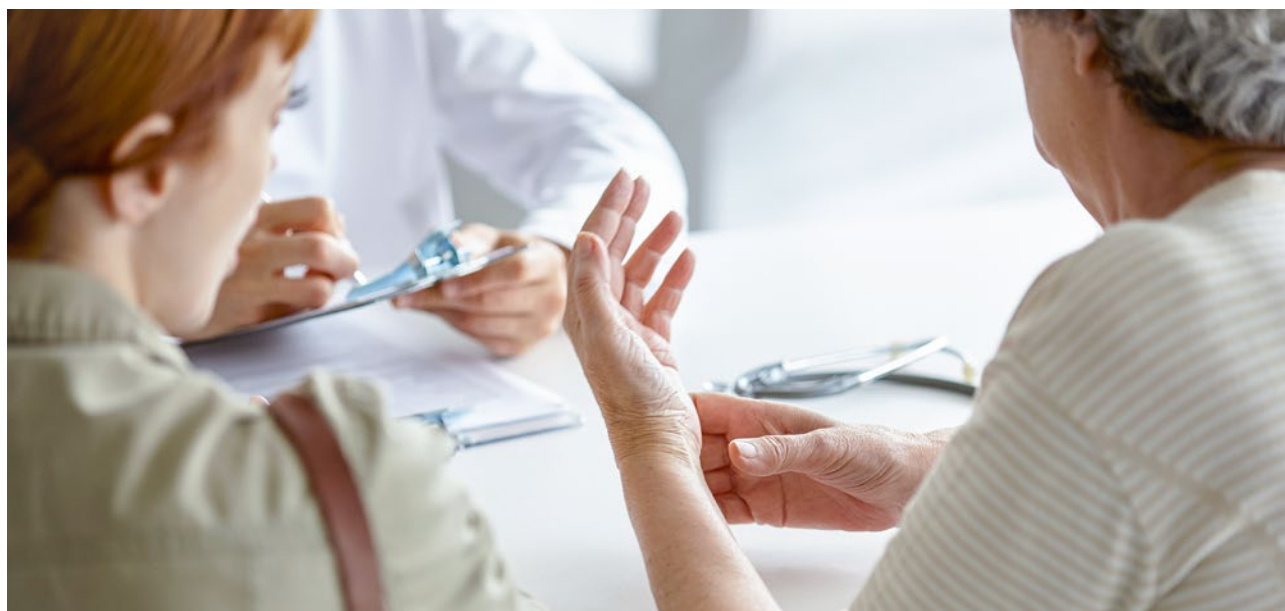


Guidance

FMH advance directive
Short version and detailed version



I. General information about the FMH advance directive

An advance directive reinforces your self-determination. It is only used when you are no longer able to communicate your wishes regarding medical care.

Regardless of your age and state of health, it is advisable to complete an advance directive. To do so, you must have decision-making capacity. This means that you must be able to decide the goals of treatment and which medical procedures you wish to undergo and which you wish to refuse if you are unable to speak for yourself.

You can opt either for the **short version** or the **detailed version** of the FMH advance directive. The detailed version allows you to set out your wishes in more detail than in the short version, and record your preferences regarding end-of-life care.

Both the short and the detailed versions distinguish the following three situations:

Situation 1:

This concerns an emergency in which you are suddenly unable to communicate. The outcome is uncertain but you can be expected to make a full recovery (e.g. head injury in a road traffic accident; cardiac arrest due to heart attack).

—> **Emergency – sudden loss of decision-making capacity**

Situation 2:

Due to illness or an accident you are unable to make decisions about medical care for days or weeks. The outcome is uncertain but recovery is possible (e.g. prolonged unconsciousness (coma) as a result of accident or illness).

—> **Serious illness – prolonged loss of decision-making capacity**

Situation 3:

Due to illness or an accident, it is highly unlikely that you will ever regain capacity to express your wishes regarding medical care (e.g. after-effect of a severe brain injury without possibility of social interaction; advanced dementia).

—> **Permanent loss of decision-making capacity**

In day-to-day medical practice, the transition from prolonged to permanent loss of decision-making capacity is often fluid by its very nature. In uncertain situations your healthcare proxy will make decisions on your behalf in consultation with the healthcare team.

Why should you draw up an advance directive?

Drawing up an advance directive is voluntary. In an advance directive you record in writing what medical care you wish to receive when you are no longer able to decide for yourself. This ensures that

- the healthcare team can respect your wishes,
- your healthcare proxy and/or relatives are supported in the decision-making process,
- the healthcare team doesn't have to make any decisions without being aware of your wishes.

Do you need a healthcare proxy?

Not all situations can be considered in an advance directive. This is why it is important to designate what is known as a healthcare proxy where possible. Your healthcare proxy can be a relative, a friend, or someone else who is close to you. To ensure that this person can make decisions in your interest, they must be aware of your wishes and preferences regarding treatment. This means that you should discuss your advance directive with them.

The healthcare proxy must always consider your presumed intentions and wishes. This means that they must make decisions on your behalf in specific situations.



Don't forget to give your healthcare proxy a copy of the advance directive.

Does the healthcare proxy have access to your medical records?

In principle, medical confidentiality prohibits information being passed on, apart from to authorised persons. The person designated as your healthcare proxy is authorised in this case. If you don't appoint a healthcare proxy, the persons who are authorised to represent you by law will be notified and involved in decision-making (see the cascade arrangement below). These persons will then have access to your medical records where this is necessary for decision-making.

What happens if you don't draw up an advance directive or if you haven't appointed a healthcare proxy?

If you haven't drawn up an advance directive and find yourself in a situation in which you lose capacity of judgement and cannot make decisions regarding medical care, the cascade arrangement set out under Art. 378 of the Swiss Civil Code applies.

Under this provision, the following persons are entitled in the following order to represent the person lacking capacity of judgement and to grant or refuse consent to the planned medical care:

1. a person appointed in a patient decree or in an advance care directive (proxy);
2. a deputy with a right to act as proxy in relation to medical procedures;
3. any person who as a spouse or registered partner cohabits with the person lacking capacity of judgement or who regularly and personally provides him or her with support;
4. any person who cohabits with the person lacking capacity of judgement and who regularly and personally provides him or her with support;
5. descendants who regularly and personally provide the person lacking capacity of judgement with support;
6. the parents, if they regularly and personally provide the person lacking capacity of judgement with support;
7. siblings, if they regularly and personally provide the person lacking capacity of judgement with support.

This legal order also applies if you have not appointed a healthcare proxy in your advance directive and have not communicated your wishes regarding a treatment.

When is the advance directive used? Was does loss of decision-making capacity mean?

The advance directive is only used if you cannot express your wishes regarding treatment yourself, for example if you are unable to make decisions and/or cannot communicate them. This may be due to an illness or accident. This is referred to as a loss of decision-making capacity or loss of judgement.

Who can advise you on drawing up an advance directive?

In principle, you can draw up an advance directive alone or with your healthcare proxy or relatives. However, it is highly recommended that you seek advice from an experienced professional. This may be your GP or specialist doctor. Nurses and experts in relevant information centres may also be able to advise you on the importance, opportunities and risks of the individual medical procedures.

What can you request or refuse in an advance directive?

Your healthcare team is obliged to respect your wishes regarding treatment. Your wishes may therefore not be contrary to legal regulations. You can request or refuse medical treatments in a specific situation. But you cannot request any medical treatments that are not medically reasonable. You can, however, refuse treatments for which there would be a medical rationale. Healthcare professionals can only accommodate your wishes for or against a treatment if the external circumstances allow it. For example, home care cannot be requested if the illness or accident (e.g. a femoral neck fracture) can only be treated in hospital.

How should you store your advance directive so that it is accessible when needed?

You can keep a copy of your advance directive with your attending doctor and with your healthcare proxy. It is also advisable to fill out a notice card and to carry it with you in your wallet

You can find a notice card at the following link:

—> www.fmh.ch/patientenverfuegung

If you have an electronic patient record (EPR), you can store a copy of the advance directive there yourself. The EPR is a collection of personal documents containing information about your health. This information can be accessed by you and by your healthcare team at any time via a secure internet connection. You decide who can view which documents when and grant the relevant access. You therefore decide which healthcare professionals can access your EPR.

You can also authorise the healthcare proxy you appointed in your advance directive to view your whole record.

If you are undergoing a planned procedure (e.g. an operation in hospital), let your attending doctor know that your advance directive is stored in your EPR.

If you would like all healthcare professionals to have access to your advance directive in an emergency, including those to whom you have not granted access, you need to set the document confidentiality level to 'normal access'. These persons will not have access to documents with confidentiality level 'restricted access' or 'secret'.

You can update or delete an advance directive recorded in the EPR yourself at any time.

Find out more about the EPR at:

—> www.patientrecord.ch

When and how often should you update your advance directive?

You can modify or revoke your advance directive at any time. It is advisable to review the advance directive every two years. An update is particularly important if your health situation or circumstances change.

Even if you do not update your patient record, it remains valid. However, the longer the time between when you draw up the advance directive and when it is used, the more likely it is that the wishes preferences expressed in it will no longer reflect your actual wishes.

Please inform your healthcare proxy and everyone who has a copy of your advance directive about any updates or date changes. Don't forget to save an updated copy in the EPR if you have one.

II. Treatment goal and medical procedures

The treatment goal is about deciding what the treatment should seek to achieve and what it should not. In both the short version and the detailed version of the advance directive, a distinction is drawn between the **treatment goal of sustaining life** and the **treatment goal of relieving suffering**.

In the treatment goal of sustaining life, the medical procedures are generally geared towards prolonging or sustaining life. Obviously, in pursuing this treatment goal, the treatment of distressing symptoms is considered very important. If you opt for the treatment goal of relieving pain and suffering, the focus will be on treating distressing symptoms, while prolonging/sustaining life through medical procedures will not be the top priority.

Medical procedures refer to emergency and intensive care procedures such as resuscitation, treatment in an intensive care unit with or without ventilation, and artificial nutrition and hydration.

If you choose the treatment goal of sustaining life, you are opting for resuscitation and for life-sustaining emergency and intensive care procedures. In this case, to achieve this goal you are also prepared to accept certain burdens (such as being intubated to help you breathe).

With the treatment goal of sustaining life, the healthcare team will assume that you consent to artificial hydration (e.g. through an intravenous drip) and artificial nutrition (e.g. via a nasogastric tube, via PEG tube inserted into the abdominal wall, or through an intravenous drip).

If you opt for the treatment goal of relieving pain and suffering, and sustaining life is not the priority, the healthcare team will not administer artificial nutrition with the goal of prolonging life. However, fluids may be administered in some circumstances via an intravenous drip if there is a chance you may suffer distressing symptoms such as thirst or confusion.

III. Resuscitation and invasive ventilation

Resuscitation

Resuscitation refers to emergency procedures used when your heart stops (cardiac arrest) or you stop breathing (respiratory arrest). Attempts to resuscitate include cardiac massage and the controlled administration of electric shocks to the heart muscle (defibrillation). Resuscitation is successful in 5–20% of cases; however, in the majority of cases, people die following cardiac arrest despite resuscitation. The older and sicker a patient is, the higher the likelihood that resuscitation will be unsuccessful. In some people who are resuscitated, circulatory flow is restored but with severe damage to the brain and often a permanent loss of capacity. Treatment in an intensive care unit is usually required after resuscitation.

Invasive ventilation

If you can no longer breathe on your own, breathing may be supported by a machine (ventilator). This ventilation involves a tube being inserted into the patient's windpipe (intubation). This form of ventilation can only be performed in an intensive care unit. If invasive ventilation is carried out over several weeks, it is a highly stressful and draining procedure, especially as it requires the patient to be sedated.

IV. Emergency situations

An emergency situation can occur if you can no longer communicate your wishes as a result of an accident (e.g. serious head injury) or a sudden illness (e.g. stroke). In such situations, it is often difficult to gauge whether or not you will make a full or partial recovery.

If your life is in acute danger, life-saving procedures may have to be initiated before your advance directive can be located and consulted. In some circumstances, your wishes may therefore not be taken into account. But as soon as your advance directive is available, the healthcare team can adapt the procedures administered in line with your preferences and wishes.

V. Organ donation

You can consent to or refuse to donate your organs.

If you opt to donate your organs, you should discuss this with your healthcare proxy and your relatives. Depending on the situation, the prospective donor will undergo organ preservation procedures in the intensive care unit or operating theatre before organ donation. This may be very distressing for your healthcare proxy or relatives. If you wish to donate your organs, you consent to the preparatory organ preservation procedures in the advance directive.

You will find more information (in German or French) on [swisstransplant](http://www.swisstransplant.org):

—> www.swisstransplant.org/de

VI. Autopsy

You can also give your consent to the performance of an autopsy (also called post-mortem examination). This involves a detailed external and internal examination of a body after death. An autopsy is used to determine the precise cause of death and as a quality assurance tool for the treatment provided prior to death. Particularly in the case of potential diseases, an autopsy can provide important information for descendants. It can also provide relatives, the hospital and the medical profession with valuable information. A properly-performed autopsy will not leave any visible trace on the corpse when it is laid out.

VII. Information on the short version of the FMH advance directive

In the short version, you provide details about yourself, your healthcare proxy and your attending doctor. You then set out your attitudes to life. You can also record what matters to you, what you still want to experience, and what your hopes, fears and concerns are. Attitudes to life are very important as they allow your healthcare team to get to know you better. This gives them important information which will allow them to act in your interests.

You can also choose a treatment goal for the three different situations set out on page 2 of this guidance document. If you opt for the life-sustaining treatment goal in the short version, the healthcare team will perform all possible life-sustaining procedures in the given situation, in particular resuscitation, treatment in an intensive care unit with invasive ventilation, and artificial nutrition and hydration where necessary. If you opt for the relief of pain and suffering treatment goal, the healthcare team will forego these life-sustaining procedures and prioritise the alleviation of pain and suffering instead.

The short version also gives you the option of expressing your wishes regarding the treatment of pain and other distressing symptoms such as breathing difficulties, anxiety and nausea. You can complete the short version with your decision regarding organ donation.

If you would like to address your future health situation in more detail and set out your different treatment preferences, we recommend the detailed version of the FMH advance directive.

VIII. Information on the detailed version of the FMH advance directive

In the detailed version, you first enter details about yourself, your healthcare proxy and substitute healthcare proxy and on your attending doctor.

The detailed version then contains five different parts. It is modular, which means it is up to you how many sections you wish to complete. You decide if you want to end with part 1 or if you wish to proceed right up to part 5. The parts are structured as follows:

- | | |
|---------|--|
| Part 1: | This section is about your attitudes to life. You can express what is important to you, what you still want to experience, and your hopes, fears and concerns. Your attitudes to life are very important to get to know you as a person. This provides the healthcare team with important information so that they can act in your interest. |
| Part 2: | In this section you can choose a treatment goal for one of the three situations set out on page 2 of this guidance. You can select the life-sustaining treatment goal with all intensive care procedures, the life-sustaining treatment goal with certain reservations (e.g. no resuscitation and no invasive ventilation), or you can select the relief of suffering treatment goal. ¹ |
| Part 3: | This section is about pain management and treatment of other distressing symptoms such as breathing difficulties, anxiety and nausea. It can be important for the healthcare team to be aware of your wishes in this regard. |
| Part 4: | This section deals with wishes regarding end-of-life care. When you reach end of life and can no longer make decisions yourself, it is important that your healthcare team and your healthcare proxy are aware of your wishes so that they can provide you with the best possible care. Among other things you can decide whether you wish to accept or refuse artificial nutrition. This explicitly concerns artificial nutrition as a life-sustaining measure at end of life and not artificial nutrition as a requested treatment (e.g. as part of treatment in an intensive care unit or neurological rehabilitation). |
| Part 5: | This section allows you to express your wishes regarding organ donation and undergoing an autopsy |

You will find the short and detailed versions of the FMH advance directive and the notice card at:

—> www.fmh.ch/patientenverfuegung

¹ Inspired by 'beizeiten begleiten' ('care in good time'), German Interprofessional Association, Advance Care Planning.