HVD Humanistischer Verband Deutschlands | ZENTRALSTELLE PATIENTEN VERFÜGUNG

STANDARD LIVING WILL
QUESTIONNAIRE AND MORE

Pursuant to judicial standard

Übersetzung: Katrin Ruh. Diese Übersetzung wurde ermöglicht durch Mittel der HUMANISMUS STIFTUNG BERLIN

 Berlin 2022

STEP-FOR-STEP INSTRUCTIONS

Issuance for an individually extended

STANDARD LIVING WILL

- Complete
- Mail
- Issuance

Read the instructions in part **A** and part **B** carefully. These parts are to be understood as the key messages of a standard living will (SPV).

You may state individual additional details in advance (in accordance with your present situation) as well as in a more comprehensive way in part **C**.

Part **D** covers all information with respect to an order placement.

Your choice of whether or not to donate an organ (vide "last, but not least") will be included in the standard living will, issued by us.

Self-determined and independent

▪ For more 25 years, we are engaged in strengthening self-determination at the end of life.

▪ In advising capacity, we contributed to the elaboration of the given "Patient's Living Will Act" of the Federal Ministry of Justice.

▪ We contribute to a dying with dignity by public relation activities.

Responsible body of the Central Office Living Will (ZPV) is the Human Association of Germany, Regional Branch Berlin-Brandenburg /corporation under public law/. We tightly co-operate with other institutions and branch offices of the Human Association. Possibly, these documents had been handed over to you by one of these branch offices.

Please, be so kind as to return the four pages with the striped rim **to the address** of the Human Association, **mentioned in part D**.

Our staff will check your information and will offer assistance and advice in filling out the questionnaire – individual **advice by telephone is possible** as well.

Basing on your information, we will prepare a **STANDARD LIVING WILL, ready for signature**. It will be submitted to you by mail. In addition, you will receive the proxy documents and we will print in names and contact data of persons of trust, mentioned by you.

We shall charge a fee amounting to **60 €** to cover our costs.

A reduced amount will be possible, and, a **voluntarily paid higher amount in form of a charitable donation**, will be mostly appreciated. The fee has to be paid after receipt of the finished documents, only.

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QUESTIONNAIRE FOR A

STANDARD-LIVING WILL

This questionnaire is not to be understood as the final Decree

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Authorized party with first name and surname | Date of birth

Address | Telephone

Based on my **current (!) situation** - if there would occur a **sudden case of emergency** (for example by accident or stroke)

a) Should the following measures of intensive care be implemented and exploited?

☐ Yes, as long as there are realistic prospects to regain a worthwhile and environmentally related life, I do agree to measures of intensive-care.

☐ No, already now, I do not wish to be treated by intensive-care in principle (because of advanced age, serious illness or due to similar reasons).

☐ No statements/undecided

b) Should ***attempts at resuscitation*** be made (reanimation)?

☐ In principle, I allow or accept attempts at resuscitation on condition that these measures start within a short time (five minutes) after cardiac arrest, only.

☐ As of today, I do not allow any further attempts at resuscitation in any case.

☐ No statements/undecided

In the event not being able to give voice to my wishes or to express my decision, I hereby specify:

A Situations, where my living will shall apply

The following "standard" situations are to be understood as "hopeless" in the sense of healing or improvement of the underlying disease. Nevertheless, they cannot automatically be considered as senseless, hopeless or useless. At the end of life there still remain more or less palliative (relieving) and caring measures.

To that effect, I do wish primary nursing care as well as pain and symptom relieving measures. In any case, a prerequisite for these wishes is that I am not (longer) able to decide upon the necessary medical measures, i.e., that I am incapable of understanding or intending.

- If I am unavoidable in the **state of dying** or in the **terminal stage** of a deadly disease, respectively
  - ☐ even if the date of death in incurable serious illnesses cannot be predicted, yet.
- If I lost consciousness by a **serious brain damage**[1], and this might be irreversible ("permanent coma")
  - ☐ even if there are no indications for significant improvements in the foreseeable future for me being **capable of understanding** or **getting into contact with others**.
    (Possibilities of a temporal limitation, vide part C, item 6)

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- If I will no longer be able to eat in a natural way - despite assistance, due to **advanced brain degeneration process[2]** (i.e., dementia according to type Alzheimer's)

  ☐ even in case of a stadium of dementia not yet so far advanced, but, added by an organic threat to life (for example by kidney failure) which would be averted by intensive medical or onerous medical procedures (for example by dialysis), only.

Re. superscripts, vide "medical explanations"

B Medical regulations for situations, referred to in item A

1. Indispensable basic care

I wish and expect appropriate care and personal hygiene. Professional, i.e., palliative measures aimed at alleviating psychological and physical symptoms, pains and discomforts as respiratory distress, nausea, fear and restlessness – I take for granted, too.

2. Rejection of intensive medical procedures

In case of situations referred to in item A, I reject any life-prolonging measures. I do not want any stressful procedures, connected therewith. Dying will be desired or accepted by me, respectively. In case of inability to consent, that means in detail:

- **No life-sustaining procedures and measures** as dialysis, no surgeries or amputation.
- **No artificial respiration or already initiated ones, shall be stopped**. I take it for granted to get medication for a sufficient alleviation of breathlessness.
- **No resuscitation attempts**

☐ With cardiac arrest (in home environment) no emergency physician shall be called in situations referred to at item A

3. Rejection of artificial nourishment[3]

Alleviation of hunger and thirst feeling belongs to the basic measures of any relieving therapy. As long as possible, I would like to **eat food naturally**—if necessary, with eating and drinking assistance.

Under the "hopeless" conditions* referred to at item A, I renounce **artificial nourishment[3]** of any kind, i.e., neither by stomach tube (e.g., through the nose, or by means of a PEG tube through the abdominal wall), nor by calorie intake by infusion. Careful moistening and care of the mouth shall have priority.

☐ I also renounce **artificial hydration[3]**, unless it is justified by terms of palliative treatment to a reasonable extend, for the administration of medication for example. I that very case, I wish to get liquid being consumed via the mouth in a natural way, only.

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4. Possible side-effects with the alleviation of pains and relief of symptoms[4]

When pains, respiratory distress or other agonizing symptoms cannot be alleviated in an adequate way at the end of life, I also agree to take medication which even cause drowsiness and dizziness.

☐ Then I expect sedation **medication for consciousness clouding**. I accept the unlikely possibility of life-limitation as side-effect not-intended by physicians.

5. Antibiotics and other medication

This issue exclusively refers to situations described in item **A**.

Aimed at a noticeable tendency, please, choose two alternatives, only.

☐ I also renounce this kind of medication. I do not want any stabilisation or possible life-prolonging measures.

☐ I wish or allow medication for the relief of symptoms, only.

☐ These decisions shall be decided upon or taken by the healthcare guardians at a later time.

It is recommended to add an additional notice covering your personal intentions about a (still) worthwhile life, your hope for improvement as well as about acceptable physical and mental handicaps by outlining already existing health problems. Moreover, please note down all persons to be informed etc. We will submit you such an additional form “What’s important for me” in the course of the finished documents.

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C Possible additional information and wishes to be taken into consideration

In the following, you should add further details basing on your personal values and wishes with reference to the end of life. However, there will always remain difficulties within the determination of time as well as of other unforeseen circumstances. Thus, for example, no one will be able to predeterminate any activities referring limited attempts of revival - nor the desired place of death can be guaranteed. Moreover, the desire of treatment abandonment in case of long-term care will be much too vaguely defined to be considered as an (important) indication to let you passing away finally.

6. Other situations of inability to understand or intend in which medical definitions of part B shall apply:

Before deciding upon the decisions to follow, it will be recommendable to seek medical advice. In case of any doubt, you should skip the following options.

☐ In case of **inability of consent** as well as of communication by speaking caused by a **severe brain damage[1],** the **expectation of a significant improvement shall be limited to**:

…… Week(s), day(s) **or** month(s)
Please, enter a figure and strike out the terms not applicable.

7. Situations of most advanced care with (even temporary) inability to understand or intend

☐ In case of **permanent physical long-term impairment** with most advanced care (for example caused by stroke, organ damage or accident), **I do not wish any more life prolonging interventions**.

With the items to follow, you have the choice of different options.

8. For later decision-making and interpretation of my will.

☐ After full informed medical consent, **those persons, appointed by me** in the enclosed healthcare proxy shall "have the final say" in the decision-making process. With necessary interpretations, they **shall have an own power of discretion** in the framework of my stipulations.

☐ All stipulations laid down in this document, shall be binding and directly applicable conditions for physicians. As long as I do not revoke these stipulations, no changes of my will shall be assumed under the given circumstances.

☐ Whereas in case of **dementia**, there shall be carefully considered any activities to what shall be undertaken **in equivalent to my wellbeing and presumed intention**. This shall be found out basing on my gestures, glances or other expressions of life, i.e., preferably with the approval of those involved.

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9. Desired place to be at the end of life

I want…

☐ to be in a place where my dignity, care and self-determination will protected be best way ever.

☐ to stay in a familiar environment if at all possible.

☐ to be transferred in a hospital in case of complications at the end of life.

☐ to dye in a hospice.

10. Desired support at the end of life

Please, insert name and phone number when appropriate.

I want the following persons/institutions to be informed and involved

☐ Nursing/care service, ambulatory hospice service:

……..

☐ Representatives of the following church / religious community or community of conviction / organization:

……

☐ Physician of my choice:

……..

D Further details

11. Organ and tissue removal

☐ I agree to an **organ removal** for the purpose of transplantation. **Intensive-medical measures** aimed at definition of brain death and organ removal to follow, are **allowed to be pursued**.

☐ I refuse the organ removal.

☐ I am not sure about.

The following permit applies regardless of the three options mentioned above:

☐ I consent to a post mortem organ and tissue removal for the purpose of medical-scientific research.

For processing

☐ I would like to ask for an **urgent processing** (due to a forthcoming medical intervention).

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Filling in forms online

Please, enter our web page www.patientenverfuegung.de and save time by filling in your personal data online and by clicking on the respective option, yourself. According to this, the mentioned amount of fee will be less (compared with the undermentioned).

Refund of charges

The average expenses for the issue of an individual standard living will amount to appx. 60, - EUR.

Aimed at supporting our objectives, you could make a charitable donation. Your donation would help those who cannot afford the fees for issuing the necessary health care documents.

After receipt of my documents,
(Standard living will ready to sign – and, if desired, proxies, ready to sign – in duplicate)
I agree to transfer the (checked) amount of

☐ **60,- EUR - regular**

☐ **30,- EUR - reduced**
Please state the reasons for the reduced amount:
……
……
……

A bank transfer form will be annexed to the submitted documents

We would like to thank you for your assistance in advance

Please, submit to:

☐ I agree to the storing and processing of my personal data aimed at executing my order. Persons mentioned by me (and to be included into my proxies) had been informed about these arrangements by me, and, agree to this procedure, too. I took notice of the annexed privacy statement of this Living Will

Place/Date *Signature*

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MEDICINAL EXPLANATIONS

*Referring to the definitions with superscripts**

Brain damage: Permanent unconsciousness / severe dementia

1. Usually affects **sudden severe brain damages** (for example accidentally by **head injuries**, by **stroke** or by **insufficient oxygen supply** of the brain). The most severe form is a probable expiration of all functions of the cerebrum (permanent coma). Patients in **coma** do not react to stimuli of all kinds and artificial nutrition will be vital. In such cases, organ functions as breathing activities, intestinal and kidney functions will more likely remain unchanged. Especially, with young people **favourable developments** may be observed, i.e. depending on the coma cause after approximately 3, 6 or even after 12 months – but the longer the coma lasts, the more permanent (multiple) damages could be caused.

   By no means all patients with brain injuries are or stay in a comatose state. They can also be "only" mentally handicapped, and, due to these reasons, **unable to understand** and to enter into contact with other people by speaking. But they react quite well to stimuli, achieve true sentiments, and, they can learn to eat again, to communicate in simple words and to move in a coordinated way. Best prospects for a successful rehabilitation are within the first six to eight weeks. Possibly, there could even live independently.

2. It affects irreversible brain injuries caused by progressive impairment of brain function, most common with dementia (Alzheimer's disease). In a very advanced final stage, the patient will be completely bedridden, will not be able to recognize close relatives, and, will be unable to eat and drink in an appropriate natural manner. This is to be distinguished from a stage not yet so far advanced. In this very stage, symptoms could be noticed as personality disorders, fear and disorientation. Even if people are no longer aware of own mental deficiencies, the concerned will be able to associate positive feelings. The affected persons may enjoy life (in a world of their own) or eating.

Artificial nutrition and supply of fluids

3. Alleviation of hunger and thirst feeling belongs to the basic measures of any relieving therapy. However, many seriously ill **do not feel hunger** any more – this applies without exception during dying processes, and, most probably, for persons in long-lasting coma, too. With people suffering of serious illnesses the sensation of thirst lasts longer than the sensation of hunger. Mainly, it is caused by dryness of the mouth. Aimed at the alleviation of these symptoms in dying, it is very important to execute a professional mouth care beside of moistening the beathing air. In contradiction, the artificial supply of larger fluid quantities with the dying is very dangerous because this leads to fluid retention in the body, resulting in agonizing consecutive symptoms (as respiratory distress).

Pain relief and reduction of illness discomforts

4. In general, **professional palliative medical treatment** which includes the administration of morphine will have no effect on life expectancy as well on reduction of consciousness. One example of this is the quite well controlled tumour-induced pain with cancerous diseases. This kind of treatment could even "revive spirits to get new energy". But with all other unbearable pains and not controllable symptoms, especially with fear of suffocation, it will be necessary to decide upon a higher dosage of pain killers and sedatives.

   When "conventional" palliative treatment reaches its limits, narcotics for a so-called sedation (reduction of awareness or temporary deep sleep) shall be used. With extraordinary emergency cases (and unintended by physicians), the risk of an unintended shortening of remaining life-span is not excluded. If this will be accepted and aimed at meeting the principles of legal certainty for physicians, an appropriate passage shall become part of the living will.

Resuscitation ("Reanimation")

5. **Resuscitation procedures** will never serve the reduction of suffering, but, are intended exclusively to rescue lives. Per minute elapsed till the beginning of lifesaving, the chance to survive will reduce by appx. 10 per cent. When resuscitation will be successful after **more than 5 minutes**, only, severe permanent brain damages by hypoxia in the brain will have to be taken in consideration (survival in comatose state). The especially vulnerable brain tissue will be damaged irreparably much quicker than other organs. Unconditional prohibition of resuscitation could be considered for a very senior or terminally ill patient who doesn't – under no circumstances - want to be operated. Within the framework of (still) planned medical interventions there might occur occasional short-term problems which can be solved without health damages by **immediate** resuscitation procedures.

** To a large extent, these explanations within the meaning of the Hospice and Palliative Counselling Service are adapted from the brochure "Living Will" edited by the Federal Ministry of Justice*

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Our free services

▪ We provide free assistance and care in many fields as end-of-life- care by volunteers, for example.

▪ We offer free downloads of documents – vide: www.patientenverfuegung.de

▪ All prospects will get a PV-Newsletter by E-Mail for free, containing updated specialized information.

▪ To relatives and authorized representatives, we render support for the enforcement of the patient's will in a situation, subsequently occurred.

▪ We organize training sessions in health care and nursing facilities.

Please, contact us:

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☎ 030 2062178-02, -03
mail@patientenverfuegung.de

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

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