

National Strategy for Palliative Care 2010–2012 Summary



Schweizerische Eidgenossenschaft
Confédération suisse
Confederazione Svizzera
Confederaziun svizra

Swiss Confederation

Federal Department of Home Affairs FDHA
Federal Office of Public Health FOPH



GDK Schweizerische Konferenz der kantonalen Gesundheitsdirektorinnen und -direktoren
CDS Conférence suisse des directrices et directeurs cantonaux de la santé
CDS Conferenza Svizzera delle direttrici e dei direttori cantonali della sanità

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Summary

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Preamble

Today only 10 percent of deaths that occur each year in Switzerland are sudden and unexpected. The majority of people die after a more or less lengthy period of illness and nursing care.

In the future a greater number of people will need more end-of-life care. This is mainly because the people in Switzerland are living increasingly longer, and incurable, chronic illnesses occur more frequently in old age. However, also younger, incurable sick patients often need comprehensive medical and nursing care over extended periods.

Consequently, there is a need for action in regard to health policy. Palliative care is one answer to this coming challenge. It concerns the provision of health care for incurable sick and dying people.

In the context of the "National Health Policy" the Confederation and Cantons have resolved to promote palliative care in Switzerland. The "National Strategy for Palliative Care 2010-2012", sets the objectives for strengthening the offer of palliative care. Furthermore, it is planned to improve the training of the medical and nursing personnel and to better inform the population. Together with all the partners, the measures will be realised and the means purposefully adopted.

Moreover, the strategy focuses on a strengthened coordination as well as on improved synergies at the national and cantonal level. It provides the decisive impulse for the realisation of a medium and long-term improvement in end-of-life health care.

We support the "National Strategy for Palliative Care 2010-2012" and thank all the parties concerned for their considerable commitment.



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Head of Federal Department of Home Affairs



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President of Swiss Conference
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Palliative care improves the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement.

1. The significance of palliative care in health policy

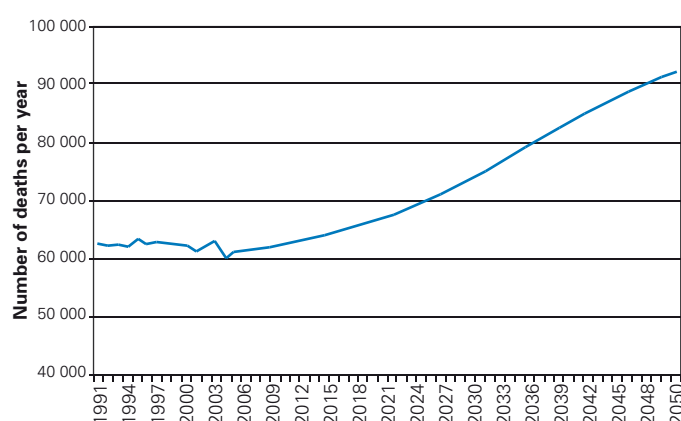
Today only about 10% percent of deaths that occur each year in Switzerland are sudden and unexpected. The majority of people in Switzerland die after a lengthy period of increasing long-term care. In this last phase of life¹ the quality of care in Switzerland varies. Thus, pain and other discomforts, physical or psychological problems (e.g. anxieties) are often not adequately alleviated. Most people in Switzerland die in residential homes or nursing homes, although the majority wishes to die at home.

A greater number of people in their final phase of life need more care. This is mainly because the people in Switzerland are living increasingly longer, and incurable, chronic illnesses occur more frequently in old age. Multi-morbidity – the simultaneous existence of a plurality of illnesses in the same person – as a characteristic phenomenon of old age, will likewise become more prevalent in the future, and will make treatments significantly more complex. However, also younger, severely ill patients suffering from cancer, neurological disorders or chronic illnesses often need comprehensive medical and nursing care over extended periods.

This trend represents a problem because the number of annual deaths on demographic grounds in Switzerland will also increase in the coming years. Today, the annual death rate in Switzerland is of the order of 60 000 people of all ages. The Federal Office of Statistics estimates that this number will increase by 50% to reach 90 000 by the year 2050.

Innovative health policy models, such as palliative care, are needed in order to meet these challenges with success.

Figure 1: Evolution of the number of deaths in Switzerland up to 2050



Source: Federal Office of Statistics

¹ The FOPH defines the "last phase of life" as a period of up to 2 years prior to death.

2. Palliative Care: Definitions and Services

Palliative care is an offer from the health care service for the incurable and dying as well as for their relatives. The alleviation of physical discomforts is paramount, but also anxieties and uncertainties. Patients will be accompanied and supported by a network of qualified personnel, support staff and volunteers. They will decide as far as is possible how and where they would like to spend their last phase of life. “Better life, less suffering”, “At the place of choice” and “Together, not alone” are the three central aspects of palliative care.

Better life, less suffering

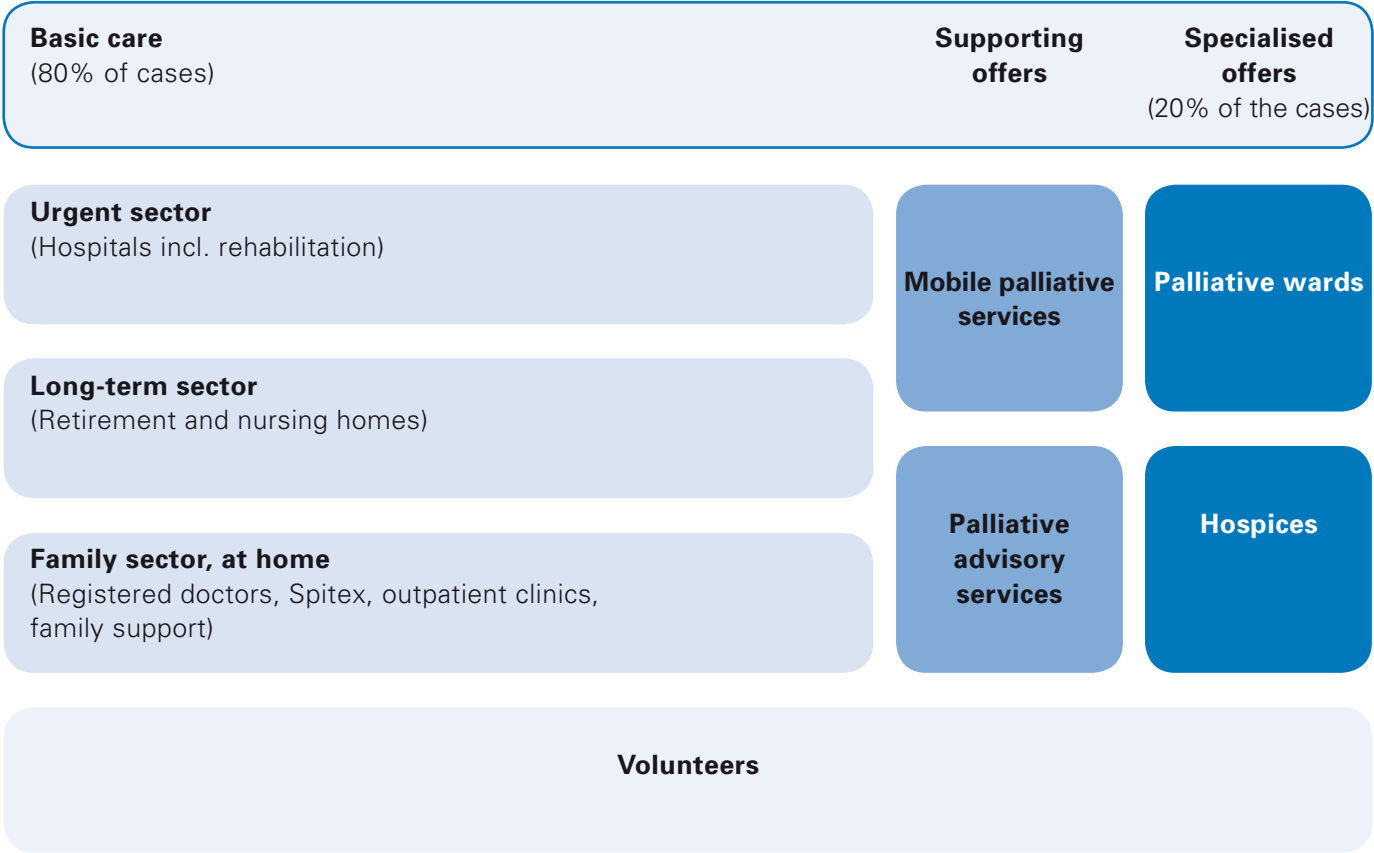
Palliative care alleviates symptoms such as pain, nausea, shortness of breath or weariness. It helps with end of life psychological disorders such as fear or depression. Palliative care also offers support for psychosocial disorders such as loneliness or family conflicts as well as in the area of spirituality (pastoral care). In addition,

it provides guidance for self-help to cope with the symptoms. Palliative care can also contribute to reducing a death wish sentiment and thereby prevent the recourse to assisted suicide.² Palliative care and curative medicine complement each other and can be employed in parallel with medical indication.

At the place of choice

Palliative care is not fixed to a particular place of care. The severely ill person should – as far as possible – choose himself where he would like to spend his last phase of life. 80% of patients who require palliative care services can be looked after by means of primary care (by nursing and doctors in the hospital or in the retirement or nursing home, at home by family doctors or ambulant care staff). Support services such as mobile palliative care teams have the required expertise and unburden the carers. Specialised services, such as for example palliative wards in hospitals or in a hospice are only required for patients with complicated illnesses (see Figure 2).

Figure 2: Care structures for palliative care



Source: palliative ch, adapted by the FOPH

² See Gómez, Sancho M./Ojeda, Martín M. (2008): Medicina paliativa y eutanasia. In: Gómez, Tornillo et al. (Hrsg.): Aspectos médicos y jurídicos del dolor, la enfermedad terminal y la eutanasia. Madrid, S. 519-572

Together, not alone

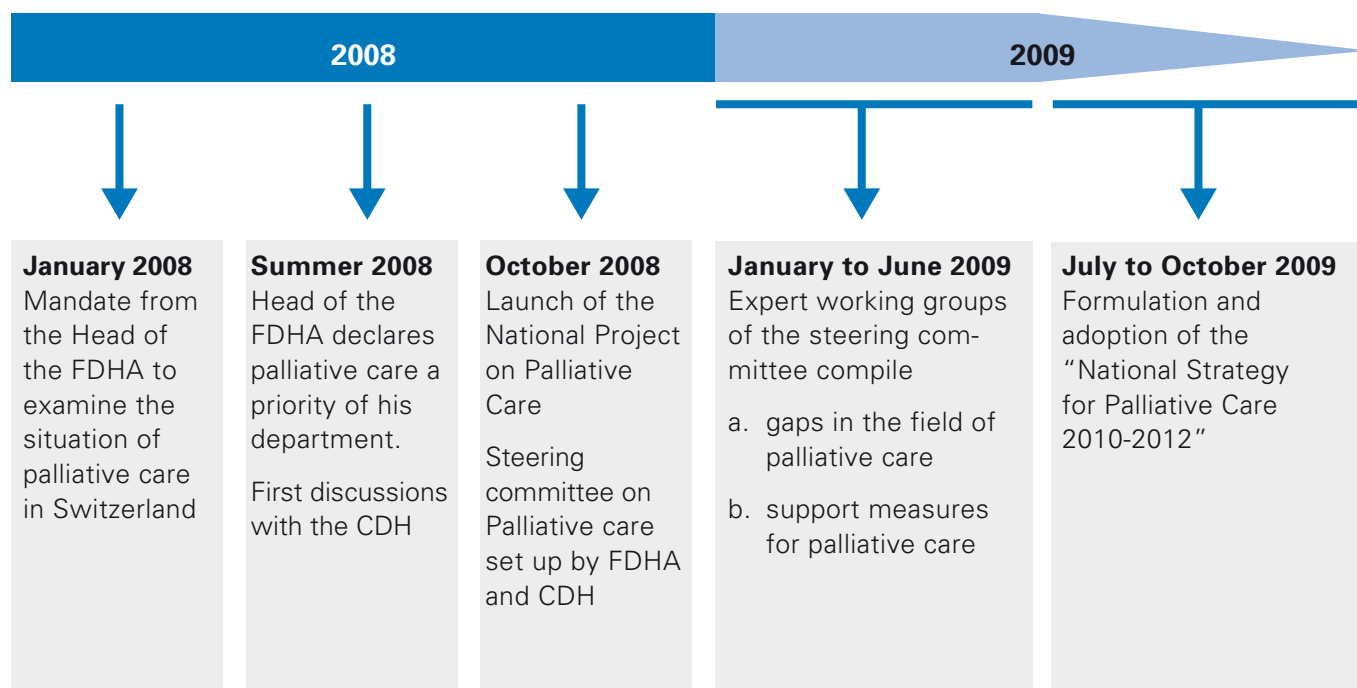
The cooperation between the different occupational groups is a cornerstone of palliative care. In addition to the central medical care by doctors, specialised care personnel or Spitex organisations, it is also important to integrate volunteers and when necessary offer psychological and spiritual support. Thanks to this reliable support network – especially outside the hospital – a longest possible stay at the place of choice is ensured and an unnecessary admission into an intensive-care hospital is avoided.

3. Political activities and mandates for palliative care

The need for action in the area of palliative care has been recognised by the political authorities. The Head of the Federal Department of Home Affairs (FDHA) commissioned the Federal Office for Public Health (FOPH) in January 2008 to clarify the situation concerning palliative care in Switzerland (see Figure 3). The clarification clearly showed the inadequate establishment of palliative care in the public health sector and the urgent need to raise awareness both among health professionals and the general public. Consequently in the summer of 2008, the Head of the FDHA declared the promotion of palliative care to be a priority of his Department. Mandated by the FDHA, the FOPH entered into discussions with the Swiss Conference of the Cantonal Ministers of Public Health, which likewise viewed the promotion of palliative care as an important public health issue. At the end of October 2008, the FDHA and the Swiss Conference of the Cantonal Ministers of Public

Health jointly set up a National Funding Committee "Palliative Care" consisting of a steering committee (Department Directors of FOPH, OPET, SER, FSIO and the Presidium, Vice Presidium and the Central Secretary of the Swiss Conference of the Cantonal Ministers of Public Health) and four expert-working groups on the themes "Care and financing", "Information", "Training" and "Research". Under the direction of the FOPH and the Swiss Conference of the Cantonal Ministers of Public Health, from January to June 2009 the circa 80 experts prepared a report on the need for action in the field of palliative care in Switzerland.³ Based on this report and further studies, the FOPH and the Swiss Conference of the Cantonal Ministers of Public Health jointly prepared from July to October 2009 the "National Strategy for Palliative Care 2010-2012". In this, the Confederation and Cantons set the main objective of establishing palliative care together with the most important actors in the spheres of healthcare, social, training and research. The strategy was adopted on 22 October 2009 from the discussion on National Health Policy.

Figure 3: Political Activities 2008–2009



⁴ INFRAS (2009). Report on the need for action in palliative care. Final report. Zürich. www.bag.admin.ch/palliativecare

4. Palliative Care in Switzerland: Actual situation

Palliative care is gaining increased importance in Switzerland. The palliative and hospice movement evolved in the 1980s and was characterised by isolated initiatives. The first palliative ward was founded in Geneva in 1979. Others followed in the Cantons Basel City (1983) and Vaud (1988). Offers of support for outpatient palliative care and for palliative care in hospital wards were made in Tessin in 1990. In the following years these Cantons extended their offers. Other Cantons, such as St. Gallen, Basel-Land, Zürich, Neuchatel, Berne or Valais began to establish new offers.

In spite of these various activities there are still gaps and a need for clarification in some areas. The survey of the Palliative Care funding committee shows a need for action in the five areas "Care", "Financing", "Awareness", "Training" and "Research":

Care

There is an unequal access to offers of palliative care for people in Switzerland. Depending on the region, age, socio-economic status or type of illness there is greater or lesser equality of access. In particular, patients who are not suffering from cancer have a more difficult access to palliative care.

A reason for the unequal access is that there are different availabilities in the individual Cantons and regions. Care is often insufficient, principally in the outpatient services. Moreover, a comprehensive plan for care does not exist in the majority of Cantons. Criteria that patients must meet in order for them to be able to claim access to palliative care are also lacking, however (indication criteria).

Financing

For the financing it must be clarified how palliative care benefits over and above HIA standard benefits are intended to be financed. A further difficulty is that

- a) for certain services the HIA defined limits are exceeded, or

- b) the compensation arrangements are not specific enough, because the cost of care and treatment for palliative care patients is somewhat higher.

Solutions need to be found principally concerning services for the remote patient.

In both of the cited cases (a and b) other sources of funds such as e.g. the Cantons with supplementary benefits and/or social aid benefits, patients and their families assume these services. If it is the patients or their families, then the assumption of the services depends on their financial situation. People with little financial means are disadvantaged.

Awareness

The term, "palliative care" is almost unknown to the public, and the population is virtually unaware of the objectives and role of palliative care. Although the term is known to specialists in the field of health care, on the other hand they are frequently not fully aware of the objectives and the approaches to palliative care. In some cases there is a lack of knowledge concerning specific treatment possibilities (e.g. in the field of pain therapy).

Training, further education and continuous education

Concerning training, various ideas prevail in regard to the required expertise for palliative care. In the basic training there exist fundamentals for all health professions at the secondary level stage II as well as for the tertiary level stage A and B; palliative care can be

integrated into these courses. However, the commitment to and the implementation of these guidelines vary to a great degree. In further education and continuous education there are gaps, principally in the outpatient area and in long term care. For example, the specialised knowledge on palliative care of general practitioners, who take care of patients in retirement homes and nursing homes, is often insufficient. Problems arise with diagnoses, communication and the therapy, e.g. of pain.

The existing training courses are confusing, poorly coordinated and not systematically checked in regard to their quality. The offer of inter-professional training is also very sparse, there being individual initiatives in the field of further education (nursing and human medicine). However, interdisciplinarity must also be promoted, e.g. collaboration between the carers for outpatient services for the basic care and the specialists in the hospitals (e.g. oncology).

Research

In Switzerland up to now, little research has been carried out in the field of palliative care. The research landscape is characterised by few researchers and small, barely established research teams having very different specialisations.

The research should contribute to a better understanding of the situation of palliative care in Switzerland, such as for example on the needs of the affected people and

families or on the effectiveness of regional care structures and models. In this regard, both medical and also humanitarian contributions are important. However, a considerable amount of fundamental data needed for the ongoing comprehension and development of palliative care in Switzerland is currently unavailable.

Research in the field of palliative care is weakly integrated in the overall research system. Moreover, the researchers in the field of palliative care are poorly interconnected and collaborate only sporadically. This is also the case for collaboration with other disciplines.

5. Palliative Care in Switzerland: Desired status

The FOPH has formulated three general principles, which should be respected in the promotion of palliative care in Switzerland.

- Palliative care services should be offered.
- Palliative care services should be available to all.
- The quality of the palliative care services should meet professional standards.

6. National Strategy for Palliative Care 2010–2012: Objectives

With the National Strategy for Palliative Care 2010–2012, the Confederation and Cantons have established objectives to fill the identified gaps. Together with all the partners, the measures will be realised and the means purposefully adopted. The strategy focuses on a strengthened coordination as well as on improved synergies at the national and cantonal level. It provides the decisive impulse for the realisation of a medium and long-term improvement in end-of-life health care.

Major Objective of the National Strategy for Palliative Care

The Confederation and Cantons will collaborate with the most important actors in the field of public health and in other areas to integrate palliative care. This will allow all chronically ill and dying people in Switzerland to receive palliative care that is adapted to their situation in order to improve their quality of life.



1. Field of action “Care”

Overall objective

Sufficient offers of palliative care are available throughout Switzerland.

Subordinate objectives

- 1.1 The offers for palliative care are defined in the basic medical care and in the specialised sector and quality criteria are put into place.
- 1.2 Offers for palliative care are established in all regions of Switzerland. They will be coordinated and interconnected. Their quality will be regularly checked.
- 1.3 Criteria for claiming support and specialised palliative care services are laid down (indication criteria).



2. Field of Action “Financing”

Overall objective

Access to palliative care services is made available to all, independently of their socio-economic status.

Subordinate objectives

- 2.1 The services of the mobile palliative care teams can be accessed by all as the need arises. The funding responsibilities of the Cantons, of the compulsory health insurance and of the patients as well as of other cost-bearers are clarified.
- 2.2 For indicated need, the palliative care services provided by outpatient facilities and in long-stay institutions can be used by all. The funding responsibilities of the Cantons, of the compulsory health insurance and of the patients as well as of other cost-bearers are clarified.
- 2.3 The services of palliative care provided in the urgent inpatient sector can be accessed by all as the need arises. The funding responsibilities of the Cantons, of the compulsory health insurance and of the patients as well as of other cost-bearers are clarified.

- 2.4 For indicated need, the palliative care services provided in the outpatient sector are available to all. The responsibilities of the Cantons and of the compulsory health insurance in regard to the financing of the interconnection and coordination services are clarified.



3. Field of Action “Awareness”

Overall objective

The population in Switzerland knows about the benefits of palliative care and is aware of their availability.

Subordinate objectives

- 3.1 The information on palliative care is developed and available for specific target groups.
- 3.2 The information is based on uniform definitions and messages.

4. Field of Action “Training, further education and continuous education”

Overall objective

Specialists and volunteers who are active in palliative care are provided with the required appropriate level of expertise.

Subordinate objectives

- 4.1 A common educational concept for palliative care is developed for all occupational groups.
- 4.2 Palliative care is an integral component of the training, further education and continuous education of the university medical professions and of the non-university health and social professions as well as for other relevant occupational groups.
- 4.3 Volunteers for palliative care are provided with expertise in palliative care and receive the required support to accomplish their tasks.



5. Field of Action “Research”

Overall objective

Research in palliative care is established. It supplies research results of high quality and significant contributions to social issues at the end of life.

Subordinate objectives

- 5.1 Research into palliative care is integrated into existing structures such as universities, universities of applied sciences and university hospitals, and the coordination with related fields is ensured. For that purpose one or two competence centres for research in the field of palliative care will be established.
- 5.2 Researchers in palliative care take advantage of the national and international funds for the promotion of research.
- 5.3 The investigation of the statistical bases for palliative care is monitored and adapted at the level of the Confederation/Cantons. Existing statistical bases are evaluated in more detail in regard to palliative care.



The National Strategy for Palliative Care 2010–2012 in German, French and Italian, as well as the enquiry report on the need for action (German, with a summary in French and German) are available under:

www.bag.admin.ch/palliativecare

6. Overall field of activity “Implementation of the strategy”

Overall objective

The prerequisites for the implementation of the national strategy for palliative care are created with appropriate instruments.

Subordinate objectives

- 6.1 In Switzerland there exist national guidelines for palliative care, which are recognised and supported by the actors of palliative care.
- 6.2 The exchange of information between the national actors of palliative care and the transfer of knowledge between science and practice, “putting evidence into practice” are guaranteed.
- 6.3 The effectiveness and appropriateness of the measures is regularly evaluated.

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