

## Roadmap for the implementation of advance care planning (ACP) in Switzerland

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Further information on the background to the development of this roadmap is available on the [SAMS website](#) and on the website of the Federal Office of Public Health (available in [French](#) / [German](#)).

## 1. Background

In May 2021, at the request of the Federal Council, the Federal Office of Public Health (FOPH) and the Swiss Academy of Medical Sciences (SAMS) set up a broad-based national Advance Care Planning Working Group (ACP WG) (see page 10).

- The task of the ACP WG is to develop a framework for strengthening and embedding advance care planning in the health system.
- For this purpose, the ACP WG developed a model comprising modules and specific recommendations, which underwent broad public consultation. The input received has been incorporated in the present roadmap.

ACP promotes self-determination. Everyone should have the opportunity to specify what medical treatment and care they wish to receive in the event of future incapacity. The focus is, firstly, on ACP for a sudden loss of capacity (e.g. as a result of an accident) and, secondly, on the improvement of ACP in the treatment of diseases and/or increasing frailty.

## 2. Aims of ACP

The aims of ACP are

- to promote individual autonomy, self-determination and participation;
- to ensure that decisions on therapeutic goals and treatments – both in an emergency and in the event of prolonged or permanent incapacity – are made in accordance with the wishes of the person concerned;
- to provide decision-making support for close persons;
- to inform healthcare professionals about the values and preferences of the individuals concerned;
- to provide support for healthcare professionals, particularly in cases where life-sustaining measures are to be instituted or withheld;
- to facilitate the planning and coordination of care and treatment;
- in the event of progressive illness, to ensure that the treatment plan is implemented in accordance with the patient's wishes.

ACP, for which responsibility is shared by all parties, is a continuing process of communication, involving varying degrees of elaboration.

## 3. Target groups

ACP is a matter for everyone, regardless of their age, stage of life, place of residence, origin, socio-economic status, health literacy and state of health. It thus by no means only concerns those at the end of life. ACP is also possible for persons lacking (full) capacity.

A key role is played by close persons, as in the event of a loss of capacity (e.g. as a result of an accident, cardiac arrest or dementia), they have to (help) make decisions. Whenever possible, they should be involved in the ACP process. Everyone can reflect on and document their own values and preferences regarding situations of incapacity, either independently or together with close persons. For ACP concerning medical interventions, it is advisable to consult a professional.

ACP is voluntary. Accordingly, if someone rejects ACP, despite having been informed about its advantages, their decision must be respected.

#### 4. Timing

There is not generally *one* right time for ACP. People are often prompted to consider ACP by decisive events in their lives.

This roadmap on the implementation of ACP distinguishes three types of situation:

- Situations involving a *sudden* loss of capacity (e.g. cardiac arrest, traumatic brain injury) and/or prior to a surgical procedure with potential complications. These may concern anyone at any age.
- Situations involving *chronic* physical and/or mental illness (treatment of newly diagnosed illness), increasing *frailty*, cognitive *disability* and/or early *dementia*.
- Situations involving *complex* and/or advanced chronic physical and/or mental (multiple) conditions and/or *severe* cognitive disability and/or if the *end of life* is approaching.

#### 5. Goals of the roadmap

This document

- should help to facilitate and strengthen the implementation of ACP throughout Switzerland;
- answers the “who, when, what and how” questions about ACP;
- provides a basis enabling more people to undertake ACP and to define treatment or therapeutic goals in an advance directive which can be complied with in practice;
- addresses unresolved questions and outlines measures required to achieve these goals for the whole population;
- fleshes out Switzerland’s national framework concept for ACP from 2018.

## 6. Modules for implementation

In the roadmap, the elaboration/implementation of ACP is divided into three modules:

### General ACP

*For people at any stage of life and in any situation thinking about treatment in the event of illness, accident, disability or at the end of life, and about organ donation.*

A loss of capacity can occur at any time and at any age. This module focuses on the question of what treatments a person does/does not wish to receive in such a situation. It also covers the choice of an authorised representative best suited to make decisions on behalf of the person concerned.

### Detailed ACP

*For people at any stage of life and in any situation thinking in detail about their own values and/or treatment goals with regard to medical interventions.*

People with chronic physical or mental conditions, increasing frailty, cognitive disability and/or early dementia, in particular, should think in detail about their personal values and treatment goals. A treatment plan can then be drawn up for situations which may arise. Personal wishes concerning medical interventions are recorded in writing in an advance directive and/or treatment plan.<sup>1</sup> For detailed ACP, it is highly recommended to seek professional advice.

### Disease-specific ACP

*For people with advanced incurable disease, chronic physical and/or mental (multiple) conditions, including those with severe cognitive disability and children/adolescents with life-limiting illnesses and/or people nearing the end of life.*

The treatment goals should be defined in consultation with a professional and if possible discussed with close persons, specifying in detail the individual's wishes and expectations regarding end-of-life treatment and care.

The chart provides an overview of the three modules described above:

<sup>1</sup> In some cases, health matters, as well as administrative and financial matters, can be covered by a power of attorney. However, for medical decisions, an advance directive is more suitable and more flexible. The authorised representative specified in the advance directive may, but need not be, the same person designated in the power of attorney.

<b>Advance Care Planning</b>		
<b>General</b>	<b>Detailed</b>	<b>Disease-specific</b>
<b>Who / When</b>		
Any stage of life or in any situation	<p>If desired, after detailed consideration</p> <p>Recommended in the event of</p> <ul style="list-style-type: none"> <li>- chronic physical/mental conditions</li> <li>- increasing frailty</li> <li>- cognitive disability</li> <li>- early dementia</li> <li>- major surgery and treatments</li> </ul>	<p>In complex disease situations and/or when the end of life is approaching</p> <p>Recommended in the event of</p> <ul style="list-style-type: none"> <li>- advanced incurable illness</li> <li>- chronic physical/mental (multiple) conditions, including children and adolescents with life-limiting illnesses</li> <li>- severe cognitive disability</li> </ul>
<b>What</b>		
Consider treatment options, accidents and disabilities, end-of-life care, and organ donation	Give in-depth consideration to personal values and treatment goals with regard to medical interventions	Define treatment goals and plan treatment in advance
Advance planning for situations involving sudden loss of capacity due to an accident, cardiac arrest, or complications during surgery		
	Disease-specific advance care planning	
<b>How</b>		
Independently, if possible in consultation with close persons, and potentially using low-threshold advisory services	For specification of medical details: in consultation with an appropriately trained professional	In consultation with professionals with specific expertise in ACP and palliative care
<b>Results / Documentation</b>		
<ul style="list-style-type: none"> <li>- Conversation with authorised representative has taken place</li> <li>- Personal values have been clarified</li> <li>- An Advance directive (including storage location) and a declaration of wishes regarding organ donation are available</li> </ul>		
	<ul style="list-style-type: none"> <li>- Treatment plan</li> <li>- Medical order for life-sustaining treatment</li> </ul>	

## 7. Recommendations

To achieve the objectives of the roadmap, twelve recommendations have been drawn up, highlighting aspects of the ACP process which require particular attention.

### 7.1 Recommendations for the individuals concerned, close persons and interested parties

#### Recommendation 1: Designate and inform the authorised representative

Everyone should appoint an authorised representative, who should be informed about and accept their role and responsibilities. In the event of incapacity of the individual concerned, the authorised representative must be guided by this person's advance directive and presumed wishes, making decisions on their behalf and in their interests.

#### Recommendation 2: Document personal values

Decisions on medical treatment in the event of incapacity are based on personal values (attitude to life, illness and dying). If these are known or recorded in writing, this helps the medical team, in an emergency, to act in accordance with the wishes of the person who has lost capacity. Conversations with close persons and/or low-threshold advisory services can be helpful when recording personal values in writing.

#### Recommendation 3: Formulate wishes regarding treatment goals and medical interventions

In order to specify treatment goals and decisions for or against certain medical interventions (e.g. resuscitation, mechanical ventilation) and treatments (e.g. antibiotic therapy, artificial nutrition) in the event of incapacity, it is advisable to consult a trained professional.

#### Recommendation 4: Plan treatment and care for complex situations and/or approaching end of life

Detailed planning covers medical and nursing care, as well as psychosocial and spiritual aspects, in accordance with the treatment goals. It is recommended for people with advanced incurable illness, chronic physical and/or mental (multiple) conditions and/or severe cognitive disability, or if the end of life is approaching. This applies to all age groups.

#### Recommendation 5: Keep documents updated and accessible

The results of ACP should be recorded in writing and regularly reviewed and updated, especially if there are significant changes in a person's life or health situation. The documents must be accessible in an appropriate form – preferably in the electronic patient record.

### 7.2 Recommendations on awareness raising and public information

#### Recommendation 6: Make key questions available for ACP

Suitable questions promoting reflection on personal values, wishes and preferences should be developed on the basis of existing materials and in consultation with professionals and/or advisory organisations.

#### Recommendation 7: Raise awareness and provide information for specific target groups

Awareness-raising activities and information campaigns should encourage people to consider ACP. Information should be provided in different forms and tailored to specific target groups, e.g. through booklets, short films or web applications. These should be accessible and comprehensible for all population groups and in various languages. Information events and expert advice can make the topic accessible for the public. Professionals should also be addressed via targeted awareness-raising activities and/or training events.

### 7.3 Recommendation for professionals

#### **Recommendation 8: Strengthen communication and methodological skills**

For professionals in healthcare and in the social/advisory service sector, communication and methodological skills and expertise in ACP and palliative care should be strengthened in a level appropriate and institution-specific manner. Appropriate basic and further training and continuing education programmes should help professionals to provide sound advice on ACP.

### 7.4 Recommendations on quality improvement

#### **Recommendation 9: Define minimum standards for advance directives**

Advance directive templates should be developed and implemented to ensure minimum standards regarding content and quality.

#### **Recommendation 10: Ensure cross-institutional access to treatment and care plans**

It should be possible for treatment and care plans to be accessed and applied across institutional and professional boundaries. This requires (also) technical solutions. It is recommended that ACP documentation should be incorporated in the electronic patient record.

#### **Recommendation 11: Clarify the role of medical orders for life-sustaining treatment (MOLST)**

In a MOLST form, therapeutic goals and treatment preferences are specified for acute emergencies. The significance of MOLST forms and their relationship to other ACP documents should be clarified and their use made consistent throughout Switzerland.

#### **Recommendation 12: Review the framework for remuneration of ACP services**

The remuneration of professional services in the area of ACP should be reviewed and, if necessary, improved so that ACP can be strengthened and embedded in the health system.

## 8. Next steps and outlook

The roadmap is designed to provide guidance, and the recommendations are to be implemented step by step. New ideas and measures are required to raise awareness of ACP among as many people as possible, and to ensure that it can be undertaken by everyone who wishes to do so. This also applies, for example, to people with a mental illness or cognitive disability, or to children with a life-limiting illness. It must be ensured that, in an emergency, the wishes of a person lacking capacity are known and respected. One key objective is to design the documentation (advance directive, MOLST, treatment and care plan, etc.) in such a way that it can be rapidly located in a specific (emergency) situation, clearly indicates the person's wishes, and can be complied with.

The twelve recommendations provide a basis for the implementation of specific projects and activities. To this end, subgroups with appropriate expertise will be established and mandates defined.

## 9. Glossary<sup>2</sup>

<b>Medical order for life-sustaining treatment (MOLST)</b>	<p>A form documenting the treatment goal and related measures for acute emergencies involving a sudden loss of capacity.</p> <p>At present, a variety of MOLST forms, definitions and approaches are used; their role is to be clarified in accordance with the recommendations given in the roadmap (Section 7.4).</p>
<b>Treatment or care plan</b>	<p>Here, the medical professional, together with the person concerned – ideally with the involvement of the authorised representative and/or a close person – defines the type and setting of diagnostic and therapeutic measures to be provided in the event of an unfavourable course and/or the onset of complications. Depending on the circumstances of the person's life and illness, this may cover situations at home, in hospital or in a long-term care institution. The plan should also document the procedure to be adopted in an emergency and include details of the most important family and work contacts.</p> <p>Firstly, as an aid to self-help, the treatment or care plan ensures that, if acute problems arise, the individual concerned and close persons can take the appropriate measures, promptly and with self-efficacy. Secondly, it enables medical professionals to act in accordance with the wishes of the individual concerned in a situation of incapacity (even if they have not previously been involved).</p> <p>The terms <i>treatment plan</i> and <i>care plan</i> are used interchangeably in this document.</p>
<b>Treatment or therapeutic goal</b>	<p>The change in or stabilisation of a person's condition aimed for at a given time. The treatment or therapeutic goal can comprise a number of individual goals, the pursuit of which may even have opposing effects. Measures aimed at sustaining life may impair quality of life and, conversely, measures to improve quality of life may shorten (or prolong) life. To formulate a consistent treatment goal, priorities must therefore be assigned to the individual goals.</p> <p>The terms <i>treatment goal</i> and <i>therapeutic goal</i> are used interchangeably in this document.</p>
<b>Care plan</b>	<p>See <i>Treatment or care plan</i>.</p>
<b>Advance care planning (ACP)</b>	<p>The umbrella term for reflections, discussions and decisions on personal values, wishes and preferences in relation to treatment and care in the event of illness, accident, dependency or at the end of life, and especially in the event of incapacity. The individual's wishes should be specified and documented for third parties (e.g. in an advance directive or in a treatment or care plan). This is a continuing process, involving varying degrees of elaboration, and revision of the documentation if necessary.</p>
<b>Cognitive disability</b>	<p>A mental impairment, likely to be permanent, which makes it difficult or impossible for a person to perform everyday tasks, engage in social contacts, obtain education and training, or work (Art. 2 DDA).</p>
<b>Medical intervention</b>	<p>Medical interventions are broadly defined in this document to include, for example, prescribing a drug, performing a surgical or nursing procedure, or employing mechanical ventilation. They are based on an intention, within the framework of an overriding treatment goal. They are performed in the context of the clinical condition (indication), taking into account alternative treatment options and the wishes of the person concerned, and they require informed consent. The continuation of an existing treatment and the deliberate withholding of certain medical actions are also considered to be medical interventions.</p>
<b>Presumed wishes</b>	<p>A justified assumption as to what someone who is no longer able to express their wishes would decide if they were in a position to do so. A person's presumed wishes are determined by assessing all the available information. This includes their own earlier written or verbal statements, the interpretation of an advance directive, and the testimony of authorised representatives or close persons and, where appropriate, the care and treatment team.</p>
<b>Close persons</b>	<p>Close persons include not only family members (immediate relatives, spouses or registered partners) but also life partners and close friends. Depending on the particular circumstances/situation, neighbours from the patient's living environment and other persons providing care or support (deputy, social worker, etc.) may also be deemed to be close persons.</p>

<sup>2</sup> The information in this glossary is based on definitions in the following publications:

- FOPH and palliative.ch: Gesundheitliche Vorausplanung mit Schwerpunkt "Advance Care Planning". Nationales Rahmenkonzept für die Schweiz, 2018 (in French/German).
- FOPH: Förderprogramm "Entlastungsangebote für betreuende Angehörige 2017–2020" Hintergrundinformationen zum Begriff "betreuende Angehörige", 2018 (in German).
- FOPH: Das interprofessionelle Team in der Palliative Care. Die Grundlage einer bedürfnisorientierten Betreuung und Behandlung am Lebensende, 2016 (in French/German).
- FOPH/GDK: "National Guidelines for Palliative Care", 2011.
- SAMS Medical-ethical Guidelines:
  - Management of dying and death (2018, updated 2022).
  - Assessment of capacity in medical practice (2019).
  - Coercive measures in medicine (2015).
  - Advance directives (2009, updated 2013).

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Palliative care	<p>Palliative care is the care and treatment provided for people with incurable, life-threatening and/or chronic progressive diseases. It is taken into account in advance but concerns in particular the time when it is no longer considered possible to cure the disease and this no longer represents a primary objective. Palliative care prevents suffering and complications. It includes medical treatments, nursing interventions and psychological, social and spiritual support.</p>
Advance directive	<p>In an advance directive, a person with capacity specifies the medical interventions that they wish or do not wish to receive in the event of their incapacity (Art. 370 para. 1 Swiss Civil Code). They may also designate a person who, in the event of their incapacity, is to discuss any medical interventions with the attending physician and make decisions on their behalf (authorised representative). The advance directive must be executed in writing, and be dated and signed (Art. 371 para. 1 Swiss Civil Code). It may also be incorporated in a power of attorney (Art. 361 ff. Swiss Civil Code).</p> <p>The physician must comply with the advance directive unless it contravenes legal requirements or there are reasonable doubts as to whether it was voluntary or reflects the patient's presumed wishes (Art. 372 para. 2 Swiss Civil Code).</p>
Therapeutic goal	<p>See <i>Treatment or therapeutic goal</i>.</p>
Capacity, mental	<p>Under Art. 16 of the Swiss Civil Code, a person is deemed to have mental capacity if he or she does not lack the ability to act rationally on account of minority, or as a result of a mental disability, a mental disorder, intoxication or similar conditions. In a medical context, capacity is assessed in relation to a specific situation and a specific decision (e.g. consent to a medical intervention) and it presupposes certain abilities. The following criteria help to establish capacity:</p> <ul style="list-style-type: none"><li>- the ability to understand information regarding the decision to be made;</li><li>- the ability to weigh up the situation and the consequences of possible alternatives;</li><li>- the ability to assess the information received in a coherent manner in the context of a value system;</li><li>- the ability to express one's own choice.</li></ul>
Incapacity, ascription of	<p>Ascription of a lack of capacity based on a significant impairment of mental abilities (cf. definition of <i>Capacity, mental</i>), taking into consideration the principles of respect for individual autonomy and beneficence. The ascription is thus based on ethical/normative considerations. Incapacity is ascribed in relation to a specific decision and at a given time. Capacity is to be reassessed if there is evidence that the condition of the person concerned has changed. If possible, the person lacking capacity is to be involved in decision-making (Art. 377 para. 3 Swiss Civil Code).</p>
Authorised representative	<p>Someone who represents a person lacking capacity in medical matters. Everyone is entitled to decide for themselves and specify in an advance directive who is to serve as their authorised representative in such a situation. The authorised representative undertakes to represent the presumed wishes and interests of the person lacking capacity. If no authorised representative has been designated, the following persons are entitled, in the following order, to exercise this function in accordance with Art. 378 Swiss Civil Code:</p> <ol style="list-style-type: none"><li>1. Persons designated in an advance directive or power of attorney.</li><li>2. A duly authorised deputy.</li><li>3. A spouse or registered partner who shares the same household as or regularly provides personal support for the person lacking capacity.</li><li>4. A person who shares the same household as and regularly provides personal support for the person lacking capacity.</li><li>5. Offspring, if they regularly provide personal support for the person lacking capacity.</li><li>6. Parents, if they regularly provide personal support for the person lacking capacity.</li><li>7. Siblings, if they regularly provide personal support for the person lacking capacity.</li></ol> <p>If two or more persons are entitled to act as representatives, physicians may assume that each acts with the agreement of the others.</p>
Power of attorney	<p>By means of a power of attorney, a person with capacity to act may appoint a natural person or legal entity to perform specific tasks on their behalf in the event of their incapacity. These may include both personal and financial affairs as well as representation in legal matters. The interests of the person concerned must be strictly safeguarded. Detailed requirements concerning the power of attorney are specified in Art. 360 ff. Swiss Civil Code.</p>
Values	<p>A person's values shape their attitude to life, expressing what they believe to be important, together with their goals, expectations and fears. Reflection on and determination of personal values (the "values history") may also include a description and assessment of the individual's health situation and will to live. This represents a snapshot, which may change over time and may need to be revised. The description of personal values is of major importance for advance care planning. In the event of incapacity, it provides guidance when decisions are to be made for or against medical interventions.</p>

## 10. Information on the preparation of the roadmap

### Mandate

In the report on Postulate 18.3384 “Better end-of-life care and treatment”, the Federal Council requested the National Health Policy section of the Federal Office of Public Health (FOPH) and the Swiss Academy of Medical Sciences (SAMS) to set up a national Advance Care Planning Working Group in order to improve the general framework and quality standards. The task of the standing working group is to guide the entire process of implementation of ACP measures in terms of strategy and content, and to define priority areas.

### National ACP Working Group

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### Consultation

A consultation involving medical societies, national organisations and interested parties was held from 17 May to 15 July 2022. The 170 responses received have been taken into account in the final version and/or will be fed into subsequent work.

### Approval

The final version of this roadmap was approved by the SAMS Board on 30 January 2023 and by FOPH Senior Management on 1 February 2023.

## Publication details

### Issued by

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### Recommended form of citation

National Advance Care Planning Working Group (2023): Roadmap for the implementation of advance care planning (ACP) in Switzerland. Issued by the Federal Office of Public Health (FOPH) and the Swiss Academy of Medical Sciences (SAMS), Bern.

### Language versions

This publication is available as a PDF file in English, French, German and Italian.

Bern, March 2023.