



WISSENSRAUM NO. 4

# PALLIATIVE CARE 2026 – THE ARCHITECTURAL FOUNDATION

*Legal foundations, care pathways and decisions at the end of life*

*“A house that holds when the ground becomes uncertain.”*

AKADEMIE DER WEISHEIT — WISSENSRÄUME

## ◆ 1. When a Life Needs a House

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**Anyone who accompanies a person through the last weeks of life soon realises that it is not only about medicine.**

There is a person in pain, and perhaps afraid. There are relatives who want to help and do not know what they are allowed to do. There is a home care service, a family doctor, perhaps a hospice service, and somewhere in the background a long-term care insurance fund that demands applications, sets deadlines and uses terms no one has ever explained. What begins as a simple question at the bedside, such as whether Mother can stay at home, touches in the next breath on benefits law, powers of attorney, responsibility and the question of who is actually entitled to decide.

This Wissensraum arranges that web of relationships like a building. Laws and guidelines form the foundation. The different forms of care carry the structure, the funds' benefits secure its statics, and inside, protected by everything else, stands the will of the person around whom the house was built in the first place. The image is chosen deliberately. A house is not built to be admired but so that someone can live in it, protected. In the same way, law in palliative care should not be a hurdle but a space in which a person may remain a person to the very end.

Behind the paragraphs stand very concrete questions, which this text walks through one by one. When is a person considered palliative? Who decides on a hospital admission, and who on admission to a hospice? What roles do the family doctor, nursing professionals and relatives play? What may children decide for their parents, and what not? And what happens to the spouse when the everyday life they managed together can no longer continue?

The status of the following pages is 1 October 2026. That is not a minor detail, because a good deal has moved in precisely this year. Where something is still in the making, it is named as such.

“*A house is not built to be admired but so that someone can live in it, protected.*”

## ◆ 2. Palliative Does Not Automatically Mean Dying

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**There is no day on which a person officially becomes “palliative”.**

Even the word “pre-palliative”, which occasionally appears in everyday speech, does not denote a legally defined level of care. Palliative care can begin when a serious, life-threatening or life-limiting illness creates a particular need for relief, support and forward planning. It can start early and exist alongside treatments that slow the disease or prolong life. Palliative care therefore means

neither automatically giving up therapy nor that death is imminent. Its aim is to improve quality of life and to relieve suffering, which is also how the World Health Organization understands it.

To be distinguished from this are the narrower requirements that social law sets for certain benefits. General outpatient palliative care is provided by family doctors, specialists, care services and others involved, and in most cases it is sufficient. Specialised outpatient palliative care, SAPV for short (Spezialisierte Ambulante Palliativversorgung), by contrast, presupposes an incurable, progressive and far-advanced illness, together with a limited life expectancy and a particularly complex need: pain that is hard to control, for instance, breathlessness, neurological symptoms, distressing wounds or recurring crises. The details are regulated by the SAPV guideline of the Federal Joint Committee.

The requirements for an inpatient hospice are narrower still. The illness must be progressive and incurable, and a physician who knows the illness, its course so far and the current need sufficiently well must confirm the necessity in writing. In the outpatient setting this is usually the family doctor, the treating specialist or a palliative physician; in hospital, the ward physician or a palliative physician called in. In the case of advanced heart disease, the family doctor, the cardiologist or the treating hospital physician would therefore come into question. In their professionally reasoned assessment, life expectancy must be limited to days, weeks or a few months. At the same time, no acute diagnostics or treatment may be needed that is only possible in hospital. That does not mean a hospital “can do nothing more”. It means that inpatient treatment is precisely not necessary, or no longer corresponds to the jointly agreed treatment goal. And it must be established that care at home, in a nursing home or in another facility can no longer be ensured despite all available help.

*“A care level does not arise from this automatically. Palliative status and care level belong to different benefit systems.”*

### ◆ 3. The Foundation: Four Levels of Law

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**Not everything that appears in practice as a rule is law — and not every law explains itself.**

Anyone wishing to find their way around the law of palliative care is helped by a simple distinction between four levels. At the top stand statutes and ordinances, that is, directly applicable law: Books V and XI of the Social Code, the Civil Code, the Criminal Code, the Caregiver Leave Act and the Family Caregiver Leave Act, as well as professional and pharmaceutical regulations. Below them lie guidelines and contracts, for instance the SAPV

guideline, the guideline on home nursing care and the framework agreements on hospice care. They give concrete shape to entitlements and quality requirements and are binding for benefit systems and contracting parties. One level further down come clinical guidelines and expert standards: the S3 guideline on palliative medicine, the expert standards of the German Network for Quality Development in Nursing, and professional recommendations such as those on palliative sedation. They are not laws, but they can carry considerable weight for professional diligence and for assessing professional conduct. At the very bottom are the rules of the individual facility, standard operating procedures, emergency plans, medication standards. They translate the higher levels into daily work and may override neither the law nor the patient's will.

This order sounds dry and in everyday life often becomes a relief. Anyone who knows on which level a statement stands also knows how much weight it carries. An internal instruction cannot override a law, and a guideline is a reasoned recommendation, not a prohibition. Where it is departed from in an individual case for good reasons, weighing the matter is part of the process and should be documented comprehensibly. The guidelines, too, keep moving: the S3 guideline on palliative medicine for people with incurable cancer has applied in its new version 3.0 since 21 July 2026, valid until July 2031. It replaces the previous version 2.2 and for the first time devotes chapters of its own to relatives and to the spiritual and existential dimension.

Six bodies of law carry most of what is regulated in a binding way. Social Code Book V governs medical and specialised care, SAPV and hospice. Social Code Book XI is based on the care level and not on the diagnosis. The Civil Code orders consent, advance directives, representation and court approvals. The Criminal Code draws limits at confidentiality, deprivation of liberty and killing on request. The Nursing Professions Act and the new rules on the expansion of competences determine which tasks nursing professionals may take on, and narcotics law strictly prescribes how strong painkillers are prescribed, stored and accounted for. None of these bodies of law tells the whole story on its own. Many a conflict at the sickbed arises precisely where two of them answer different questions: one about the benefit, one about responsibility, the third about permission.

*“Anyone who knows on which level a statement stands also knows how much weight it carries.”*

## ◆ 4. Who Decides on a Hospital Admission?

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**A palliative illness does not rule out hospital — nor does it make hospital mandatory.**

Whether inpatient treatment is medically necessary is decided by the treating physicians and ultimately by the admitting hospital. Whether it is carried out is, in principle, decided by the person themselves, provided they are capable of consenting. A person receiving palliative care can also agree to an admission or refuse it, and what matters is whether the treatment corresponds to the agreed goal. A readily treatable infection, a fracture, a haemorrhage or a symptom crisis that cannot otherwise be controlled can make an admission sensible. An avoidable admission, on the other hand, can be omitted if the symptoms can be treated safely at home and that corresponds to the person's will.

One can picture the path of such a decision as a short sequence of questions. Is the measure indicated at all? If not, it is not carried out. If so: is the person capable of consenting to this specific decision? Then they decide for themselves, and their current will takes precedence over everything else, even when others consider it unreasonable. If they are not, one asks whether an advance directive exists and whether it fits the present situation. If it fits, it must be implemented as binding. If it does not fit or none exists, the presumed will is determined by the people entitled to represent the person. These are a representative appointed by power of attorney or by the court or, under certain conditions, the spouse. In an urgent emergency one starts with what corresponds to the presumed will and clarifies everything else immediately afterwards.

From this follows something that often surprises families. Adult children do not have a right to decide merely because they are related. They may not decide “over the head” of a parent who is capable of consenting about hospital, discontinuing treatment, hospice or nursing home. Conversely, necessary treatment may not be omitted simply because relatives reject it. The medical indication and the patient's will remain decisive.

It is therefore worth recording early what is wanted and what is not: resuscitation, ventilation, hospital admission, how to deal with acute breathlessness, pain, bleeding or delirium, as-needed medication and escalation paths, reachable contacts, along with an advance directive and authority to represent. Such an emergency plan takes away part of the crisis's force, because what could have been discussed weeks earlier does not have to be decided for the first time at three o'clock in the night.

*“An emergency plan takes away part of the crisis's force.”*

## ◆ 5. An Advance Directive Is Not a Wish List

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**The advance directive answers the question of what is to happen. The lasting power of attorney answers the question of who may do it.**

Since the reform of guardianship law, the advance directive has been regulated in § 1827 of the Civil Code. It determines, for the case of one's own incapacity to consent, which medically indicated measures a person consents to and which they refuse. Concrete provisions are sensible for specific illness situations, for resuscitation, ventilation, artificial nutrition and hydration, dialysis, antibiotics, hospital admission, and for pain and symptom relief. It can also state whether consciousness-dampening medication may be used for symptoms that cannot otherwise be controlled. What it cannot do: establish a claim to treatment that is not medically indicated. Official text modules are provided by the Federal Ministry of Justice.

The lasting power of attorney gives a trusted person the authority to take the place of the person concerned. It should state explicitly what it covers: health care, residence and housing, care and nursing home contracts, public authorities, assets, insurance, mail. For particularly risky medical decisions and for measures or placements involving deprivation of liberty it must be granted in writing and mention these powers explicitly. For banking, a separate bank power of attorney may additionally be needed; for real estate or certain loans, special notarial forms may apply. A power of attorney is responsibility, not a licence to impose one's own values: the authorised person is bound by the will of the person represented.

Documents help only if they can be found. In the Central Register of Advance Care Documents of the Federal Chamber of Notaries, lasting powers of attorney, advance directives, guardianship directives and an objection to the spousal emergency representation right can be registered. The register does not keep the originals; it stores information about existing documents, trusted persons and the place of storage. Treating physicians can consult it for urgent decisions, but the originals must still remain findable.

One step earlier comes health care planning for the last phase of life (§ 132g of Social Code Book V). Inpatient care facilities and facilities for people with disabilities can offer their residents such forward-looking conversations, the costs of which are borne by the health insurance funds. They are voluntary. What is discussed are treatment wishes, emergency situations and care goals, if desired together with physicians, relatives and other trusted persons. The result is documented and carried into the care chain so that in an emergency it also reaches the care service, the family doctor and the emergency services, and it can be combined with an advance directive.

*“Provision takes effect only when it has been discussed and can be found.”*

## ◆ 6. Who Speaks When a Person Can No Longer Speak?

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**Whoever speaks for another does not speak for themselves.**

Many relatives assume that as spouse, daughter or son they may automatically speak for a sick person. It is not that simple. Who may really represent depends on what was arranged beforehand, and every form of representation has its own limit. The lasting power of attorney represents within the scope specified; for the particularly risky decisions, such as refusing or discontinuing life-sustaining measures or a placement involving deprivation of liberty, the authority must be granted explicitly and in writing (§ 1820 paragraph 2 of the Civil Code). A guardianship directive on its own does not confer power of representation. It merely names wishes for the case that a court has to establish legal guardianship. The court limits legal guardianship to specific areas of responsibility, and it does not abolish self-determination: anyone capable of consenting continues to decide for themselves even as a person under guardianship.

One particular rule relieves many families. If a representative appointed by power of attorney or by the court is to refuse or withdraw consent to a life-sustaining measure, this in principle requires the approval of the guardianship court (§ 1829 of the Civil Code). That approval is not needed, however, if the representative and the treating physician agree that the decision corresponds to the patient's established will (§ 1829 paragraph 4). The court is thus needed above all where there is dispute or doubt about that will, and not merely because a grave decision arises at the end of life.

Since 2023 there has also been the emergency representation right between spouses, regulated in § 1358 of the Civil Code. It is limited to health matters and urgent measures directly connected with them. The representing spouse can consent to treatment or refuse it and can conclude necessary treatment, hospital and urgent care or rehabilitation contracts. General asset management, ordinary banking, comprehensive arrangements for housing or a representation designed to last are not covered by the right. It ends after six months at the latest, and it does not apply in case of separation or if the person concerned has objected. It is a bridge, not a substitute for the lasting power of attorney.

This makes it understandable why early willingness to talk weighs so heavily. A power of attorney that no one knows about is of little use; a will that was never spoken has to be laboriously reconstructed. Anyone who has not made timely provision is not, for that reason, without rights

or protection. The paths can only become longer, because it must first be clarified who may act. What is clarified during one's lifetime spares those who remain doubt and guilt later.

*“Representation is a service to another person's will, not a right to one's own decision.”*

## ◆ 7. Hospice and Palliative Care Unit: Two Houses, Two Tasks

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**A hospice is not a hospital, and a palliative care unit is not a hospice.**

The inpatient hospice is intended for people who no longer need hospital treatment but cannot be adequately cared for at home, in a nursing home or in another facility. It is a place to live in the last phase of life. The palliative care unit, by contrast, belongs to a hospital. It treats acute, complex symptom crises with the aim of enabling the person, where possible, to be discharged again, to go home, to a nursing home or to a hospice. For adults with statutory health insurance, the usual co-payments of ten euros per day for a maximum of 28 days per calendar year apply there, unless an exemption exists.

A person is not admitted to a hospice solely through the decision of relatives, care staff or the family doctor. Several conditions must come together: the person wishes hospice care, or a representative decides on the basis of their will. A statutory health insurance physician or hospital physician confirms the medical necessity in writing. The requirements for inpatient hospice care are met, the hospice has a suitable free place, and the health insurance fund issues the cost approval. In practice the path begins with contacting a hospice or a hospital's social service. Then the medical certificate is drawn up, availability is clarified, the documents go to the fund, and cost approval and admission date are coordinated. The hospice or the social service usually helps with this. The benefit is initially confirmed for four weeks; if the necessity continues, it can be extended but must be justified again to the fund.

For people with statutory insurance, the health insurance fund pays under § 39a paragraph 1 of Social Code Book V a subsidy of 95 percent of the daily needs rate agreed with the hospice, and possible benefits from long-term care insurance are credited against it. The remaining five percent must be raised by the hospice itself, above all through donations and volunteer commitment. This is not an own contribution by the guest; for subsidised hospice care, no co-payment may be demanded or accepted from people with statutory insurance. For privately insured people, the 95 percent rule does not apply directly in the same form. According to the PKV Association, private health insurance also covers inpatient hospice care, reimbursement follows the respective contract, private compulsory long-term care insurance contributes where there is a need for care, and for those entitled to Beihilfe (civil-service benefits) the Beihilfe office

is added. Contractual deductibles or costs that are not fully reimbursable should be clarified with insurers and hospice before admission, and written cost approvals obtained.

*“A hospice is a place to live in the last phase of life.”*

## ◆ 8. The Way Home: Outpatient Care

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**Most people would like to die where they have lived — and much depends on whether that home can bear the load.**

If care is to take place at home or in a care facility, many building blocks come into consideration: palliative care by the family doctor or a specialist, home nursing care and an outpatient care service, general outpatient palliative care, SAPV, an outpatient hospice service with volunteer companions, care counselling and the care support point (Pflegestützpunkt), day care, short-term and respite care, aids and adaptation of the home. A net arises from these building blocks only in their interplay.

SAPV is prescribed by the treating statutory health insurance physician. Hospital physicians can also prescribe it within discharge management, as a rule for up to seven days, and the prescription should reach the health insurance fund by the third working day after issue at the latest. As a team service, SAPV can advise, coordinate and take over care in part or in full; not every prescription means full care. With full SAPV care, additional home nursing care for symptom control is excluded, because the two would duplicate each other.

At the centre is often the family doctor. They recognise changes and palliative needs early, discuss prognosis, treatment goals and the patient's will, prescribe medication, aids, home nursing care and SAPV, confirm the necessity of hospice care, draw up a crisis and emergency plan, and coordinate specialists, care service, SAPV team, hospice service and hospital. After a hospital stay they take over further care and inform relatives about expected changes. They do not, however, decide alone about a person's path in life. Their task is to advise medically, to determine indications, to explain risks and, together with the person concerned, to develop a realistic treatment goal.

It is also important what happens when the family doctor cannot be reached. The practice must agree binding medical cover and make it known to patients. For seriously ill people, prescriptions, medication, contact details and the emergency plan should be clarified in good time. If there is no cover, the Association of Statutory Health Insurance Physicians helps or, for urgent but not

life-threatening needs, the on-call medical service at 116117; in life-threatening emergencies, 112 applies. If SAPV care is already in place, the responsible SAPV team should be contacted first.

*“A home bears the load only when many building blocks become a net.”*

## ◆ 9. The Financial Statics: Long-Term Care Insurance 2026

**Long-term care insurance does not ask how seriously ill a person is, but how much independence remains in everyday life.**

This sentence surprises many relatives, and yet it is central. Benefits from long-term care insurance are measured not by the severity of the illness but by how independent a person still is in everyday life. Someone who is palliatively ill but still manages much on their own may have a low care level; a high one does not follow automatically from the diagnosis. A care level requires a separate application to the long-term care insurance fund. If the person is in a hospice or receives outpatient palliative care, a shortened deadline of five working days applies to the assessment, so that the decision does not take longer than the time that remains.

For care at home, the following monthly amounts apply in 2026:

| Care level   | Care allowance (monthly) | Care benefit in kind (monthly) |
|--------------|--------------------------|--------------------------------|
| Care level 2 | €347                     | up to €796                     |
| Care level 3 | €599                     | up to €1,497                   |
| Care level 4 | €800                     | up to €1,859                   |
| Care level 5 | €990                     | up to €2,299                   |

The care allowance goes to relatives who provide care themselves; the benefit in kind is available for an outpatient care service. The two can be combined. In addition, in all care levels there is the relief allowance of €131 per month and care consumables of up to €42 per month. Since July 2025, people in need of care in care levels 2 to 5 also have a joint annual amount of up to €3,539 for short-term and respite care, each for up to eight weeks. This is the room to manoeuvre for anyone who needs a break or whose carer drops out.

## CARE REFORM IN THE MAKING · STATUS 1 OCTOBER 2026

On 30 September 2026 the Federal Cabinet adopted the draft of the Care Reorganisation Act (Pflegeneuordnungsgesetz, PNOG). According to the key points known so far, the relief allowance is to be converted into a “social-space budget” and the joint annual amount for short-term and respite care into a “bridging budget”, among other things; some provisions are to apply from 2027, others only in later years. The act is not yet in force: the Bundestag and Bundesrat must still deliberate, and details may change during the procedure. Until it is promulgated, the previous law applies and the amounts stated remain unchanged.

*“A palliative diagnosis is not a care level.”*

## ◆ 10. Limits That Protect

**There are actions that look similar and lie far apart legally and ethically.**

Anyone accompanying someone at the end of life encounters four terms that are often mixed up. Limiting treatment means that a measure is omitted or ended because it is no longer indicated or the patient does not want it; it allows the natural dying process and is permissible. Palliative symptom therapy, including with sedation, serves to relieve suffering and not to bring about death; it requires care and consent and is carried out by medical staff. Assisted suicide has no longer been punishable under § 217 of the Criminal Code since the 2020 decision of the Federal Constitutional Court, because that provision was declared void. It is therefore not punishable, but so far not regulated by statute, and the last step is taken by the person who wishes to die. Killing on request remains punishable under § 216, for here another person brings about the death.

Palliative sedation deserves a closer look, because it is the most frequently misunderstood. It comes into consideration only when symptoms such as breathlessness, pain, anxiety or restlessness cannot be adequately relieved despite exhausted treatment, that is, when they remain refractory. Depth and duration are guided by the symptom and must be proportionate. It requires the person’s consent or, if they can no longer express themselves, their documented or presumed will. And it is continuously reviewed and documented in a comprehensible way.

There are also two areas in which nurses and physicians look particularly closely. Anyone who places a person in a facility, restricts them with bed rails or gives medication intended mainly to inhibit their movement needs, for persons under guardianship, the approval of the guardianship court. Consented palliative sedation solely for symptom relief, by contrast, is not deprivation of liberty. And in narcotics law, prescription, as-needed medication, maximum dose, minimum

interval and escalation path must be absolutely unambiguous; stock and whereabouts must be documented traceably. Professional opioid therapy is clearly to be distinguished from deliberate killing, and precisely for that reason the strict form protects patients and practitioners alike.

*“The strict form protects patients and practitioners alike.”*

## ◆ 11. Relatives: Responsibility That May Be Shared

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**Family carers may help. They do not have to bear everything alone.**

Adult children should know: parents who are capable of consenting continue to decide for themselves. Without a power of attorney there is no unrestricted entitlement to medical information, and a lasting power of attorney is responsibility, but not permission to impose one's own values. Care may be shared among siblings, care services, day care, hospice services and other helpers. Exhaustion, lack of sleep, irritability, physical complaints and social withdrawal are warning signs, and relief should be organised before the carer drops out. Where social assistance pays “help with care” for uncovered nursing home costs, children are as a rule drawn upon only when their gross annual income exceeds €100,000; the individual assessment remains decisive.

Anyone who is employed themselves has several statutory ways of being released from work, which all have one thing in common: they are not additional paid leave. In an acute care situation, employees can stay away from work for up to ten working days, regardless of the size of the company (§ 2 Caregiver Leave Act). They must inform the employer immediately; on request, a medical certificate must be presented. If there is no entitlement to continued payment of wages, care support allowance can be applied for as a wage substitute from the long-term care insurance fund of the person in need of care; the entitlement is limited to ten working days in total per person in need of care and calendar year and is shared among several relatives. Care leave allows full or partial release for up to six months; the entitlement applies to employers with more than 15 employees. For accompanying a close relative in the last phase of life, up to three months of full or partial release are possible, at home, in hospital, a nursing home or a hospice, without a care level being required, likewise with more than 15 employees. To cushion the loss of income, an interest-free loan can be applied for from the Federal Office for Family and Civil Society Functions; with smaller employers a voluntary agreement can be made. Family caregiver leave, finally, allows partial release for up to 24 months at a minimum of 15 hours per week, with employers of more than 25 employees. The various forms of leave can be combined but together may in principle not exceed 24 months.

*“Responsibility does not mean carrying everything alone.”*

## ◆ 12. Who Is Left Alone After the Death

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### **Palliative care concerns not only the person who is ill.**

Often the spouse's previous system of care collapses after the death. The person left behind has frequently cared for years and hardly knows how to look after themselves. Even a surviving spouse or older parent may not be taken into a nursing home against their will merely because of their age or need for help. If the person can still understand the meaning and consequences of the housing decision and act accordingly, they decide for themselves. If they are no longer able to do so, the representing person needs a sufficient lasting power of attorney or must be appointed by the court for the necessary areas of responsibility, and must follow the wishes, earlier statements and presumed will, not their own ideas. Court approval is not needed for every nursing home contract, but it is when the placement or individual measures involve deprivation of liberty. A lack of decision-making capacity does not permit arbitrary placement.

That is why, even before the death of the seriously ill person, it should be clarified how the spouse can live and be cared for afterwards: with their own advance directive and lasting power of attorney, with bank, authority, housing and postal powers of attorney, possibly their own care level, with secured medication supply and medical care, with an outpatient care service or household help, home emergency call, meals on wheels and day care, with adaptation of the home and, if necessary, short-term care or a permanent care facility. Rent, income, survivor's pension and social benefits belong here too, as do funeral provisions and digital estate. Assisted living does not automatically mean comprehensive care: tenancy agreement, basic service, emergency call, free choice of care service, additional costs and care as dependency increases must be examined carefully.

Care counselling should not begin only after care has broken down. Insured persons and, with their consent, relatives are entitled to individual counselling from the long-term care insurance fund or a care support point. A concrete care plan can arise there that coordinates medical, nursing and social help.

“*A lack of decision-making capacity does not permit arbitrary placement.*”

## ◆ 13. Care Professionals: What Changed in 2026

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### **Those who accompany others themselves stand on ground that the law helps to support.**

Since 1 January 2026, the Act on the Expansion of Competences and Reduction of Bureaucracy in Nursing has been in force. It creates the legal basis for suitably qualified nursing professionals

to provide certain services of medical treatment on their own responsibility in future. Which services these are in detail, and under what conditions, is regulated by the contracts and benefit catalogues provided for. For the area of statutory health insurance physicians an agreement is envisaged by 31 December 2026, and for hospital treatment by 31 July 2027. Implementation therefore proceeds step by step and depends on proven qualification, the care setting and organisational rules.

This strengthens the role of nursing but has a clear limit. There is no blanket authorisation to change medical prescriptions or medication plans independently, and palliative medication prescribed by a physician may not be started, stopped or changed on one's own initiative. The statutory reduction of bureaucracy also changes nothing about the duty to record decision-relevant information: treatment goal, capacity to consent, will, effects and side effects of medication, agreements within the team (§ 630f Civil Code). Anyone who documents so that the next colleague can take over safely protects the patient and themselves.

*“Anyone who documents so that the next colleague can take over safely protects the patient and themselves.”*

## ◆ 14. The Practical Check: Questions Before the Crisis

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**Legally secure care does not arise from paragraphs alone.**

It arises when medical indication, the patient's will, nursing observation, family possibilities and available services are brought together, and that takes conversations before the crisis occurs. A simple check can help: Is the medical indication clarified and the treatment goal documented? Is the person capable of consenting to this specific decision? Is there a current will, an advance directive or an emergency plan, and has the authority to represent been verified? Have benefits, burdens and the right to refuse been discussed in an understandable way? Are relatives involved only to the extent that is permissible and wanted? Are as-needed medication, maximum doses and escalation paths unambiguous, is the care network of SAPV, hospice service and aids coordinated, the emergency plan set, and are state-law and internal requirements taken into account? And is the documentation so clear that someone else can safely take over?

Anyone who does not know where to begin does not have to work through the responsibilities alone. At home, the first points of contact are the treating family doctor for the medical and palliative assessment and the long-term care insurance fund or a regional care support point for free care counselling. Privately insured people can turn to their private compulsory long-term care insurer or to compass private care counselling. If the person is in hospital, the social service

or palliative service are the right contacts. If decision-making capacity is clearly restricted and no sufficient lasting power of attorney exists, the local guardianship authority advises and, if necessary, the guardianship court decides on legal guardianship. In conflicts: do not act rashly, involve ethics consultation, the representative or the guardianship court. In an absolute emergency, the presumed will applies.

*“Legally secure care arises in conversation, before the crisis occurs.”*

## ◆ 15. Conclusion — Law as a Sheltering Space

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**In the end the question remains whether everything has been considered that a person is entitled to.**

It is no coincidence that all of this can be captured in the image of a house. There, too, it is about something holding when the ground becomes uncertain. Anyone who knows their way around the law of palliative care gains room to act, because they know what is possible, who is responsible and where decisions hold even when they are hard. And yet the most important rooms of this house are not those described by laws. They arise in conversation: Who shall decide? What shall happen in an emergency? Which treatment still makes sense? When shall the hospital be sought, is care at home really sustainable, who relieves the relatives, and who looks after the person who is left alone after the death?

All the law on these pages ultimately serves a single thought: that a person does not become the object of others' decisions, even in dying.

*“Good palliative care protects not only life until the very end — it protects self-determination, relationships and the people who share in bearing illness, care and dying.”*

## ∞ Further Exploration

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

- Wissensraum No. 1 — Navigationsatlas Demenz
- Wissensraum No. 2 — The Ethical Compass in Palliative Care
- Wissensraum No. 5 — System Break at 8:30 pm
- Wissensraum No. 7 — Beyond Listening
- Wissensraum No. 19 — Palliative Care – Illness, Suffering, Death and Spirituality

## ◇ Sources & Lines of Thought

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This Wissensraum does not make a scientific argument. The following sources show the professional and legal lines of thought its central statements connect to — above all those of chapters 3 to 13. Legal status: 1 October 2026. The titles of German laws and documents are given in the original with an English gloss; this version is a working translation.

- Sozialgesetzbuch Fünftes Buch (SGB V) [Social Code Book V – Statutory Health Insurance], in particular §§ 37b, 39, 39a, 73d, 112a and 132g. Federal Ministry of Justice.
- Sozialgesetzbuch Elftes Buch (SGB XI) [Social Code Book XI – Social Long-Term Care Insurance], in particular §§ 7a, 18c, 36, 37, 39, 40, 42 and 45b.
- Sozialgesetzbuch Zwölftes Buch (SGB XII) [Social Code Book XII – Social Assistance], in particular § 94 on recourse to relatives owing maintenance; and the Angehörigen-Entlastungsgesetz [Relatives Relief Act] (€100,000 income threshold), Federal Ministry of Labour and Social Affairs.
- Bürgerliches Gesetzbuch (BGB) [Civil Code], in particular §§ 630d, 630f, 1358, 1820, 1827, 1829 and 1831.
- Pflegezeitgesetz (PflegeZG) [Caregiver Leave Act], §§ 2 to 4, and Familienpflegezeitgesetz (FPfZG) [Family Caregiver Leave Act]. In practice: information portal “Wege zur Pflege” of the Federal Ministry for Family Affairs.
- Gesetz zur Befugnisserweiterung und Entbürokratisierung in der Pflege [Act on the Expansion of Competences and Reduction of Bureaucracy in Nursing; working translation]. In force since 1 January 2026. Federal Ministry of Health.
- Federal Joint Committee: SAPV-Richtlinie [Guideline on the prescription of specialised outpatient palliative care] and Richtlinie über die Verordnung von häuslicher Krankenpflege [Home Nursing Care Guideline], each as amended.
- GKV-Spitzenverband and the relevant hospice associations: Rahmenvereinbarung nach § 39a Absatz 1 Satz 4 SGB V [Framework agreement on the nature, scope and quality assurance of inpatient hospice care]. Version of 18 November 2024.
- National Association of Statutory Health Insurance Physicians and GKV-Spitzenverband: Bundesmantelvertrag – Ärzte [National Framework Contract – Physicians], in particular § 17 on medical cover.
- German Guideline Program in Oncology: S3-Leitlinie Palliativmedizin für Patienten mit einer nicht heilbaren Krebserkrankung [S3 guideline on palliative medicine for patients with incurable cancer]. Version 3.0, status 21 July 2026, valid until 20 July 2031, AWMF register number 128-001OL; replaces version 2.2.
- German Network for Quality Development in Nursing (DNQP): Expert standards.
- World Health Organization (WHO): Palliative care. Fact sheet. Definition of palliative care.
- Federal Ministry of Health: Leistungsbeträge der Pflegeversicherung 2026 [benefit amounts of long-term care insurance 2026]; Pflegeberatung nach § 7a SGB XI [care counselling]; assessment deadlines; Pflegeneuordnungsgesetz (PNOG) [Care Reorganisation Act], ministerial draft of June 2026, Cabinet decision of 30 September 2026, legislative procedure still open.
- Federal Ministry of Justice: Patientenverfügung – Textbausteine und Hinweise [advance directive – text modules and notes]. Federal Chamber of Notaries: Zentrales Vorsorgeregister [Central Register of Advance Care Documents].

- Association of Private Health Insurers: palliative and hospice care for privately insured people; compass private Pflegeberatung; National Association of Statutory Health Insurance Physicians: patient service 116117.
- German Society for Palliative Medicine: information on hospice and palliative care for patients and relatives.

## ○ WISSENSRÄUME — Appreciation

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## △ WISSENSRÄUME — Notice

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The WISSENSRÄUME offer professional orientation, deeper reflection, and personal engagement with topics 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 consult appropriately qualified professionals.

This Wissensraum reflects the legal and informational status of 1 October 2026 and refers to German law. Laws, benefit amounts and procedures change; in individual cases the long-term care insurance fund, a care support point, the guardianship authority or a lawyer can advise.

If this topic weighs on you personally: in Germany, the telephone counselling service Telefonseelsorge is available around the clock and free of charge on 0800 111 0 111 or 0800 111 0 222; in an emergency, call 112.