method is unfolded in Wissensraum No. 17 — Radical Presence, the fear that precedes dying in Wissensraum No. 15 — Fear as the Longing for What Must Happen.

Perhaps this is exactly where the invisible dimension of palliative care lies. Not beyond medicine and not against it, but where professional knowledge knows its limit and the person nevertheless does not slip from view. Where pain is treated without suffering being reduced to pain. Where religion is known without a person being pinned to his religion. Where hope has room without being demanded, and reconciliation remains possible without becoming a duty. Where a life may end unfinished. And where a person is accompanied even when no one can say any longer where his path leads.

Palliative care therefore asks not only: What can we still do? Alongside it, it can pose a second question: What does this person need in order to be perceived, even now, as the one he is? And sometimes an even quieter question opens within it, the one with which this Wissensraum began: What sustains you? Not every answer is spoken. Some shows itself in a memory, a touch, a prayer, a doubt, an opened window or in the silence of two people. What remains of accompaniment when we can neither take away a person's suffering nor answer his last question? Can we stay with him without filling his experience with our own interpretation? Perhaps spiritual care at this point has nothing to add.

“Perhaps its deepest task is to leave nothing out of the human being.”

∞ Further Exploration

Those who wish to pursue the questions touched on here will find adjacent explorations in the WISSENSRÄUME series:

- Wissensraum No. 2 — The Ethical Compass in Palliative Care
- Wissensraum No. 8 — The Echo of Life
- Wissensraum No. 10 — Depression as a Blocked Transition
- Wissensraum No. 15 — Fear as the Longing for What Must Happen
- Wissensraum No. 17 — Radical Presence
- Wissensraum No. 20 — Three Bodies, Five Sheaths
- Wissensraum No. 21 — The Right to Suffer

◇ Sources & Lines of Thought

This Wissensraum does not make a scientific argument. The following works show what its professional and scientific statements connect to — above all those of chapters 3, 5, 6, 8, 10 and 11.

- Cicely Saunders: *The Management of Terminal Illness*. London 1967. Origin of the concept of total pain.
- D. Clark: 'Total pain', disciplinary power and the body in the work of Cicely Saunders, 1958–1967. *Social Science & Medicine* 49 (1999), 727–736. On the development of the concept.
- World Health Organization (WHO): *Palliative care*. Fact sheet. Definition of palliative care including physical, psychosocial and spiritual problems.
- C. M. Puchalski et al.: Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. *Journal of Palliative Medicine* 12 (2009), 885–904. Consensus-based description of spirituality and spiritual care.
- C. Puchalski, A. L. Romer: Taking a spiritual history allows clinicians to understand patients more fully. *Journal of Palliative Medicine* 3 (2000), 129–137. Structured spiritual history.
- E. Frick, C. Riedner, M. J. Fegg, S. Hauf, G. D. Borasio: A clinical interview assessing cancer patients' spiritual needs and preferences. *European Journal of Cancer Care* 15 (2006), 238–243. Interview guide for spiritual history-taking.
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- K. I. Pargament, B. W. Smith, H. G. Koenig, L. Perez: Patterns of positive and negative religious coping with major life stressors. *Journal for the Scientific Study of Religion* 37 (1998), 710–724.
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- H. M. Chochinov et al.: Dignity therapy: a novel psychotherapeutic intervention for patients near the end of life. *Journal of Clinical Oncology* 23 (2005), 5520–5525. On life review and appreciation.
- S3 Guideline Palliative Care for Patients with Incurable Cancer (Germany). Version 3.0, July 2026, AWMF register no. 128-001OL.

○ WISSENSRÄUME — Appreciation

The WISSENSRÄUME series is a labour of love — free of charge, but not to be taken for granted. If these impulses have meant something to you and you would like to give something back, I welcome a voluntary donation: [PayPal.me/VossKati](https://www.paypal.me/VossKati)

Thank you for your appreciation. It helps such content continue to come into being — quietly, lovingly, and in the service of wholeness.

△ WISSENSRÄUME — Notes

The WISSENSRÄUME serve professional orientation, deepening and personal engagement with themes from health, nursing, palliative care, spiritual care, psychology and philosophy. They do not replace individual medical, therapeutic, nursing or legal advice — for acute or serious concerns, please turn to appropriately qualified professionals.

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