# *QUESTIONNAIRE*

# *FOR AN OPTIMAL LIVING WILL*

***This questionnaire is NOT to be understood as the final decree***

First name and surname | Address

Date of birth | Telephone | E-Mail

**Important hints - your personal views are required**

Here, you can **highlight wordings**, insert words (keywords are sufficient) or marginal notes, you can ~~**delete**~~ words and phrases, especially **options in brackets** as [very] or [relatively] or [at least realistic prospects] etc. in case, these terms do not suit your specific situation. Moreover, there is the possibility to mark at least one option with **"according to the situation"**. Delete words or longer phrases […] in square brackets which do not suit your situation. **Questions 6, 7 and 8 relate to descent quality of life - acceptable by you.** If an acceptable quality of life cannot be kept consistently, you may define something else.

**Example for filling in question 6:**

□ ***According to the situation…***

*to continue living at home // sufficient mobility ~~[including by wheelchair]~~ …. living independently/ only [little] need for care or assistance with everyday tasks*

Your personal, individual decisions shall be considered and noted down with "according to the situation". Multiple answers are provided in each case. Explanations of starred terms are in the ***glossary***. If you are uncertain about treatment measures for any diseases, contact your doctor.

**Advice is available by phone or personally**.

**Please, be so kind as to submit the legibly filled out questionnaire to the CENTRAL OFFICE FOR LIVING WILLS.** After evaluation and possibly further necessary consultation, a compressed text document will be created for you. This is done by the medical experts and experienced staff.

***We are at your disposal***


***Please contact us:***

***ZENTRALSTELLE PATIENTENVERFÜGUNG***
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***Office hours:***
***Mon., Tues., Thurs.: 10.00 a.m. – 05.00 p.m.***
***Friday: 10.00 am. – 2.00 p.m.***
***or by arrangement***



*Übersetzung: Katrin Ruh. Diese Übersetzung wurde ermöglicht durch Mittel der*

## 1. My living situation, attitude and/or motivation for a Patient Decree

***Possible questions for you to consider:***

*Do I live alone or with others? Am I (very) attached to life - or has it perhaps increasingly become a burden for me? Do I look back on a fulfilled life? Do I want to achieve something special (e.g., relief for relatives in case of later possibly difficult decisions)? Do I have any special worry (need for long-term care, dementia, distressful death and helplessness)?*

**Supplementary field**

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## 2. What is my attitude towards the end of life?

□ *I hope it's a **distant event** in the future*

□ *It's a current, **acute threat***

□ *Dying as terror, **fear** and helplessness*

□ *Death as **long desired deliverance***

□ *It's a transition to the **world hereafter (of spirituality)***

□ *Death as a **natural end to life***

□ *I'd **rather not know exactly** what I'll have to face if the prognosis is bad*

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## 3. *My basic attitude towards hope at the end of life: Balancing opportunity and risk*

In medicine, even in the case of incurable "hopeless" conditions, it is not possible to clearly predict the progressive course of an illness, but only to a greater or lesser extent. Provided that, given this lack of insight, there is still **hope for stabilization** by medication or non-intensive medical measures:

**How should a decision be made?**

□ *I'm determined to seize **every opportunity** to postpone death.*

□ *The opportunity should no longer be taken if there is an **unbearable underlying condition** and there is **no reasonable** hope for improvement.*

□ *I want at all costs to **avoid any risk** of having to live on with severe suffering and the decision should **consequently** be made to **let me die**.*

□ *I accept the **life-prolonging effect** of drugs and measures [only] if they are [absolutely] necessary to relieve suffering.*

□ *In that very case complications as pneumonia, heart failure (treatable by medication or by infusions) would be welcome as "deliverance" as above mentioned. But, also in that case, I **consequently** refuse treatment*

□ ***Already today, I am in the position** (unbearable suffering, high age, weary of life) and I **refuse all life-prolonging measures absolutely.***

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## 4. State of health or existing Illness(es) and/or disability(ies) which should be taken into consideration in connection with my living will

□ *I am [relatively]* ***healthy or not seriously ill***

□ *In the past, I have had the following serious illness(es) or diagnosis(es) (e.g., stroke, heart attack, cancer, other disease in (year) .....):*

□ *I live with chronic ailments / a degree of care / medical aids (e.g., pacemaker):*

□ *I am [very]* ***ill*** *(seriously and incurably)*

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## 5. Intensive care, emergency rescue and resuscitation (= reanimation)

With a serious accident, illness-related emergencies*, organ failure, or similar events, patients rely on life-saving intensive care *. Many continue to live afterwards, some as well as before, others with heavy limitations. Some die despite maximum therapy. After cardiovascular arrest, death comes sooner if resuscitation is not done very quickly*. Therefore, basic measures are initiated immediately—sometimes on the road by laymen or paramedics—and generally are unavoidable then. One (at least presumably) consent* to this, but **outside an acute emergency situation** consent is required: for continuing (advanced) resuscitation, artificial respiration *. These measures are then carried out by physicians and health care professionals in an ICU.

**Is this what I want?**

□ ***Yes,*** *I expect [demand] maximum intensive therapy, as long as there is [the least] hope of saving my life.*

□ ***It depends on the situation****.*
Possible options*: I wish intensive measures to be taken, but not "infinite" and "at any price"//only so long as no permanent [serious] damage is expected/if there is no realistic prospect of recovery of quality of life/only as long as there are very good prospects//if the benefits (above all with progressive age or disease) are greater than the burdens and risks//Otherwise let me die humanely*
*Supplementary field*

□ ***No****, just give me basic medical care (e.g., for a bone fracture) and appropriate palliative measures. I already [absolutely] refuse intensive care and rescue efforts.*

- □ *In other cases, if I am home and non-responsive, do not call an ambulance!*
  (Your social environment should know about this)
- □ ***Because I am*** *already [very] old and sick.*

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**Possible special arrangements for resuscitation under general conditions existing today (!)**

In many acute situations, the will of the patient and also what has happened in the past cannot be determined. Therefore, there is no guarantee of binding enforcement of a specification. Nevertheless, one of the following rules can be helpful and important.
Within 3-4 minutes of cardiac arrest, permanent brain damage* must be expected. After 5 minutes, the probability increases every minute by appx. 50 %, surviving only in a coma *.

□ *As of today….*

- □ *I allow **no** further attempts at resuscitation*
- □ *I allow such treatment only if a cardiac arrest is no longer ago than ……. minutes max. or occurs unobserved (as otherwise no surgery would be done).*

□ *I allow attempts at resuscitation in case of a cardiac arrest in the course of a medical intervention, only* (otherwise, no surgery would be done).

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## 6. Quality of life in the case of permanent physical disability (or chronic illness)

Some people may cope better than others with living with severe physical disabilities or chronic impairments - e.g., with advanced cancer, or needing permanent care – when a medical decision-making situation will be aggravated by a mental confusion. Of course, in acute inability to give consent this could be diagnostically foreseeable consequences of a stroke *.

**Are (would) permanent physical injuries and suffering (probably be) acceptable to me?**

□ ***Yes**, even in severe cases, I want to go on living.*

□ ***It depends on the situation.** To be able to live with it, the following conditions would be essential for me:*
Possible options*: [If possible] to continue living at home / sufficient mobility [including by wheelchair] / regaining or maintaining mental clarity // living independently / only [little] need for care or assistance with everyday tasks (e.g., by outpatient nursing service) // it is absolutely essential: that I would not be permanently bedridden—no "languishing" with paralyzing exhaustion, loss of control over bodily excretions (bladder, bowel) and other distressing symptoms.*

Supplementary field

□ ***No**, if I need permanent care [even not so serious] I should rather be left to die.*

□ ***My suffering** today is already [often] hardly [or no longer].*

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## 7. Living with (progressive) dementia, in particular, impairment of mental abilities

If one's memory and perhaps personality are becoming increasingly lost, then it is a question of (creeping) brain degeneration processes. In many cases those affected can live well for many years and remain mobile. Progressive degrees of dementia *are mainly caused by Alzheimer's disease in old age. Communication skills, certain preferences etc. often remain for a long time. In the end, however, there are considerable deficits in the emotional, physical and consciousness areas.

**For me, would this be a life that should be medically maintained with life-prolonging means?**

□ ***Yes**, every level of dementia [except the terminal stage] is worth living with and therefore I request all medical treatments, including intensive therapy.*

□ ***It depends on the situation***

□ Possible options: *if there were not [considerable] chronic physical complaints [being bedridden] // as long as I can still feel [even the slightest] joie de vivre, am not permanently depressed and/or "grumpy" // as long as I am still able to show interest in my environment // as long as I can still recognize my relatives [or close friends] // that I can still eat food naturally – if necessary, with help.*
Supplementary field

□ ***No**, if my mental abilities are impaired, I no longer want artificial life support.*
*□ I am aware that in a state of dementia the life of the self is qualitatively different. However, my present vision of a relationship-capable, mentally clear life should take precedence.*

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## 8. Severe brain injury, coma, chance of reawakening, permanent damage

Severe disturbances of consciousness are acutely life-threatening. They are caused by brain injury/damage, e.g., in an accident with craniocerebral trauma, by stroke * and by insufficient oxygen supply to the brain. The most severe case is coma * (deepest unconsciousness). Then the ability to react to stimuli of all kinds is lost and artificial nutrition is absolutely vital. The best chance for rehabilitation (a return to a largely independent life—at home or in a nursing home—is possible) is in the first few weeks. Reliable prognoses are usually rarely possible. Especially with younger patients, after head injury it cannot be completely excluded that consciousness is regained even after one year (the longer the duration of the coma, the more serious are the permanent disabilities). On the other hand, acute coma can be followed by a transition to a permanent coma lasting for years, with probably hardly any sensation or reaction capacity (misleadingly also called "waking coma", scientifically: vegetative status *) where the eyes typically remain open in daylight but look into emptiness. Externally similar states with (possibly minimal) remnants of consciousness must be viewed in a more differentiated way. By no means are all people with brain injuries comatose or bedridden. They can also stay mentally handicapped or impaired, but they can learn to eat again, to communicate in simple words and to move in a coordinated way.

**In the circumstances described above, would I want everything possible (life support, rehabilitation) to be exhausted?**

□ ***Yes**, life in a permanent coma is to me still worth maintaining and living.*

□ ***It depends on the situation***
Possible options*: as long as there is [the slightest] hope of awakening from coma // even if [more severe degrees of] brain damage remains permanent [unless organic damage is added] // at most with probably only slight permanent damage // to be able to have contact with people and to communicate*

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*through normal language. Insofar as this is not achieved within ..... months or ..... weeks, I should be allowed to die without any suffering accompanied by palliative care [no admission to a nursing home] // (it is absolutely essential) that there be a realistic prospect (i.e., not only hope) of a self-determined life with [full] recovery of mental abilities //*
Supplementary field

□ ***No,*** *immediately cease all life support—even if the prospects for improvement are still good, or there is only minor brain damage.*

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## 9. Artificial feeding (usually by PEG stomach tube) in case of inability to consent

The ability to absorb enough nutrients, or even to eat (even with the help of others, in the normal way, or as porridge) may be lost, e.g., if, due to specific ailments, patients can no longer swallow. In such cases, patients are usually fed artificially* by stomach tube (e.g., through the nose, or by means of a PEG tube through the abdominal wall) with industrially manufactured products. With a PEG tube, artificial nourishment is permanently possible (even at home, but usually in a nursing home). As a rule, the feeling of hunger * decreases in seriously ill people and finally disappears completely when they are dying.

**Should I be fed artificially* – usually by PEG tube – even if I cannot (can no longer) agree to it?**

□ ***Yes, absolutely.*** *Even in the "final state" [or in the process of dying or permanent coma *, respectively], I wish artificial nourishment.*

□ ***It depends on the situation***
Possible options: *At most (in the hospital) calorie intake* ***by infusion*** *// inserting* ***a PEG tube*** *[only] under a [strict] medical indication that allows for bridging / at most for a period of …… weeks or ..... months (in case of – please compare with the period mentioned in question 8)*
Supplementary field

□ ***No, under no circumstances*** *do I consent to surgery to insert a PEG tube.*

□ *I strongly reject any form of artificial calorie intake, including intravenously, already today*

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## 10. Expectations for pain management, symptom relief, palliative care

Pain management, maximum alleviation, continuing clear awareness (even by administering morphine*) are goals of palliative* and hospice* care. The fundamental concept behind (quality of life to the very end) excludes intentional "active" mercy killing *

□ *In all cases I expect [demand]* ***palliative medical and care measures to alleviate shortness of breath**** *and other ailments (such as nausea, nagging unrest, thirst, etc.) and especially* ***professional pain therapy*** *even with morphine* or similar medicines.*

□ ***I accept*** *the related side effects—in rare cases—of death acceleration and consciousness clouding.*

□ **Furthermore, I explicitly agree to** so-called **palliative sedation*** at the end of life. This should be done, if necessary, with narcotics* and will lead to unconsciousness, especially in the case of uncontrollable unbearable pain and agonizing conditions such as suffocation.

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## 11. At the end-of-life – just alleviation, not extension of life

In the "final stage" of life, or with serious illness, there is often no further prospect of fundamental improvement and (imminent) death is very likely. The persons concerned do hardly response to words. There may also be severe multi-organ failures following septic shock. "Passive" mercy killing would then be illegal in many cases without an express declaration of intent or corresponding living will.

- ☐ *[In the final stage of a fatal illness], or in the case of imminent death, **I [bindingly] reject any apparatus, intensive care or other stressful measures to prolong life** (such as invasive diagnostic procedures, resuscitation*, mechanical or artificial respiration*, dialysis*, surgery, amputation*, stressful chemotherapy*, etc.). In such cases, I want only pain therapy and palliative care according to **question 10**.*
- ☐ *My pacemaker/defibrillator shall be de-activated within the **final stage**.*
- ☐ ***Furthermore**, especially in the dying process [as well as in other hopeless and unbearable situations]: I also renounce the treatment of cardiac insufficiency, pneumonia or other complications as well as of already existing chronic diseases.*
  *This means **I do not want any more means and measures that have a life-prolonging, strengthening or stabilizing effect**, such as antibiotics, blood transfusions, means for stabilizing circulation. Existing permanent medication shall be stopped, too.*
- ☐ *If I no longer **accept** sufficient **liquids** or r**efuse** to drink them, then artificial liquids should also be avoided or, if necessary, administered in a greatly reduced form in palliative care (usually intravenously). The most careful moistening and care of the mouth has priority.*

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## 12. What is my attitude towards euthanasia?

In Germany, killing on demand*, often also called "active euthanasia", is punishable under all circumstances in accordance with § 216 StGB (German Criminal Code) and is therefore excluded. On the other hand, suicide/voluntary euthanasia is permitted and assisted suicide is punishable only under certain circumstances.

- ☐ *In principle, **I am in favor of all mercy killing*** and wish that, should the need arise, **legally permissible** possibilities for a peaceful and quick "twilight" will be **fully exploited on my behalf**.*
- ☐ ***I reserve the right** to decide upon timing and manner of my own death. (Where there is serious illness, suicide is then not just a spontaneous act of desperation.)*
- ☐ *Should I ever decide upon the **method voluntary renunciation of food and liquid (death fasting)** at the end of life, all my wishes for palliative (dying) support stated here would take effect.*
- ☐ ***I fundamentally reject mercy killing*** in any form. Even if it were to be carried out **indirectly** or as an aid to suicide, in my opinion it would still be an ethically unacceptable killing.*

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## 13. Last wishes: How and where would I like to die?

- ☐ *If possible, **at home**, or in familiar surroundings*
- ☐ *Assuming admission requirements are met, in a **specialized institution** (hospice* or palliative care unit*)*
- ☐ *In **peace and with dignity***
- ☐ *I see **sudden cardiac death** as an "**opportunity**."*
- ☐ *If possible, **in the presence of those close to me***
- ☐ ***Spiritual or religious support** is to be called for me if requested:*

*For example, denominational allegiance, belief or philosophy of life, being important for me*

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## 14. Special binding force of my advance directive

The provisions of your living will be **directly binding** upon physicians (until revoked expressly granted discretionary authority). Any violation of this is illegal.

□ *In the framework of my decisions, persons, mentioned in my **healthcare proxy** shall act according to their own judgment.*

□ *If I should (apparently) revoke a waiver of treatment, especially **if I have dementia**, it must be confirmed by a medical specialist that my necessary ability to understand is undoubtedly (!) still present. This also applies to any signs of interest in life that may arise later. I am aware that having dementia does not necessarily mean that I will suffer later.*

□ ***Possible limitation**: In cases of doubt (especially with dementia) the question should be weighed as to what is best for my well-being which corresponds best to my "natural will".*

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## 15. Guidelines for doctors and treatment teams

□ *In case of any difficulty interpreting my advance directive, **support** (if necessary, also for my patient representatives and/or relatives) **should be sought from**:*
Options*: my trusted doctor / other reference persons / Humanist Association of Germany / hospice service / church community / treatment team / ethics committee / Guardianship Court.*

Supplementary field

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## 16. Provisions after brain death/death

**Should organ donation* after confirmed brain death* be allowed**? Note: This is possible only in the intensive care unit under "organ conservation" measures (such as respiration) pending the completed diagnosis of brain death and about 12-24 hours beyond that.

□ ***Yes*** □ ***No*** □ ***Don't know***

Should a tissue biopsy after my death for purposes of medical-scientific research be allowed?

□ ***Yes*** □ ***No*** □ ***Don't know***

***Wishes for funeral arrangements:***

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## ORDER for the elaboration of an OPTIMAL LIVING WILL (OPV)

The CENTRAL OFFICE FOR LIVING WILLS will elaborate an OPTIMAL LIVING WILL (OPV), and, will prepare all necessary proxy documents, tailored individually for you, in duplicate.
Please, be so kind as to let us know which PROXIES shall be prepared for the person(s) of your trust or if you wish to enter a guardianship directive, alternatively.

The documents will base on the elaboration of your OPV-QUESTIONNAIRE as well as on counselling interviews. The OPTIMAL LIVING WILL covers your moral concepts and ethical values (on the basis of living conditions, gained experience or existing illnesses), and, will refer to specific decision-making medical processes. THE CENTRAL OFFICE FOR LIVING WILLS, Berlin, disposes of medical experts and experienced staff, necessary.

The following charges are to be paid once, i.e., after you received your OPTIMAL LIVING WILL ready to sign.

Regular charges

□ for an individual drafting - 160 €
□ for (married) couples per person – 130 €

Reduced charges / social tariff

□ for an individual drafting - 90 €
Justification:

□ I took notice of the data privacy statement

First and family name

Different invoice address

**X**

Date Signature

We thank you for filling in this questionnaire.

In case of any questions in the course of elaborating your OPTIMAL LIVING WILL, we will contact you.

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