



# Guidelines

Advance health  
care directive

Living will



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Dialog Ethik  
Interdisziplinäres Institut für Ethik im Gesundheitswesen  
Schaffhauserstrasse 418  
8050 Zürich  
Tel.: 044 252 42 01  
Fax 044 252 42 13  
Switzerland  
info@dialog-ethik.ch  
www.dialog-ethik.ch

### **Authors**

Lic. phil. Patrizia Kalbermatten-Casarotti, MAS, Scientific Staff Member for Living Wills, Institut Dialog Ethik, Zürich  
Lic. phil. Daniela Ritzenthaler-Spielmann, Scientific Staff Member for Living Wills, Institut Dialog Ethik, Zürich  
Dr.med. Christoph Cottier, former Medical Director of Emmental Regional Hospital, Burgdorf  
Hildegard Huber, MAS, Care Expert, Uster Hospital  
Dr. oec. Markus Breuer, Head of Department of Education, Institut Dialog Ethik, Zürich  
Dr. med. Franz Michel, MD, Medical Director Outpatient Clinic at the Swiss Paraplegic Centre Nottwil  
Dr. theol. Ruth Baumann-Hölzle, Director, Institut Dialog Ethik, Zürich

### **Lectureship**

Ulrich Bosshard, Senior Pastor for Pastoral care, Evangelical-Reformed National Church of Zürich  
Anja Bremi, Swiss Association for Senior Citizens' Issues, Reinach  
Lic. iur. Jürg Gassmann, a member of the expert commission for the revision of guardianship law, lawyer specialising in health and guardianship law, Winterthur  
Prof. Dr. med. Andreas U. Gerber, Medical Director (emeritus) for Internal Medicine, individual member of SAMS  
Dieter Graf, Senior Pastor for Pastoral Services at Zürich University Hospital  
Daniela Jerusalem-Stucki, Senior Pastor for Pastoral Services in Care Centres, Rotacher Care Centre, Dietlikon  
Dr. med. Bruno Regli, Deputy Medical Director, Department of Intensive Care, Bern University Hospital  
Prof. Dr. Reto Stocker, Director, Department of Anaesthesiology and Intensive Care, Klinik Hirslanden, Zürich

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## Foreword

Dear Reader,

This is a guideline to composing your own living will from the Swiss Dialog Ethik institute for medical health care ethics. This booklet will help you with questions you might have in completing your living will.

The first part of the booklet will walk you through the directives, and give you some important tips on what to do with the document once you have completed it.

Please refer to the information given in the second part of this guideline on page 25 if you find you have further questions that need qualified consultation as you complete your living will.

The third part of this brochure on page 27 provides details on our partner organisations and further reading. You will find more information at the end of the document on the activities of Dialog Ethik and partner organisations as well as the principles that have guided us in preparing this advance directive.

We hope that our guideline will help you make decisions to match your personal requirements.

The Dialog Ethik Team

## Why would you need a living will?

As long as you are in full possession of your decision-making capacity, you are free to agree or disagree with any therapy that your attending physician might suggest.

Anyone can suddenly find themselves in a different situation that makes it difficult for them to make their own decisions –

- situations such as coma after a serious accident where you are physically unable to speak for yourself,
- a stroke that has caused such serious brain damage that you cannot communicate in any way,
- or advanced dementia preventing any clear thought or decision-making process.

Would you still want everything medically possible performed on you to keep you alive in this kind of situation, or would you prefer these measures to be limited?

Doctors and family members are often faced with the question of how far to go in treatment and whether life-sustaining measures should be applied to people with severe illness or accident injuries. But you are the final authority to decide which medical procedures would be reasonable and should be applied in your particular case.

A living will is your written advanced directive as to what kind of medical treatment you would approve of if you ever come into a situation where you are unable to make that decision. Your living will is a clear and legally binding set of directives addressed to the professionals responsible for you.

## Key points

- Your living will must be legible (block letters recommended).
- Remember to sign and date your living will on page 25.
- Review your living will every two years or so, and add any codicils as necessary. Add the current date and sign your living will again on page 26.
- Keeping your wording as exact as possible will play a major role in ensuring that your living will is applied according to your intentions. Make sure that the wording in any additional supplements is exact and consistent with the rest of your living will.
- You don't need to complete every point on the form at once; however, make sure that your personal details, date and signature are included for your living will to be legally binding. For your living will to be recognised as a legal document, you must appoint at least one health care proxy or draw up health care directives (pages 12 to 18 in your living will).
- Be sure to tell your health care proxy about your living will, and make sure that they are willing to support you in applying your living will.
- Think about where and how you want to keep your living will available if needed. You can ask your health care proxy or family doctor to keep a current copy of your living will with them and pass it on to the hospital as necessary.
- Have the location of your living will recorded on your health service ID card.

# Your living will, step by step

These explanations will help you in formulating your living will. A few points to remember:

- Please leave the preprinted parts as they are. The formulations are tested medically and legally, and will give your medical team the necessary informations.
- You don't need to complete every part of the form at once; you can leave some decisions until later.
- Fill out the form in clearly legible block letters.

Directive  
page 7

## 1. Your personal data

Initial each page of the living will, to show that you have read every page.

Remember that

- you will only be able to write a living will if you are in full possession of your decision-making capacity.
- Drawing up a living will is your personal right – you cannot have your living will drawn up by anyone else.

Directive  
page 7

## 2. Personal reasons for drawing up a living will

### 2.1 Existing illnesses

Information about existing conditions will give your doctor important information as to why you have drawn up your living will.

Directive  
page 8

### 2.2 Objective of medical treatment and care

Describing your therapy objectives will give your doctor important information in situations that you have not made detailed arrangements for.

Addressing these questions can help in this process of clarification\*: Do you have any specific fears, such as inability to breathe, pain, or dependence? How do you define quality of life – keeping your cognitive skills, relationships with others, mobility, your own dietary habits? What situation would you like to avoid – such as being bedridden, paralysed, unable to recognise other family members or communicate with others?

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\* Some points have been taken from the SAMW guideline on living wills (<http://www.samw.ch/de/Ethik/Richtlinien/Aktuell-gueltige-Richtlinien.html>)



### 3. Health care proxies

**Page 9 in the living will is helping you to understand who is legally entitled to make medical decisions on your behalf – your health care proxy – if you cannot personally make these decisions for yourself.**

#### Remember that

if you don't appoint a health care proxy yourself, the mentioned persons will be automatically entitled to decide on your behalf by default if you are physically incapable of making decisions.

#### Duties of health care proxies

Refer to page 9 of the living will for the obligations of health care proxies.

#### Remember:

Your health care proxy will be entitled to consent to or refuse any treatment, but will also be bound by the directives you have given in your living will. If you haven't made any specific arrangements for actual situations in your living will, health care proxies will act upon what they think your intentions would be. If there is no way of judging this, a health care proxy has to act according to your well-being and best interests if you are incapacitated.

So you should definitely talk to your health care proxy about your requirements and your living will.

You might like to talk to your family doctor if you can't think of anyone you would like to grant power of attorney to; you may be able to appoint your family doctor as your health care proxy.

Your living will may include other health care proxies for contacting if your first health care proxy cannot be reached.

Make sure you take down all the contact details of these health care proxies so they can be reached in an emergency. This information should give your care team all they need to know to contact your health care proxies and find the right people.

If you haven't appointed a health care proxy and would like your family members to make decisions on your behalf, tick the corresponding box on page 10.

If you haven't appointed a health care proxy and don't want your family members to have this health care power of attorney, the authority responsible for adult protection (Erwachsenenschutzbehörde) will appoint legal counsel for medical treatment. The legal counsel will make decisions on any medical procedures that you haven't arranged for in your living will. If you would like to choose this option, tick the corresponding box on page 11 of your living will.



## 5. Medical directives

**Apart from naming your health care proxy, medical instructions will take up a major part of your living will.**

**Chapter 5.1 is essential. Make sure you answer all of the questions asked here!**

What can a dispositive person refuse or demand?

Medical possibilities and patient self-empowerment both decide on any medical treatment to be applied. As a patient, you have **almost unlimited rights to refuse treatment** – this is referred to as your defensive right. This does not include medical procedures that may be taken if you pose a danger to others, such as in an epidemic. However, you **can't demand every potential treatment available** – your doctor will have the right to refuse any form of therapy that does not meet modern medical standards.

What you can't include in your living will

- Your living will cannot demand anything that runs against Swiss law, such as active euthanasia.
- You cannot demand assisted suicide in your living will, as assisted suicide assumes that you are in possession of your decision-making capacity.

### 5.1 Life-sustaining measures

Your living will lists five common situations that involve difficult decisions in practice.

Situations:

- **Should I become irreversibly unable to communicate (whether by accident or illness, such as stroke), with very little chance of ever being able to relate to other people again, I would like (even if it is not yet possible to predict when I might die):**

You might be in this situation after suffering irreversible brain damage according to clinical opinion. Your condition indicates a very high probability that you will never again be able to express your desires either verbally and nonverbally, that is, with gestures or communication aids; there is as yet no way of telling how long you will survive.

- **Should I be receiving intensive care with a poor long-term prognosis, I would like (even if I may briefly improve):**

The situation assumes that you are dependent on intensive medical care; your doctors have given you a poor long-term prognosis, although they cannot rule out the possibility of temporary improvement. Temporary improvement might mean leaving the intensive care unit, possibly allowing a brief return home.

## Situations:

The scope of your living will is not restricted to specific stages of illness – **you can determine which phases apply in your directives**. The following three situations take the course of illness into account; you may make arrangements for the course of a serious illness, the final stages and the situation just prior to entering the terminal phase:

- **Should I develop a progressive, incurable illness such as cancer or dementia, involving serious physical and/or mental disability, I would like (even if it is not yet possible to predict when I might die):**

Impairments to living every day life take a gradual course in a progressive disease; the illness itself is terminal. However, there is no way of telling how long you will survive with this illness at the time that life-sustaining measures become necessary.

If you wish to refuse life support in this situation, give some thought as to whether you also want this to apply to dementia. Do you still wish to refuse life-sustaining measures if you are no longer capable of making a decision but you can express happiness, and your caregivers see your quality of life as relatively good from an outside perspective? You can give your directive in this case under “Specific dispositions”.

- **In the final stages of an incurable and fatal condition, I would like (even if it is not yet possible to predict when I might die):**
- **When it is clear that I am dying, and am close to death, I would like:**

Your life will be drawing to a close in this situation; death is imminent, but the final phase has not yet begun.

## Possible options:

- **... life-sustaining treatment (including resuscitation) should be discontinued, and replaced by state-of-the-art palliative care.**

This option aims at the best possible palliative care (see page 12 in the living will for a definition of palliative care).

- **... life-sustaining treatment options should be exhausted as part of the treatment plan to keep me alive.**

This option aims at life preservation; this means that all procedures known to modern medicine will be applied in order to keep you alive.

You may also take down personal directives in the Specific dispositions section.

## 5.2 Resuscitation in a hospital or residential home

### Cardiac arrest – sudden cardiac death

Sudden cardiac death occurs when the heart suddenly stops pumping; this immediately causes circulatory arrest followed by unconsciousness and respiratory arrest within a few seconds. It will only take ten minutes of cardiac arrest to cause irreparable damage to the central nervous system, which will correspond to the time of death. There would not be much time to apply resuscitation measures between cardiac arrest and the onset of death.

#### What does resuscitation mean?

Resuscitation refers to those immediate emergency measures to revive you after cardiac and/or respiratory arrest. Resuscitation is an attempt to give you the most rapid recovery of vital cardiovascular and respiratory functions to supply your vital organs – especially your brain, heart, and kidneys – with oxygen.

Heart-lung resuscitation measures include CPR, defibrillation – controlled release of electric shocks to the heart muscle with the aim of restoring normal heart function, intubation – inserting a tube through your mouth or nose to keep air coming to and from your lungs, ventilation, and additional drugs to support your circulation. If resuscitation measures fail or are not applied, you will inevitably die.

#### Chances of success in resuscitation attempts

In Switzerland as in the rest of the world, **around 5%** of patients survive **acute** cardiovascular arrest **outside the hospital**.

Survival rates are higher **inside of hospitals**. When and where resuscitation is applied also plays a major role, whether inside or outside hospital – survival rates for cardiac arrest **with cardiac cause will be over 70%** in a cardiac catheterisation lab, coronary care unit, or in a cardiac intensive care unit.

However, the hospital survival rate for cardiac and circulatory arrest **with a non-cardiac cause or progressive general deterioration** is only **0-2%**.

Resuscitation is considered successful if you survive cardiac arrest without neurological complications, that is, without damage to your central nervous system; this cannot be estimated on a case-by-case basis either in advance or during the actual situation with a good degree of reliability. Some survivors show good neurological recovery, while others show moderate to severe neurological disorders (Source: SAMW (2008). Reanimationsentscheidungen. Medizinisch-ethische Richtlinien und Empfehlungen).

So, whether or not you can be resuscitated successfully depends on the individual background and the circumstances. Prognosis is highly individual, with the following factors playing a role:

- Time between the cardiac arrest and the start of resuscitation measures or restoration of cardiovascular function
- Underlying medical condition – your chances will be poor in progressive conditions such as multiple organ failure
- Any concomitant conditions that become more serious with increasing age

Your living will allows you to make arrangements for these last two situations, amongst others.

**Every patient with decision-making capacity has the right to opt for or against resuscitation measures, and that's why you should give some thought to the possibility of cardiac arrest and any resuscitation on admission to hospital or a residential home.** One of the aims of a living will is to encourage dialogue on this question:

**Should I be admitted to a hospital or residential home, and especially before an operation, I direct my attending physician, should I be unable to decide myself, to discuss the eventuality of cardiac arrest and any resuscitation measures with my health care proxy.**

Situation:

- **Should I develop an incurable progressive disease that could also last months or years, I would like:**

Doctors find it especially difficult to judge whether to apply resuscitation measures to a patient with an incurable, progressive condition that may continue for months or years. Your own intentions as a patient are especially important in situations such as these. We recommend you discuss this matter with your doctor to help you make an informed decision.

If you would like to refuse any type of resuscitation measure, you may do so in the "Specific dispositions" section; you might like to take the likelihood of successful resuscitation (see above) into account in your decision. We recommend that you discuss your decision with your doctor.

Possible options:

- **... not to be resuscitated in the event of cardiac arrest.**
- **... to be resuscitated as part of my treatment plan in the event of cardiac arrest.**

## Resuscitation attempts outside of a hospital or a residential home

Your living will, if you have one, probably won't be immediately available if you suffer cardiac arrest outside a hospital or residential home; in addition, law requires that assistance measures are applied and failure to provide assistance may be prosecuted. This specifically means that the emergency team will initiate life-sustaining measures first, then (ideally at the same time) make enquiries as to whether or not you have drawn up a living will. If you do have a living will refusing resuscitation, the emergency team must stop any attempts at resuscitation at once.

In practice, however, the resuscitation measures outside a hospital or residential home will already have been applied before anyone has the opportunity to consult your living will if you have one. Any treatment plan will take your living will into account after you have been admitted to hospital.

For further questions about resuscitation measures, please contact the Swiss Heart Foundation (see page 29 for the address).

## 5.3 Artificial respiration

### Respiratory failure

Suffocation is a very common fear in thinking about how life might end; actually, death usually comes peacefully in respiratory failure. Breathing difficulties may be sudden or chronic; the aim of respiratory support is to prevent sudden respiratory failure and relieve the effects of chronic breathing difficulties.

### Respiratory support in emergency situations

Respiratory support measures in acute conditions primarily serve towards keeping you alive in illnesses with a good prognosis of substantial recovery or lasting improvement, such as in pneumonia. This form of respiratory support is provided in full form according to medical need with the aim of preserving life in the hopes of a good quality of life.

### Respiratory support in chronic, progressive disease or at times close to death

Relief from breathing difficulty is usually the main aim here, more so than preserving life; you can direct the limits to these forms of respiratory support in your living will. Depending on the situation, you can also alter these limits during the course of disease. Whenever possible, you should discuss this with your care and treatment team. Examples of possible limitations might be: "I do not want intubation or tracheotomy." Your living will allows you to make arrangements for these particular situations.

### What are respiratory support measures?

There are two methods of mechanical respiratory support:

- Non-invasive mechanical ventilation  
This refers to respiratory support equipment using a mask.
- Invasive mechanical ventilation  
This method leads air mechanically into the trachea (windpipe) through a tube inserted into the mouth or nose (intubation) or directly into the throat (tracheotomy).

Both methods of mechanical respiratory support can be applied continuously – that is, twenty-four hours a day – or on demand, such as in nocturnal respiratory support.

Your living will lists the following two common situations that involve difficult decisions in practice.

Situations:

- **Should I develop a chronic, incurable and progressive disease such as neuromuscular or muscle disease that makes me too weak to breathe, e.g. ALS, multiple sclerosis, Duchenne muscular dystrophy, cancer or chronic obstructive airways disease (COAD), I would like:**

Doctors find it especially difficult to judge whether to apply respiratory support measures to a patient with an incurable, progressive condition that may continue for months or years. Your own intentions as a patient are especially important in situations such as these. We recommend you discuss this matter with your doctor to help you to make an informed and a balanced decision.

- **In the final stages of an incurable and fatal condition, I would like (even it is not yet possible to predict when I might die):**

Possible options:

- **... no artificial respiration. Breathing difficulties should instead be effectively combated using optimal palliative care (medication and oxygen).**

**Breathing difficulties may be alleviated without mechanical respiratory support;** medical and nursing measures together with additional oxygen can effectively help you breathe. Pharmacological measures particularly include opiates such as morphine as the most effective remedy for breathing difficulty. **Doctors and caregivers have guidelines for administering these drugs properly.**

- **... artificial respiration via mask, intubation or tracheotomy as part of my treatment plan.**

Your caregivers and doctors will give you respiratory support if you direct them to do so in your living will and the treatment team sees this as necessary.

## 5.4 Artificial nutrition and hydration

Decisions on whether or not to administer artificial nutrition and hydration pose a major challenge in medicine.

### Artificial nutrition as a temporary measure

Acute conditions may weaken you, leaving you incapable of ingesting enough food in any natural way for a time. In these cases, artificial nutrition and hydration will tide you over and help you recover.

### Artificial nutrition as a permanent measure

Some situations may permanently prevent natural food intake for medical reasons – conditions such as neurological disease (stroke, multiple sclerosis and similar with permanent swallowing impairment), permanent loss of consciousness (coma), oesophageal (food pipe) blockage caused by tumours, or advanced dementia where you “forget” how to eat and swallow. Your living will allows you to make arrangements for these particular situations.

Modern artificial nutrition and hydration technologies have been keeping many patients alive for weeks, months or even years. If your doctor sees that you need artificial nutrition, the question arises as to whether this is what you would want. The measure is regarded as a **medical procedure requiring patient’s consent**. If you are incapable of judgment, the doctor will make this decision according to your living will; if you haven’t drawn one up, your health care proxy will have to decide on your behalf. If you have directed your doctor or caregivers not to apply artificial nutrition, ceasing therapy would be passive and not active euthanasia according to your directive.

### How does the body react without food and water?

If you are capable of expressing consent and refuse food and fluids, you will remain fully conscious at first as long as no fever is present and no sedatives have been administered. You will become progressively weaker after a time. The cause of death will be loss of fluids – dehydration – after your final fluid intake; you will experience drowsiness, and eventually your heart will no longer be able to beat and you will die of cardiac arrest in your sleep. This may occur as early as five to seven days without food and water. The whole process can take weeks or even months if you refuse just food but not fluids.

Your living will lists three common situations that often involve difficult decisions.



## Situations:

- **Should I become irreversibly unable to communicate (whether by accident or illness, such as stroke), with very little chance of ever being able to relate to other people again, I would like:**

Due to a damage of the brain you are no longer capable of communicating with other people either verbally or nonverbally. Experts have given you a very poor prognosis. This may arise if you are in a permanent vegetative state or after a stroke.

Your condition is stable although your prognosis is poor. Artificial nutrition would be vital for you since you will not be able to take in any food or fluids in any natural way. This raises the question as to whether you would give your consent for these measures to be administered. The decisive factor in such situations is your consent, and may be kept as a directive in your living will.

- **In the final stages of an incurable and fatal condition, I would like (even if it is not yet possible to predict when I might die):**

You are in the final stages of an incurable, terminal condition such as cancer or cardiovascular diseases, and your doctors do not see any chance of recovery. You are incapable of judgment, you cannot take food and water in any natural way, and the question of artificial nutrition and hydration arises.

- **Should I develop irreversible severe disabilities or advanced dementia leaving me bedridden and unable to communicate, I would like:**

Your general condition is poor due to your advanced age or dementia; you are bedridden, you cannot communicate with your surroundings and you can no longer take nutrition in any natural way. Your directives in your living will can make decisions easier for your family members and the care and treatment team.

## Possible options:

- **... no artificial nutrition or hydration. I realise that this may shorten my life. Hunger and thirst should be relieved by optimal palliative medical and nursing care.**

Remember that if you take this option, **absence of artificial nutrition will not mean the end of treatment and care**. The treatment and care team will have a variety of palliative care and nursing measures available to ensure your quality of life. Professionally applied, this will lead to a peaceful end; adequate mouth care will relieve your thirst caused by your mouth drying out. Keeping the inside of your mouth moist will rapidly reduce your feeling of thirst. Reducing fluid and food will stimulate your body to produce endorphins, your body's own "happy drugs", which will reduce any pain and lighten your mood. Painkillers will support this effect.

- **... artificial nutrition and hydration as part of my treatment plan.**

Your doctors will fulfil your directive in your living will for artificial nutrition. Situations where artificial nutrition is not indicated include the final phase with death imminent.

## 5.5 Relieving pain and anxiety

You can also make arrangements for situations involving pain, nausea, anxiety and restlessness:

Situation:

- **My directive for pain, nausea, anxiety and restlessness:**

Select an option and take down any special arrangements. In making this decision, it would help to reflect on how sensitive you have been to pain so far.

Possible  
options:

- **... generous administration of painkillers and sedatives. I realise that this may impair my consciousness or shorten my life.**

If you take this option, the painkillers and any sedatives will be administered in doses so high that you will experience little or no pain or anxiety; however, this may involve impairing your consciousness. The high dosage of medication may also shorten your life, but this is controversial – recent studies have concluded that an optimum (and high-dose) pain therapy does more to prolong life.

- **... painkillers and sedatives should only be administered to make my condition bearable. I want to remain conscious as long as possible.**

Some patients prefer to remain conscious as long as possible, accepting possibly increased pain. There will be no danger of inadequate pain management if you take this option. Good pain assessment allows doctors to estimate whether or not you are in pain even if you are incapable of response, and administer the dose you personally require for pain relief.

## 5.6 Admission to a hospital for severe care

Many people that feel comfortable in a nursing or retirement home would not want to be moved to a hospital on deterioration of health towards the end of their lives. If you already live in a residential home, you might like to think about when you would like to be transferred to a hospital and the situations where you would like to remain in the residential home until the end. Make sure you talk about this with your attending physician and primary caregiver.

Situation:

- **My directive in the case that I have a terminal condition or have become senile, permanently bedridden, dependent on others for help and incapable of judgement, and experience a deterioration in health:**

Possible options:

- **... no admission to hospital. This means that my basic needs will be covered for care at my current location.**
- **... admission to hospital only if this promises to improve my quality of life, or relieve an acute pain condition or other serious conditions.**  
  
If you select this option, you will only be admitted to hospital in one of the two following conditions: if this will either improve your quality of life or relieve acute pain. You will not be admitted for the only purpose of attempting to prolong your life if you take this option.
- **... admission to hospital.**  
  
By choosing this option, you direct your caregivers to transfer you to the hospital.

## 8. Donation of organs, tissues and cells

Organs, tissues and cells may be taken from a deceased person on the following conditions:

- **Brain death has been determined**
- **and you have agreed to this before death.**

Brain death is where the brain has irreversibly ceased all function.

If you have not expressed any consent or refusal, your organs can only be taken if your proxy gives his or her consent; he or she must base their decision on what they think your decision would have been. If you do not have a proxy that can be reached, your organs cannot be taken.

Donating organs, tissues and cells is possible:

- after death due to brain haemorrhage. This may be the result of an accident – head injury, traumatic brain injury – or aneurysm. Pressure increases in the skull after a brain haemorrhage; this may lead to an irreversible loss of brain function (**brain death from irreversible brain damage**);
- after prolonged cardiac arrest (after unsuccessful resuscitation attempts or discontinuation of life-sustaining measures), reducing the oxygen supply to the brain long enough to cause irreversible loss of brain function (**brain death after cardiac arrest**).

Organs, tissues and cells can be donated up to old age. Your health and your organs' condition, rather than your age, play a role in your suitability as a donor.

You cannot donate organs if you die at home since taking out organs needs special preparation as is only possible in hospital. However, some cells and tissues – such as your corneas – may be taken if death occurs outside the hospital. They can be removed for a certain period after death.

**Medical preparations** are necessary before organs can be taken out. These include:

- **Measures for assessing donor suitability**

Blood tests and immunological analyses

- **Measures to keep all your organs functioning**

The aim of these measures is to preserve the organs and keep them undamaged until removal. Organ-preserving measures play a critical role in transplant outcome. **They are not implemented in your interests, but to maintain the quality of your organs.** Organ-preserving measures may be applied **before or after the determination of death**. These measures are only permitted for forty-eight hours before brain death; after brain death they may be continued up to seventy-two hours in order that the relatives can come to a decision.

**The cause of brain death** (irreversible brain damage or as a result of cardiac arrest) **will affect the procedure the hospital will take in removing organs and the extent of organ-preserving measures taken.** For this reason, your living will allows you to give separate consent to organ donation from irreversible brain damage (*Section 8.1 of your living will*) and cardiac arrest with secondary brain death (*Section 8.2 of your living will*).

## 8.1 Organ donation after irreversible brain damage

### Procedures

The treatment objective will change if your prognosis shows no chance of recovery after irreversible brain damage (see above) and death is imminent; treatment will now focus on palliative care rather than life support. Your organs may be removed on diagnosis of brain death as long as you or your proxy has given consent.

### Organ-preserving medical measures

The following organ-preserving measures may be applied:

- Continuation of the therapy initiated despite terminal prognosis; this may include artificial respiration, administration of medication to maintain cardiovascular function
- Blood sampling to decide on further therapy

## 8.2 Organ donation after cardiac arrest

### Procedures

In this case, death occurs after final cardiac arrest after unsuccessful resuscitation attempts or decision to terminate intensive care as futile by your treatment team. Cardiac arrest may occur very quickly or only after several hours. If this terminal phase takes long, lack of blood supply to the organs may prevent organ donation.

Cardiac arrest is diagnosed using ultrasound. After a waiting period of ten minutes without resuscitation attempts, the same clinical signs as irreversible brain damage are reviewed to determine death.

**The time factor plays a vital role in donors that have died of cardiac arrest, and is far more critical than in donors that are in the state of irreversible brain damage.** Organs for transplant no longer have a sufficient blood supply after cardiac arrest; this means either **removing the organs as soon as possible, or early medical measures to preserve the organs to keep them from damage.**

### Organ-preserving medical measures

The following organ-preserving measures may be applied:

- Administration of anticoagulants immediately before cardiovascular arrest
- CPR
- Insertion of probes near the organs to be removed. The probes keep the organs cooled after cardiac arrest; this involves a surgical procedure before or after cardiac arrest.

You can also decide whether you want to donate your organs after death in a donor card; this decision must be the same in both documents, and you should inform your proxy about this.

## 9. Directives after death

Directive  
page 23

### 9.1 Autopsy

An autopsy (also referred to as a post-mortem) involves surgically opening and examining the body. An autopsy is also a way to verify diagnosis, supporting quality assurance in medicine and contributing to medical progress. Your living will allows you to decide whether your cause of death may be examined after death for teaching and research purposes. The decisions you take regarding autopsy will depend on whether you want your body to remain intact after your death.

The law may also require autopsy under certain circumstances even if you have refused an autopsy in your living will; cases include suspicion of crime or suicide.

Directive  
page 23

### 9.2 Donating your body to an anatomical institute

You can leave your body to medical research after your death, which means that you will be donating your body to an anatomical institute at a major university. To take this option, fill out the corresponding form at the University. See page 28 of these guidelines for university addresses.

Studies at anatomical institutes take several months – this is important to remember as your funeral will not be able to take place a few days after death as is usual. We recommend that you talk about this with your family.

Directive  
page 23

### 9.3 Access to patient records after death

Your patient records will not automatically be shown to your health care proxy or other family members. You will need specifically to name anyone that you want to have access to your patient records; it might be important for your family members to gain access to your patient records in order to settle insurance claims.

If a forensic autopsy is performed, your health care proxy and family members will be given access to the autopsy report.

Directive  
page 24

### 9.4 Use of my patient records for research purposes

Your treatment team is bound to absolute secrecy on your patient records. Research staff will be able to view your patient records if you allow your records to be made available for research; your diagnosis and treatment details will undergo scientific assessment in anonymous form.

## 10. Date and signature

### Decision regarding validity in case of unforeseen events

Doctors will take an aggressive therapy approach to situations where unforeseen events have hampered treatment, such as in malpractice, regardless of directives in your living will; this is because they will usually assume that you did not think of this possibility when you were drawing up your living will. You can select whether your directives should apply in situations such as these.

See page 23 in these guidelines for details on saving the location of your living will on your health service ID card.

You will need to sign your living will by hand for it to be legally valid and binding.

We are aware that these guidelines will not be able to answer all of your questions in drawing up a living will; our team at Dialog Ethik would be pleased to help you further by phone or in person (for our consulting services, see page 25 of these guidelines).



## You've drawn up your living will. What comes next?

Once you've drawn up, dated and signed your living will,

- you should talk about the content of your living will with your health care proxy, family and family doctor or your attending physician.
- Take steps to make sure your living will is available when needed. Give your health care proxy and, if applicable, your family doctor and attending physician a copy of your living will. Have the location of your living will recorded on your health service ID card (see box).

### Recording on the ID card of your mandatory health service

**From 2013 onwards, you will be able to have the existence and the location of your living will recorded on your health service ID card.** You can ask your health care proxies or family members to bring your living will into the hospital if needs be. If you don't have any living next of kin, you can ask your doctor to keep your living will and patient records on file for submission to the hospital in an emergency.

You can also ask your doctor to record the location of your living will on your health service ID card on your first visit in 2013, and you can also have any other emergency data such as your blood group, medications, allergies, or vaccinations recorded on your card.

**From 2013, your attending physician at the hospital will be legally bound to find out whether you have a living will if you are incapacitated at the time of treatment by looking for a corresponding record on your health service ID card. Therefore it will be very important for you to have the whereabouts of your living will recorded on your health service ID card.**

Please don't hesitate to ask us if you have any questions or concerns, and you are looking for a suitable place to keep your living will safe.

### On admission to a hospital or residential home

If you are planning a hospital stay, we would recommend that you take your living will with you and discuss it with your attending physician. This is often a good way to begin talking about your wishes for medical treatment; the same applies to admission to a residential or care home.

## Will a Swiss living will apply outside Switzerland?

Your living will has been drawn up according to Swiss law. Treatment decisions may be handled differently in other countries – sometimes even in neighbouring countries. If you travel abroad frequently, we would recommend talking to a doctor or local health organisation for information on how they deal with living wills.

You will find further reading in the Appendix for more information on the legal position outside Switzerland.

## Codicils to your living will

Current validity and any recent codicils ensure a living will to be applied according to your wishes whenever the need should arise. Once drawn up, we recommend that you review your living will and add any codicils as required at regular intervals; this is particularly important if your health or life situation should change.

We recommend that you review your living will every two years and alter it if necessary to prevent any suspicion that your intentions have changed since the initial draft. Sign and date any changes for confirmation on page 26 of your living will. You can make any additions or alterations by writing them directly into the document as long as you keep everything legible. You can confirm that you personally have made the alterations by signing the modified page.

## What if the hospital fails to honour your living will?

According to Art 373 of the new Civil Code (ZGB), anyone close to you – your health care proxy, a family member, attending physician or nursing staff – may call for intervention by the adult protection authority (Erwachsenenschutzbehörde) if the directives in your living will are not being honoured, or your interests are not ensured or complied with according to your living will.

Your health care proxy can also contact Dialog Ethik if they have any difficulties enforcing your living will at a hospital or residential home. We will be happy to provide our support – see page 25 in this guideline for more information on our consultation and support services.

## Finally

We hope that your living will will help you and your loved ones in talking about passing away and how to deal with it, while giving you the assurance that if you are incapable of making your own decisions, you will be cared for according to your will and nothing will happen to you against your wishes.

# Dialog Ethik consultation services

## Consultation in drawing up a living will

Our team at Dialog Ethik will be happy to give you any help you need in drawing up your living will.

- **Telephone consultation** **0900 418 814**  
CHF 2 per minute
- **Personal consultation**  
Arrange for an appointment on **044 252 42 01**  
CHF 150 per hour  
(on arrangement if your financial options are limited,  
CHF 20 for social benefits recipients)
- **Group consultation** (max. 12 persons) CHF 55 per person  
Basic knowledge on living wills and  
help in filling out the document  
Next dates available by phone on **044 252 42 01** or  
**[www.dialog-ethik.ch](http://www.dialog-ethik.ch)**

## Support in having your living will applied at a hospital or residential home

Your health care proxies can also contact us if they have any difficulties enforcing your living will at a hospital or residential home.

- **Telephone support** **0900 418 814**  
CHF 2 per minute
- **Local support** CHF 150 per hour  
Initial contact **0900 418 814**  
CHF 2 per minute

**Phone consultation is free for Dialog Ethik members. In addition, members benefit from discounts on personal and group counselling as well as local support.** For details on membership in the Dialog Ethik support society, refer to [fv.dialog-ethik.ch](http://fv.dialog-ethik.ch) or call us at Dialog Ethik (tel. 044 252 42 01).

Prices subject to change. Dialog Ethik is a charitable non-profit organisation. Your donation will help us to provide consultation at these moderate prices.

### **Dialog Ethik**

Interdisziplinäres Institut für Ethik im Gesundheitswesen  
Schaffhauserstrasse 418  
8050 Zürich  
Tel. 044 252 42 01  
Fax 044 252 42 13  
[info@dialog-ethik.ch](mailto:info@dialog-ethik.ch)  
[www.dialog-ethik.ch](http://www.dialog-ethik.ch)

Donations: Postal account 85-291588-7 IBAN: CH61 0070 0115 5001 9992 2

## Living will (including Guidelines)

- **Form in printed format** CHF 22.50 (including VAT)
- **Internet download** free of charge

The Dialog Ethik living will is available in German, French, Italian, and English.

English is only available by Internet download.

Note that Dialog Ethik has prepared **condition-specific living wills** tailored to specific diseases and facilitate it in advance to make arrangements for certain diagnoses. See page 27 and

[www.dialog-ethik.ch/patientenverfuegung](http://www.dialog-ethik.ch/patientenverfuegung)

for details.

# Appendix

## Partner organisations of Dialog Ethik

### Schweizerische Herzstiftung

Schwarztorstrasse 18  
P.O. Box 368  
3000 Berne 14  
Tel. 031 388 80 80  
Fax 031 388 80 88  
info@swissheart.ch  
www.swissheart.ch

### Schweizerischer Verband für Seniorenfragen

Geschäftsstelle  
P.O. Box 46  
4153 Reinach  
Tel. 061 713 04 22  
Fax 061 713 04 21  
info@seniorenfragen.ch  
www.seniorenfragen.ch

**Dialog Ethik and other partner organisations listed below have developed condition-specific living wills available for free download at**

[www.dialog-ethik.ch/patientenverfuegung](http://www.dialog-ethik.ch/patientenverfuegung)

## Living wills for cancer diagnosis

### Krebsliga Schweiz

Effingerstrasse 40  
P.O. Box 8219  
3001 Berne  
Tel. 031 389 91 00  
Fax 031 389 91 60  
info@krebsliga.ch  
www.krebsliga.ch

### Information and consultation:

- Cancer helpline: 0800 11 88 11  
(Mondays to Fridays 10AM – 6PM)
- Cantonal leagues, Addresses under:  
[www.krebsliga.ch/kantonale-ligen](http://www.krebsliga.ch/kantonale-ligen)

## Living wills for Parkinson's disease

### Parkinson Schweiz

Gewerbestrasse 12a  
P.O. Box 123  
8132 Egg  
Tel. 043 277 20 77  
Fax 043 277 20 78  
info@parkinson.ch  
www.parkinson.ch

### Information and consultation:

Dialog Ethik  
Interdisziplinäres Institut für Ethik  
im Gesundheitswesen  
Schaffhauserstrasse 418  
8050 Zurich  
Telephone support: 0900 418 814  
CHF 2 per minute  
info@dialog-ethik.ch

## Anatomical institutes (ordering of the form “testamentary disposition”)

Universität Basel  
Medizinische Fakultät  
Anatomisches Institut  
Pestalozzistrasse 20  
4056 Basel  
Tel. 061 267 31 11  
Office tel: 061 267 39 20

Universität Bern  
Institut für Anatomie  
Baltzerstrasse 2  
3000 Berne 9  
Tel. 031 631 84 33  
www.ana.unibe.ch

Universität Zürich  
Anatomisches Institut  
Winterthurerstr. 190  
8057 Zurich  
Tel. 044 635 53 11  
www.anatom.unizh.ch

## Further reading

Naef, J.; Baumann-Hölzle, R.; Ritzenthaler-Spielmann, D. (2012): Patientenverfügungen in der Schweiz. Basiswissen Recht, Ethik und Medizin für Fachpersonen aus dem Gesundheitswesen. Zürich: Schulthess Verlag.

### Ethical directives in Switzerland:

Schweizerische Akademie der Medizinischen Wissenschaften (2009): Medizin-ethische Richtlinien: Patientenverfügungen. Available at: <http://www.samw.ch/de/Ethik/Richtlinien/Aktuell-gueltige-Richtlinien.html> (accessed on Aug 21, 2012)

Schweizerische Akademie der Medizinischen Wissenschaften (2008): Medizinisch-ethische Richtlinien: Reanimationsentscheidungen. Available at:

<http://www.samw.ch/de/Ethik/Richtlinien/Aktuell-gueltige-Richtlinien.html> (accessed on Aug 21, 2012)

Stellungnahme der Nationalen Ethikkommission im Bereich Humanmedizin: Patientenverfügung. Ethische Erwägungen zum neuen Erwachsenenschutzrecht unter besonderer Berücksichtigung der Demenz. Available at:

<http://www.bag.admin.ch/nek-cne/04229/04232/index.html?lang=de> (accessed on Aug 21, 2012)

### Information on legislation in Austria and Germany

Borasio, G.D.; Hessler, H.-J.; Jox, R.J.; Meier, C. (eds.) (2011): Patientenverfügung. Das neue Gesetz in der Praxis. Münchner Reihe Palliative Care. Kohlhammer.

Körtner, U.; Kopetzki, C.; Kletecka-Pulker, M. (2007): Das österreichische Patientenverfügungsgesetz. Ethische und rechtliche Aspekte. Wien, New York: Springer Verlag.

### Information on palliative care:

Schweizerische Gesellschaft für Palliative Medizin, Pflege und Begleitung: [www.palliative.ch](http://www.palliative.ch)

### Information on organ donation:

- Federal Ministry of Health (Bundesamt für Gesundheit), background information on organ donation: [www.bag.admin.ch/transplantation](http://www.bag.admin.ch/transplantation)
- Swisstransplant, donor card download: [www.swisstransplant.ch](http://www.swisstransplant.ch)

Dialog Ethik is an independent non-profit organisation. Our interdisciplinary team of professionals is dedicated towards issues regarding decisions and actions in health and social services. Our organisation specialises in reciprocal knowledge transfer between research and clinical practice. Dialog Ethik supports professionals, patients, hospitals, nursing homes, and other organisations while promoting public dialogue and debate on ethical issues. A living will provides both self-empowerment to patients and relief to family members and caring staff.

Donations: Postal account 85-291588-7, IBAN CH61 0070 0115 5001 9992 2

Dialog Ethik, Interdisziplinäres Institut für Ethik im Gesundheitswesen,  
Schaffhauserstrasse 418, 8050 Zürich, Tel. 044 252 42 01, Fax 044 252 42 13  
info@dialog-ethik.ch, www.dialog-ethik.ch

### Information and consultation

Telephone support: 0900 418 814 (CHF 2 per minute)



**Schweizerische  
Herzstiftung**

*Aktiv gegen Herzkrankheiten und Hirnschlag*

Cardiovascular disease is the leading cause of death in Switzerland. The Swiss Heart Foundation is committed to ensuring relief of suffering in existing patients and preventing future suffering. The foundation is committed to humane death in addition to research, education and prevention as well as counselling and support for the bereaved. Together with Dialog Ethik, the Swiss Heart Foundation publishes a living will that includes an additional term specifically aimed at resuscitation in cardiac arrest patients.

Donations: Postal account 30-4356-3, IBAN CH21 0900 0000 3000 4356 3

Schweizerische Herzstiftung, Schwarztörstrasse 18, Postfach 368, 3000 Bern 14,  
Tel. 031 388 80 80, Fax 031 388 80 88  
info@swissheart.ch, www.swissheart.ch



**Schweizerischer Verband  
für Seniorenfragen**

Dialog Ethik has excellent connections to other organisations. Our collaboration with the Association for Senior Citizens' Issues is important to us; senior citizens often ask about explicitly ethical issues that are also important for young people – issues such as death, a discussion that this living will would like to encourage.

Donations: Bank Linth LLB AG, 8730 Uznach, Postal account 30-38170-0  
IBAN CH81 0873 1001 2904 6201 7

Schweizerischer Verband für Seniorenfragen, Geschäftsstelle, Postfach 46, 4153 Reinach,  
Tel. 061 713 04 22, Fax 061 713 04 21  
info@seniorenfragen.ch, www.seniorenfragen.ch





## The Living Will of Dialog Ethik, Swiss Heart Foundation and Swiss Association for Senior Citizens' Issue

### Medical background

Dialog Ethik has more than ten years of experience in advising fatally injured and terminally ill patients as well as their treatment teams on difficult ethical decisions at hospitals and residential homes. Experience has shown a detailed living will with clear and detailed directives to be most helpful for patients and the treatment teams, experience reflected in drafting the Dialog Ethik living will. The Dialog Ethik living will is one of the most detailed of its type in Switzerland.

### Ethical background

Dialog Ethik living wills are based on the following principles:

- **Self-empowerment**

A living will is an expression of self-determination based on the fundamental right to human dignity to which every individual is entitled, reaffirming the right to personal liberty as well as physical and mental integrity.

- **Individual values**

People have different ideas as to what constitutes a good life and, by extension, a good death. Your right to self-determination includes the right to accept or, under certain circumstances, refuse medical treatment according to your own values.

- **Dying in dignity**

Palliative medicine has proven its value in the last few years in treating terminal conditions and imminent death using all of the techniques known to modern medicine, but without the objective of healing.

- **Mutual dependence and respect**

Life and death are beyond absolute human control, and humans are dependent on each other in their existence. The way society treats its weakest members reveals its humanity and solidarity. A culture of human solidarity and decision making in medicine and nursing is aware of human mutual dependence as reflected in a partnership between all those involved in the decision process.

