

Dying in Switzerland—responding to the individual's every need

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Most people in Switzerland die in hospitals and nursing homes. Their specific needs are often not adequately met. In addition, professional caregivers are not sufficiently well coordinated. This situation could be improved by promoting palliative care, which cares for people's every need at the end of life. These are the conclusions reached by the National Research Programme "End of Life".

Death is the unavoidable, [final phase](#) of [life](#). However, how a person dies can be shaped. In youth or old age, at home in an institution, lonely or cared for, the manner in which this final phase unfolds is not the sole responsibility of that individual. Society can create conditions that allow people to die with dignity and self-determination, and as far as possible without fear and pain. However, this cannot be achieved without knowledge about where and how people die today, and how they would prefer to die. In the scope of National Research Programme "End of Life" (NRP 67), 33 research projects have studied dying in Switzerland for the past five years.

Palliative care has great potential

Regardless of age or the type of terminal illness, the majority of people living in Switzerland die in hospitals or [nursing homes](#). Sometimes their basic needs are not given sufficient consideration. The candid conversations that the dying and their next of kin hope for do not always take place. Professionals in the field often do not cooperate closely with

each other. There is a lack of coordination and, as a result, care for the dying tends to be fragmented.

Palliative care has great potential and may be able to improve this situation. It takes a holistic approach to care, focusing on pain relief, maintenance of quality of life and self-determination. "Palliative care ought to be more widely available in Switzerland," says Markus Zimmermann from the University of Fribourg, president of the NRP 67 Steering Committee. "It is therefore important to raise public awareness and ensure that caregivers and doctors receive better training in this area."

Public is willing to bear high costs

The high costs of treatments in the final phase of life are often the subject of public debate. Findings of NRP 67 show that the costs associated with dying are typically lower for older people than for younger ones. One of the reasons for this is the fact that [older people](#) are less likely to die in a hospital. The treatment of cancer patients at the end of life is particularly expensive. However, the public is on the whole willing to bear the high costs incurred at the end of life - in French-speaking Switzerland even more so than in the German-speaking part.

Decisions at the end of life can be highly diverse

Death is often preceded by decisions about medical treatment and care. In 70 per cent of the non-sudden deaths recorded in 2013, a decision was made to either forego further treatment, break off an ongoing therapy or initiate pain and symptom relief measures that might have a life-shortening effect. Only 3 per cent of deaths were preceded by life-ending decisions. These include active euthanasia on request, or in the absence of any explicit request from the patient, and assisted suicide. A

striking number of patients are sedated in their last phase of life, and they therefore do not consciously experience dying: in 2013, every sixth person who died in Switzerland died in this manner. Deep sedation is a drug-induced deep sleep until death, which medical staff resort to if certain symptoms are not otherwise containable during the dying process. However, if people who are not at the end of life are sedated in this manner, this is considered intentionally life-ending and forbidden in Switzerland.

Decision-making capacity is difficult to determine

When taking account of patients' rights, the crucial point is whether the person is still capable of making decisions or not. But this faculty is difficult to determine in many cases, and doctors are often unsure when they have to assess a patient's competence for decision-making. An ideal legal concept of the self-determined patient who independently makes end-of-life decisions is unrealistic. Any revision of the adult protection law should therefore take into account that subjective aspects necessarily play a role in the assessment of an individual's decision-making capacity. In addition, it would be important to define the roles of patient representatives more clearly.

Spiritual needs at the end of life

Dying people often have existential questions and questions pertaining to meaning. Caregivers should be aware of this, given that spiritual wellbeing or the prevention of an existential crisis can play a crucial role in improving the quality of life of the dying. In addition to traditional beliefs, for example those held by Christians of all denominations, various forms of so-called "alternative religiosity" have been gaining ground in our society. Health professionals and the relevant institutions need to take account of these changes when tending to the dying or

talking to their next of kin.

More information: Synthesis report of NRP End of Life (NRP 67).
www.snf.ch/synthesis-report-nrp-67

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