



KNOWLEDGE SPACE

THE ETHICAL COMPASS IN PALLIATIVE CARE

Medical Ethics, Cultural Sensitivity and Spiritual Care at the End of Life

*Understanding people
before accompanying them.*

KNOWLEDGE SPACE NO. 2

Long-form text accompanying the presentation · English

♦ 1. Introduction — Understanding People Before Accompanying Them

Palliative care touches far more than medical treatment.

Decisions at the end of life sit in a field of tension between self-determination, care, non-harm and justice – and are shaped at the same time by biography, culture, religion, worldview and personal ideas of dignity, meaning and dying. Anyone who accompanies a person in this phase encounters not merely a medical condition but an entire life story.

This Knowledge Space combines medical-ethical orientation with culturally sensitive communication and spiritual care. Its focus lies on ethical conflicts, patients' rights, advance care planning, religious and philosophical backgrounds, hidden spiritual needs, and the role of professional support at the end of life.

The starting point is four questions that every holistic form of care asks. **Physical:** What burdens the body – pain, breathlessness, nausea? **Psychological:** What burdens the soul – fear, grief, depression? **Social:** Who carries this person – family, friends, or loneliness? **Spiritual:** What gives life meaning and hope – faith, values, peace? The ethical compass in this text is set by the answer to all four questions, not only the first.

“What counts is not only what is medically possible – but what is true to the person.”

♦ 2. Ethics as a Framework for Thought — Why We Need It at the Bedside

Ethics is not a collection of prohibitions but the art of justifying action.

As a practical discipline of philosophy, ethics is understood today as the science of moral action. It asks how values arise, how they change and what they bring about in everyday life – and it looks for reasons why something should be right or wrong. At the end of life this work of justification is unavoidable. Here decisions meet situations without convenient answers: When does a treatment still make sense? How much truth can a person bear? What may, should or must be left undone?

Ethics works on two levels. **Descriptively**, it records which standards people in a society actually apply. **Normatively**, it formulates how one ought to act in particular situations. In doing so it draws on other sciences: on anthropology (Is the human being an individual or a social being?), on psychology and sociology (How do early experiences and social surroundings shape our actions?) and on theology and religious studies (What needs do the dying draw from their faith?).

For individual fields, **specialised ethics** have emerged: for medicine, for nursing, for professional self-understanding as a whole. Nursing ethics describes which values and duties sustain a profession – freedom from prejudice, expertise, willingness to engage in self-criticism, responsibility for one's own actions. It gives nurses goals with which they can identify, and thereby orientation and security in everyday practice.

Values, core values, virtues. Values arise through appreciating and weighing: as an agreement about what is beneficial or harmful to human beings. Core values such as equality, the right to life and bodily integrity, personal freedom, or freedom of religion and expression support everything else. Virtues such as reliability and conscientiousness are secondary values that become visible in daily professional life.

Morality and ethos. Morality (Latin *mores*, “customs”) means the rules of conduct that a group sets for particular areas. Ethos (Greek for “character”, “disposition”) is what the individual makes of them as their own attitude – their stance towards concrete people and situations. The ethos of nursing describes the values and goals that nurses fundamentally wish to bear in mind in their work.

Criteria for decision-making. When values come into tension, three criteria help: expertise, which weighs risks and benefits soberly against each other; the patient's individual life goals, which act like a filter; and general value convictions on which a society is largely agreed. Only in combination do they yield a decision that is both professionally sound and humanly coherent.

♦ 3. The Core Principles of Medical Ethics

Four principles give orientation without supplying easy answers.

Autonomy, beneficence, non-maleficence and justice form the classic framework of medical-ethical deliberation. At the end of life they come into tension with one another particularly often: the wish for self-determination can collide with the caring impulse of the team, and a life-prolonging measure can cause harm where it promises help. Each principle can be read as a question put to one's own practice:

- **Autonomy (self-determination)** – “What does the patient want?” The will of a patient who is able to consent is decisive, even when it becomes harder to understand.
- **Beneficence (care)** – “What really helps this person?” The focus is on measures that improve quality of life.
- **Non-maleficence** – “Does my intervention cause more harm than benefit?” This includes forgoing burdensome diagnostics that offer no therapeutic benefit.
- **Justice** – “Am I treating this person fairly?” Equal care, regardless of origin or status.

The principles are questions, not formulas. None stands permanently above the others, and none is a blank cheque: self-determination presupposes information, time and relationship; care must not become paternalism.

♦ 4. Navigating Ethical Conflicts

Ethical dilemmas arise when legitimate values stand in tension.

There is rarely a perfect solution, only a well-founded weighing of considerations. Three constellations appear particularly often in palliative care.

Prolonging life or avoiding suffering. The conflict is clearest with artificial nutrition at the end of life. What means care in other phases of illness can become a burden in the dying phase. The patient's will and the realistic benefit of the measure provide orientation.

Autonomy or the care of relatives. Relatives sometimes demand a therapy that the patient refuses – out of love, out of fear, out of guilt. Their concern deserves seriousness and attention, but it cannot replace the will of a patient who is able to consent: that will takes absolute precedence. The team's task is then to accompany the relatives in conversation so that they can accept the patient's will.

Relieving suffering or preserving consciousness. For severe pain and other agonising symptoms, palliative sedation can bring relief. It comes into consideration only for refractory symptoms, that is, when other means do not work sufficiently – and it requires information, agreement within the team and, as far as possible, the patient's involvement. Its aim is to relieve burdens that cannot otherwise be adequately controlled; it is not a measure intended to end life. In its very intention it differs from deliberately ending a life.

When a person expresses a wish to die. A wish to die calls, first of all, neither for agreement nor for contradiction, but for attention. It can express physical suffering, psychological strain, existential distress, the loss of autonomy or a lasting, self-determined decision. Professional accompaniment therefore begins with listening, exploring the reasons for the wish and how changeable it is, clarifying decision-making capacity and possible burdens from a professional perspective, and making palliative, psychosocial and spiritual support accessible. To be distinguished from this is the legal and ethical

question of assisted suicide: in 2020 the German Federal Constitutional Court held that the general right of personality includes a right to a self-determined death – including the freedom to seek and accept the help of third parties for this. This does not create a claim that third parties must provide such assistance. How a team deals with this remains a matter of careful weighing in each individual case, which no one should carry alone.

The ethical case discussion. Where weighing is difficult, a structured approach helps more than the gut feeling of individuals. It begins by clarifying the situation and the medical facts, asks about the patient's will and values, hears the perspectives of everyone involved, names the options for action, weighs them and gives reasons for the decision – which is then documented and reviewed after an agreed period. Ethics consultation, as offered by hospitals, hospices and care facilities, provides this structure. Its benefit: differing views are voiced before they continue to work on in the team as an unspoken conflict.

✦ 5. The Rights of Dying People

Dignity at the end of life is not an act of grace but an entitlement.

Dying people do not lose their rights – these gain rather in importance. Human dignity at the end of life rests on four pillars:

- **Right to self-determination** – The current or previously expressed will of the person is the basis of medical and nursing decisions. An advance directive is to be respected insofar as its provisions apply to the concrete situation of life and treatment.
- **Right to adequate pain and symptom relief** – Symptoms are assessed regularly and treated according to the current professional standard.
- **Right to honest information** – The patient decides how much they wish to know.
- **Right to company and privacy** – No one dies alone against their will; intimacy is protected.

In the language of those affected, these rights can be unfolded further. A dying person may be treated as a living human being until the end and may always still hope – whatever that hope may be directed at. They may express their feelings and emotions about approaching death in their own way. They may continue to receive medical and nursing care even when the goal “cure” has to give way to the goal “well-being”. They may expect their questions to be answered honestly and that no one will deceive them.

They have a right to people who are sensitive, wise and competent and who strive to understand their needs; to help for their family so that it too can accept their death; and to speak openly about their religious or spiritual experiences, regardless of what these mean to others. They may preserve their individuality without being condemned if their decisions contradict the views of others. And they may trust that the integrity of their body will be respected after death – up to what stands above all else in the end: to die in peace and with dignity.

✦ 6. Thinking Ahead – Advance Care Planning as a Conversation

Advance care planning is not a form but an ongoing process of conversation.

Planning ahead does not begin with a document but with a question: “What does quality of life mean to you?” From the conversation about values, treatment goals emerge – and with them limits, such as declining resuscitation. The process can be described as a cycle:

- **Discuss values** – What makes life worth living for this person?
- **Set treatment goals** – Which limits should apply?

- **Prepare documents** – An advance directive and a healthcare power of attorney record what has been discussed.
- **Communicate within the team** – The wishes are made transparent to the interprofessional team.
- **Review regularly** – Wishes can change; then the process begins anew.

Advance care planning is more than documenting provisions. An advance directive and a healthcare power of attorney can secure the results of planning ahead; its real core, however, lies in the recurring conversation about values, treatment goals and possible future decision-making situations. Anyone who takes this cycle seriously protects the patient from decisions that would otherwise be made over their head in an emergency, and relieves relatives and team of the burden of having to guess. The legal foundations in Germany, the pathways of care and the drafting of advance documents are set out in Knowledge Space No. 4, “Palliative Care 2026 – The Architectural Foundation”.

When self-determination can no longer be expressed directly. Even then there is an order of orientation. First comes, as far as possible, the current will – including when expressed non-verbally. If an advance directive exists whose provisions apply to the current situation, it is binding. An authorised or legally appointed representative checks this and gives effect to the person’s will. If no directive applies, previously expressed treatment wishes, values and the presumed will serve as the standard. This shows how much an earlier conversation is worth. The legal details are set out in Knowledge Space No. 4.

◆ 7. Language That Builds Bridges

Words decide whether a person feels taken seriously.

In conversation with seriously ill people, ethics shows itself within seconds. Some sentences erect barriers; others build bridges.

- **Barriers:** “It’s not worth it any more.” (devaluing) · “The tumour in room 4.” (dehumanising) · “You don’t need to worry about that.” (dismissing feelings)
- **Bridges:** “We are aligning our treatment with your wishes.” (caring) · “Mr Schneider ...” (person-centred) · “What matters most to you at the moment?” (recognising needs)

Honest information does not mean everything at once. The patient decides how much they wish to know. Some people want to know the prognosis precisely; others need room for hope. In some families relatives are expected to receive news and speak on behalf of the patient. Ethically the direction remains the same: the patient is asked, not bypassed – including about who may learn how much.

Where no common language exists, professional interpreters are a better route than relatives. This lets the family remain a family, and content is neither softened nor distorted.

◆ 8. Biography Before Label – Culture, Religion and Spirituality

Religion does not explain the person – it is only one part of their story.

Culture, religion and spirituality overlap, and at their centre stands the individual biography. Knowledge of religions is a tool, not a rulebook: not every believer wishes for religious rituals, and not every person without a faith affiliation rejects spiritual support.

Religion and spirituality. Religion is often tied to faith communities and follows fixed teachings, traditions and rituals; its centre is God or sacred scriptures. Spirituality can also take the form of an individual search beyond institutional affiliation, nourished by nature, music, family, art and memories. Religion and spirituality can be closely connected, but need not be: spirituality can find expression

within religious traditions just as it can independently of institutional religion. Both meet in the search for meaning, hope, connectedness and inner peace – and in the way suffering and finitude are faced.

Culturally sensitive care as an ethical question. In a society shaped by immigration, the share of older people who bring diverse cultural, religious and biographical backgrounds and now depend on care is growing. Caring for them demands social competence and tolerance towards the unfamiliar. If this is lacking, or if carers show no interest in wishes grounded in culture, religion or spirituality, misunderstandings quickly arise – and those affected often experience them as discrimination. Lack of consideration for cultural and religious differences is therefore not a matter of patients' inadequate integration but an expression of care that has moved away from humanity. Patient-centred care means: ask instead of assuming.

Avoiding stereotypes. Within every tradition there are currents, differing degrees of attachment and entirely personal paths. A label does not imply a need. The overview in the next section is therefore an entry point to a conversation, not a prediction.

“Cultural sensitivity does not begin with knowledge about others – but with the willingness not to know.”

♦ 9. Worldviews at a Glance – A Framework for Orientation

Anyone who knows the basics can ask better questions.

A basic knowledge of the major world religions, their rituals around dying, lived traditions and festivals makes encounters easier. The following table condenses what matters most for care – as a prompt for questions, not as an answer: what applies in an individual case depends on personal practice.

Tradition	Understanding of dying and death	What sustains and comforts	For those providing care
Christianity	Death as a transition; hope of resurrection	Prayer, anointing of the sick, communion, blessing; cross and candle	Offer pastoral care, respect religious symbols; ask about denomination and personal wishes
Islam	Life and death lie in God's hand	Qur'an, prayer and profession of faith; orientation towards Mecca; imam	Depending on personal practice, there may be particular wishes regarding privacy and same-sex care; the presence of relatives and a ritual washing by fellow believers are often important
Judaism	Life is sacred; death as a transition	Psalms, prayers, rabbi; vigil beside the deceased	Depending on the movement, rules on handling the body, involvement of the community and swift burial may matter
Hinduism	Cycle of death and rebirth (samsara)	Mantras, sacred symbols, water	Enable the family's rituals where possible; leave room for relatives
Buddhism	Dying as a conscious transition; impermanence	Meditation, quiet, encouraging words	Depending on the tradition, an atmosphere as undisturbed as possible during and after dying can be of particular importance
Humanism / non-religious	Biological end; meaning drawn from one's own biography	Music, nature, life review	Do not presuppose religious rituals

Festivals and rhythms also touch nursing: Ramadan as a month of fasting, Shabbat as a day of rest, Christian days of remembrance such as All Saints' Day or the Protestant Totensonntag (Sunday of the

Dead). And there are cases where a conviction of faith bears directly on a medical decision. Jehovah's Witnesses refuse blood transfusions on grounds of faith; what this encompasses in detail is for those affected to decide according to their conscience. Here the principle of autonomy shows itself in its clearest form: it is respected, clarified in conversation and carried by the team.

How religious and philosophical ideas sustain people in illness and dying is explored in more depth in Knowledge Space No. 19, "Palliative Care – Illness, Suffering, Death and Spirituality".

♦ 10. Recognising Hidden Spiritual Needs

What a person says is rarely all they need.

Like an iceberg, language shows only a small part of what lies beneath. Sentences such as "Why does this have to happen to me of all people?", "I still have something to sort out." or "I just want to be left in peace." are often the visible tip. Beneath lie needs that cannot at once be named:

- **Fear and worry** – existential despair and concern for those left behind.
- **Reconciliation** – unfinished business, feelings of guilt, or the wish to forgive.
- **Peace and transcendence** – the deep wish for acceptance and letting go.

Spiritual suffering is the loss of meaning in life, of identity and of autonomy. It needs no interpretation from outside. It needs someone who notices that a question may lie behind a sentence – and who stays, asks and endures. How such needs can be recorded systematically is shown in Knowledge Space No. 19; the model of the three bodies and five sheaths as a map of the human being can be found in Knowledge Space No. 20.

♦ 11. Spiritual Care – The Role and Limits of Nursing

Nursing does not have to solve existential questions – it may endure them together.

The heart of successful spiritual support is attention without judgement: respecting and valuing the individual as they are and in what they believe. The nursing toolkit for this is simple:

- **Presence** – sit down at eye level, take time, stay silently.
- **Encouraging life review** – let the person talk about family, work or special events.
- **Asking openly** – "What gives you strength in this time?"

The limits are just as important. Nursing does not proselytise and does not press its own convictions on anyone. It need not know the answer to every question about life. And it is no substitute for specialised psychotherapy in severe crises – then it is part of professionalism to call in chaplaincy, psychology or psychotherapy. Those who know their limits can allow closeness without losing themselves in it.

♦ 12. Dignity Beyond Death

Care does not end with the last breath.

For many people and traditions the time immediately after death is of special significance: the farewell, the vigil, the ritual washing, undisturbed quiet. Nurses need not know these rituals in every detail, but they can make them possible – through questions, space and time. Who is to be called? Who may touch or wash the body? How long may the deceased remain? Such wishes sometimes run up against the limits of local burial law, which varies from one German federal state to another; an early conversation helps.

Burial culture in Germany, too, has changed profoundly. For a long time church tradition shaped the farewell: blessing at the deathbed, funeral service, burial in the family grave, black clothing, grief as something private. Today there are also cremation, woodland and sea burials, anonymous graves and individually designed farewells, along with places of remembrance in public space and on the internet. The reasons given include the liberalisation of burial laws, a turning away from Christian traditions and growing individualisation, but also economic factors.

In terms of nursing ethics, this change means: the manner of farewell is part of the right to self-determination. Whoever asks about it early preserves the dignity of the dying person and relieves those who remain.

♦ 13. Moral Distress and the Responsibility of the Team

Those who carry ethical conflicts every day need structures that help carry them.

Moral distress arises when people sense what would be right and yet cannot do it. It often begins quietly – as inner conflict and a burdened conscience when measures are viewed critically in ethical terms. A feeling of helplessness leads to withdrawal; in the end come cynicism and emotional exhaustion. This downward spiral can be interrupted if the team has tools that counteract it:

- **Case discussions** – understanding different perspectives within the team.
- **Ethics consultation** – structured reflection in complex dilemmas.
- **Team culture** – accepting one's own limits and communicating them openly.

Self-care is thus not a private matter but an ethical task: only those who are held in their own conscience can hold others.

♦ 14. Attitude – Palliative Care as a Compass

The most important competence in palliative care is not only expertise but attitude.

This attitude can be summed up in three sentences. **I listen** – the person feels taken seriously. **I do not judge** – different ways of living are respected. **I can endure uncertainty** – not every question needs an answer straight away.

The ethical compass thus points in three directions. **Ethics:** Ethical conflicts do not call for perfect solutions but for deliberations oriented to the patient's will. **Culture:** Culturally sensitive care begins with genuine interest in the individual, not with stereotypes. **Spirituality:** Spiritual care does not resolve existential crises but endures them together with the patient.

“At the end of our lives, people will probably not remember how perfectly we worked. They will remember how we met them.”

♦ Palliative care begins where professional knowledge meets the person in the fullness of their biography.

Further reading:

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I am happy to answer questions or to exchange thoughts in person.

With warm regards

Kati Voß

◇ Sources & Lines of Thought

This Knowledge Space is not meant as a scholarly treatise. The following sources mark the professional, ethical and legal lines of thought to which its central statements connect – above all those of chapters 2 to 6, 10, 11 and 13.

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- A. Jameton: Nursing Practice: The Ethical Issues. Prentice-Hall 1984; G. Morley, J. Ives, C. Bradbury-Jones, F. Irvine: What is ‘moral distress’? A narrative synthesis of the literature. Nursing Ethics 26 (2019), 646–662.

The statements on religions and worldviews are meant as orientation and follow no single source; what remains decisive is always the person themselves. The legal details are set out in Knowledge Space No. 4.

*Knowledge that is shared
loses nothing of its depth.*

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