

SYNTHESIS REPORT  
NRP 67  
**END OF LIFE**



# SYNTHESIS REPORT NRP 67

## END OF LIFE

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In this publication, the Steering Committee summarises the results of the 33 research projects of NRP 67, drawing conclusions and formulating recommendations. The synthesis report will help stakeholders form an opinion, inform the political and expert debate as well as define strategic plans and measures in the end-of-life domain in Switzerland.

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## RESEARCH ON DYING

Dying is a deeply personal phase in the life of each human being and the nature of the end of life experience is influenced to a considerable degree by societal conditions. The National Research Programme “End of Life” (NRP 67) carried out research into various aspects of dying including: questions of meaning that arise for individuals and the desire to die that causes anguish at the end of life; the costs related to treatment during the last phase of life; and the situation regarding care in Switzerland including its legal requirements. The results of research in various disciplines over five years are correspondingly varied and complex. This synthesis report provides an overview of the most important findings from the 33 individual projects and formulates policy recommendations for different interest groups.



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The results of the NRP 67 projects underline the importance of palliative care – an approach that aims to ease pain and emotional distress in seriously ill and dying people. The findings also reinforce the importance of central principles such as self-determination, quality of life until the very end, and consideration of the individual's particular needs. These values, the associated behaviours and offerings are in contrast to a profit-oriented society characterized by fragmentation and foreign determination.

The insights into the differing care situations in Switzerland reveal a complex and varied landscape. The various settings in which death takes place – nursing homes, acute care institutions or dying at home – also bring their own associated challenges. End-of-life decisions are becoming more important and influential in shaping the process of dying. One aspect of this, determining a patient's decision-making capacity, has the greatest implications for those who are dying; NRP 67 has generated guidelines for better assessing decision-making capacity. Finally, the significance of questions related to meaning at the end of life and how they might be addressed were also explored.

NRP 67 presents 11 recommendations to the interested general public, practitioners and decision-makers. They reflect a common thread that is present throughout the synthesis report: the significant opportunities for improving coordination and cooperation in care at the end of life, which is also a key concern of palliative care. In order to enable death with dignity for everyone, timely, open discussions about the end of life are of great importance.

Research on the end of life is a consequence of the rediscovery of dying, of our altered perceptions during the last phase of life. At the same time, this research generates the knowledge necessary to create the medical, political, economic, legal and other conditions to allow everyone in Switzerland to die with dignity. It is therefore imperative to continue to do research into the end of life in order to better understand how processes are established and institutionalised, and then to take the appropriate political decisions.

## SUMMARY

**Death is the unavoidable, final phase of life. However, how a person dies can be shaped: in youth or old age, at home, while out and about or in an institution, the manner in which this final phase unfolds is not the sole responsibility of that individual. It is in the remit of society and its citizens to enable everyone to die with dignity and self-determination, and with the appropriate care that is as free from fear and pain as possible. In its 33 projects, the National Research Programme “End of Life” (NRP 67) examined various aspects of dying in Switzerland.**

The aim of the programme over the last five years was to gain knowledge about the final phase of life as a basis for orientation and action. The 33 projects generated new knowledge, particularly in the areas of care, decisions at the end of life, ethical principles and legal requirements, as well as societal ideals as to what constitutes a good death.

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### STRENGTHENING PALLIATIVE CARE

The majority of people living in Switzerland die in hospitals and nursing homes. Here the special needs of the dying are sometimes given insufficient consideration. What is needed are more candid conversations. Contact between the staff involved is often inadequate, and as a result patient care tends to be fragmented rather than continuous. Palliative care, a holistic approach to caring for the severely ill and dying that strives for relief of pain and maintenance of quality of life as well as self-determination for the dying, can contribute to improving this situation.

Palliative care needs to be more strongly established in Switzerland. The population should be made more familiar with it, while nursing staff, physicians and other specialists need to be better trained. Access to palliative care for people who die at home could be

improved by creating mobile teams. Although palliative care is well known in oncology, it needs to be made more widely available to dying patients who are not suffering from cancer: old people in residential care homes, people suffering from dementia, and also newborns, children and young people who are dying.

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### **FOCUS ON THE COST OF DYING**

How much does it cost to die? The costliest treatments are for cancer, which is presumably due to the expensive medications involved. The costs associated with dying are typically less for older people than for younger ones. One of the reasons for this is the fact that older people are much less likely to die in a hospital. The willingness of the population to cover costs at the end of life is high, with a greater willingness in French-speaking Switzerland than in the German-speaking part. Willingness to pay for the treatment of dying children is particularly high.

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### **MEDICAL DECISIONS AT THE END OF LIFE**

General practitioners play a central role in the dying process. A survey of 580 physicians found that they attribute great importance to including other family members when making important decisions, such as transferring a dying person to a hospital. They also feel they are not sufficiently involved in decisions taken by specialists in a hospital. When confronted by the ethical, legal and psychological challenges raised by dying patients, they often come up against their own limits.

A representative study of deaths in Swiss hospitals and nursing homes found that in three-quarters of all deaths, physicians had discussed the decision not to prolong life with the patient. “Stopping or withholding treatment while accepting or intending a life-shortening impact” was the most frequently encountered situation. However, in one out of four cases, end-of-life decisions were not discussed with the patient involved although he or she had a decision-making capacity.

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### **LEGAL REQUIREMENTS**

Decision-making capacity plays a central role when taking into account a patient’s rights and wishes. This, however, raises an important question: how does the physician ascertain a patient’s decision-making capabilities? There currently are no satisfactory definitions or valid instruments for assessing a patient’s competence for decision-making; this is why many physicians feel overwhelmed. Since such a determination necessarily includes subjective factors, binding regulations need to be created. A revision of the law protecting adults also needs to recognize that regulating end-of-life decisions should not

be oriented to the often-unrealistic ideal of a competent patient. In addition, the duties of patient representatives need to be clarified as well as their inclusion in a timely treatment plan (“Advance Care Planning”).

Switzerland is known for its liberal approach to assisted suicide. According to a study that examined all the cases of death that were forensically recorded between 1985 and 2013, almost half of those looking for assisted suicide came from abroad. Among Swiss residents pursuing assisted suicide, half came from Canton Zurich. The average age was 73, and three-fifths were women. However, only about half of the cases reported to the Federal Statistical Office during this period were forensically investigated. Judicial monitoring was therefore incomplete.

A strikingly high number of patients die in hospitals and nursing homes while under continuous deep sedation. In 2013, this affected every sixth person dying in Switzerland. This sedation normally continues until death and is accompanied by the withdrawal of food and fluids. As a rule, the patients were already at the end of their life and suffering from symptoms that were no longer treatable, so the approaching death had already been accepted. If deep sedation is applied to people who are not at the end of their life, however, this is a form of deliberate termination of life and is forbidden by law. This area requires further clarification.

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### **AWARENESS OF SPIRITUAL NEEDS**

Questions pertaining to meaning are often raised at the end of life that otherwise remain unasked. While interpretations of death and dying based on religious theologies are becoming less relevant to many people, spiritual needs continue to be expressed and often play an important role for people who are dying. Consequently, these need to be treated with corresponding awareness and seriousness. A survey of patients suffering from tumours shows, for instance, that spiritual wellbeing and a sense of purpose can positively influence quality of life. “Alternative religiosity” is also increasing, therefore traditional ideals for a good death are being replaced by new ideas and spiritual practices. These need to be addressed in homes and hospitals with greater frequency and more broadly respected in general. The ideal of self-determination leads to the desire to shape and master one’s own death in spiritual terms.

## 1. THE END OF LIFE AS A CHALLENGE FOR SOCIETY

For a variety of reasons – including an aging population, advances in medical treatments and economic considerations – public attention on the myriad issues surrounding the end of life has escalated significantly in recent years: inappropriate, over- and under-provisioning of health care, death with dignity, assisted suicide and costs at the end of life are the subject today of intensive and controversial discussions in the media and political initiatives. The heightened interest in these questions suggest that the end of life has been newly “discovered” in Western society as the final biographical phase.

This increased public attention to the end of life is no doubt also a reflection of the many actions and initiatives that have been undertaken since the 1990s: hospitals have set up palliative care units; advance directives have been established; mobile palliative care teams<sup>1</sup> have been made available; and assisted suicide organisations are offering their services. Numerous institutions today concern themselves with the last stage of life. The new law on the protection of adults (2013) deals with living wills and the nomination of representatives for medical decisions at the end of life. The “National Strategy for Palliative Care” completed in 2015, and the “National Platform for Palliative Care” aim to integrate care at the end of life into medical and health care.

Death affects each of us individually and as society: the individual is a part of a family and normally has a circle of friends and acquaintances. Healthcare institutions – homes, hospitals, general practitioners, and Spitex (i.e. home care services) – provide care and treatment for the dying. Norms have been defined for a “good” or a “bad” death, ideals such as self-determination, control, quality of life or individuality play an important role, while new spiritual offerings for the dying are beginning to replace traditional religious approaches that are, in turn, losing importance.

The end of life affects everyone – we all die sooner or later, and we also lose people to whom we are close. That this end awaits all of us has an effect on other phases of life and how we shape them. In this way, people, particularly those in the so-called third, active stage of life, ask themselves which way of life favours a pleasant old age and as painless a death as possible. In addition, many nominate a representative for medical matters and prepare an advance directive. Traditional religious interpretations of death and dying are losing their importance and are being replaced by diverse values and ideals. Death no longer has the character of a misfortune, but is increasingly seen as the consequence of individual decisions: “how, when and where will I die?” While asking these questions and making a decision gives a sense of freedom, it also brings with it a responsibility that can be overwhelming.

However the end of life is individually perceived, shaped, “prepared” and then experienced (as well as not infrequently suffered), it is nevertheless affected by political,

<sup>1</sup> According to the “National Guidelines for Palliative Care”, palliative care encompasses “the care and treatment of individuals with incurable, life-threatening and/or chronic progressive diseases. They are implemented in a forward-looking manner, their emphasis is on the time when curing the disease is no longer regarded as possible and does not represent the primary goal. Patients are assured optimised quality of life that is adapted to their situation until they die; and their caregivers are supported appropriately. Palliative care prevents suffering and complications. It encompasses medical treatment, nursing interventions as well as psychological, social and spiritual support.”

legal, economic and cultural conditions. Against this background, the end of life has become a societal challenge that requires conscious collective action.

While many endeavours are already underway, there are still many aspects related to the end of life that warrant further research. Systematically compiled knowledge on the end of life can make a contribution to how we – collectively and individually – cope with this inevitability. However, appropriate research efforts must cast a wide net, as the “end-of-life phenomenon” touches every level of social co-existence. This is where the “End of Life” National Research Programme (NRP 67) comes in.

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### **THE GOALS OF THE NATIONAL RESEARCH PROGRAMME “END OF LIFE” (NRP 67)**

National Research Programmes are an effective tool used in Swiss science policy. For more than half a century they have taken up socially significant questions, placed them under a magnifying glass and then made the resulting knowledge available to interested and affected stakeholders. NRP 67 was started in 2011 and aimed to generate knowledge that can be applied to decisions and practices when dealing with the last stage of life. Its primary objectives were to:

- *assess the health care situation of people at the end of life – what do they need? – and to identify “care gaps”;*
- *provide a basis for appropriate decision-making and action for the dying, their families and close friends as well as physicians, nursing staff and other professionals;*
- *identify the conditions and medical care required to make the end of life fair and dignified, and to reflect on the necessary legal regulations and ethical implications;*
- *understand and evaluate social developments; and*
- *identify other relevant topics for further research into the end of life and palliative care.*

This synthesis of NRP 67 presents the most important – in the view of the steering group – results of 33 research projects, and on the basis of these, formulates recommendations for policy and practice. Through this approach, the focus is placed on providing an overall perspective rather than on individual projects. Depending on the methodology and size of the study, not all the results can be generalised; they require further interpretation and research. This synthesis does not present all the research findings. The footnotes refer

to projects where, for the sake of simplicity, the name of the first applicant is shown. The names of all the researchers involved are listed in the appendix. Further information on the projects and NRP 67 can be found at: [www.nrp67.ch](http://www.nrp67.ch)

That death is a part of life was also made clear over the course of NRP 67. Two grant recipients passed away during the research phase: Christoph Abderhalden (†10.3.2013) and André Busato (†12.11.2013). The leadership of their projects was taken on by researchers Kerri Clough-Gorr and Benno Schimmelmann, respectively. We pay tribute here to the late researchers and their contribution to NRP 67.

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**PRINCIPLE** *To enable dying with dignity should be a fundamental societal aim*  
*Society's most important goal in how we deal with dying should be to ensure that people die with dignity. Respecting the dignity of the dying means to respect individual freedom and self-determination, to protect human life that is particularly vulnerable, and to treat all those at the end of life equally – regardless of social status and individual characteristics.*





Results 2.1

## **CARE AT THE END OF LIFE**

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Places of death

Medicine and care

Costs

Inappropriate care

Palliative care

## 2.1 CARE AT THE END OF LIFE

**Those entering the last stage of life normally make use of medical, nursing, psychosocial or spiritual help. A range of specialists and institutions provide this assistance; there is considerable variation in the type and extent of care available in Switzerland.**

### PLACES OF DEATH

While a majority of Swiss people would prefer to die within the familiar surroundings of home, most die today in a hospital or nursing home. Only a small proportion die at home. In addition, with an aging population, there has been a striking increase in the proportion of people who die in nursing homes.

The probability of dying at home is significantly higher in the German-speaking part of Switzerland than in the French- or Italian-speaking parts, as determined by NRP 67 researchers who analysed health-insurance data.<sup>2</sup> The probability of dying at home is also greater among people who own their home, have a higher education, or have children.<sup>3</sup> Conversely, the probability of dying in an institution increases for people living in a region with many nursing homes, or are single, divorced or widowed. Gender also plays a role: while men are more likely to die at home or in hospital, almost 50 percent of women spend the last phase of their life in a nursing home; the figure for men is just 25 percent. It is correspondingly rare for women to die in hospital or at home.<sup>4</sup>

### MEDICINE AND CARE

The care services provided by medical practices, hospitals, homes as well as Spitex (home care services), and the degree to which they are utilised, vary from region to region. There are also regional differences in the care of patients at the end of life. According to the general practitioners interviewed, rural and mountain areas suffer from a lack of both specialised facilities and Spitex services to provide needs-based care for the dying.<sup>5</sup> Given the different service-offering models, the costs involved at the end of life and the degree of care also vary greatly from region to region.<sup>6</sup> One reason for this appears to stem from regional differences in infrastructure, while the socio-economic situation of those who are dying seems to have less of an influence. For example, as the number of mobile teams and beds available in nursing homes increases, the number of people who die in hospital decreases.<sup>7</sup>

### COSTS

According to NRP 67 researchers, dying in hospital is the most expensive option in terms of direct treatment costs, even when only very few patients make use of the most

2 Clough-Gorr; Kaplan

3-4 Kaplan

5 Bally

6-7 Clough-Gorr

expensive hospital treatments. Independent of the place of care, cancer treatments incur above-average costs at the end of life, most likely due to the high cost of the medications.<sup>8</sup> Not surprisingly, treatment costs in the last year of life are considerably lower for people who die at an advanced age compared with those who die at a younger age. Lower end of life treatment costs for older people could also be attributable to the possibility that certain severe diseases are treated with less intensity among the very old and, they are less likely to be admitted to a hospital for aggressive – and expensive – treatments.<sup>9</sup>

How willing is the population to cover the high costs of treatment for a longer life? A survey of 1500 citizens found that it is high in the French-speaking part and even higher in the German-speaking part.<sup>10</sup> The majority believes that healthcare for a patient at the end of his or her life to provide an additional year in the best of health possible may cost CHF 200 000, and half of this amount for a year in which the quality of life remains the same. The willingness to pay for the treatment of children and young people with little chance of survival is particularly high, and declines as the age of the dying person increases.

Expensive treatments at the end of life are typically justified by the direct benefit to the dying individual from prolonging his/her life while maintaining the highest possible quality of life. A further benefit can be the long-term impact resulting from improvements made to expensive therapies initially developed as part of treatments with no significant benefits for the sufferer. Nevertheless, the experience gathered here could lead to innovations in the future treatment of diseases, and in this way, be of benefit to patients who have reached the end of life phase as well as those who are not yet dying.<sup>11</sup>

**RECOMMENDATION 1** **To promote coordinated and cooperative care**

*The transition from one institution to another or back home is often difficult for people at the end of their life because cooperation between the services and responsible institutions is inadequate or poorly interconnected. In order to guarantee continuity of care and treatment, more coordinated regional networks need to be created and developed. In addition, referring physicians and relatives should be increasingly involved in the transitional phase. An alternative would be to establish broad-based institutions for basic care that integrate acute medicine, rehabilitation, geriatrics, psychiatry, and long-term and palliative care under one roof.*

8–10 Beck

11 Hintermann

### INAPPROPRIATE CARE

There is a pervasive concern among the general public that patients near the end of their life are being treated incorrectly. Terms such as “inappropriate care”, “under” or “overprovision of care” are employed. When individual cases are assessed, however, there are always widely varying factors to be considered, and meaningful comparisons across cases are difficult. “Under-provision” of care is to be feared if there is a lack of adequate treatment possibilities and structures, as can sometimes be the case in rural areas.<sup>12</sup> “Inappropriate care” often occurs when patients are hospitalised for non-medical reasons because relatives are no longer able to care for them; for example, if pressure from paid employment pushes them to their limits.<sup>13</sup>

- 12 Bally
- 13 Berthod
- 14 Sottas
- 15 Bally, Liebig, Kaplan, Sottas, Fleming, Wolf
- 16 Janssens, Sottas, Wolf, Wicki, Znoj
- 17 Eychemüller
- 18 Bally, Liebig

Employers have not established any standards that could contribute towards lessening the burden on employees who also care for a relative. In addition, the burden on relatives is magnified by, among others, a lack of support from professionals, such as mobile palliative care teams.<sup>14</sup> The transfer to a hospital can also be financially motivated: the financial cost of care at home is largely borne by patients and their families, whereas in hospital it is covered by health insurance.

Hospitals are basically geared towards diagnosing patients and treating them curatively (healing) rather than palliatively (relieving pain). Focussing exclusively on physical disorders, their diagnoses and treatments increase the probability of overprovisioning. The lack of appropriate medical and nursing expertise as well as time pressure and understaffing means the psychosocial and spiritual needs of the dying are often overlooked.

### PALLIATIVE CARE

Palliative care – care that seeks to relieve the suffering of people with life-threatening illnesses, of all ages – is not well established in Switzerland.<sup>15</sup> There are only a few regions where the various stakeholders who are important in providing care at the end of life are linked together in a network. Even so, the areas of care are still fragmented: patients often face many hurdles during transitions between institutions or when returning home. In addition, healthcare staff often have inadequate knowledge of palliative care, and as a result, rarely offer it in an appropriate manner. This applies particularly to the treatment of non-cancerous diseases such as COPD (chronic-obstructive pulmonary disease), where care should be increasingly oriented towards patients’ needs in a holistic way.<sup>16</sup>

It is crucial that palliative care be initiated in a timely manner when a patient is dying from cancer, for example, in order to avoid over or under-provisioning of care and to retain the patient’s quality of life for as long as possible.<sup>17</sup> General practitioners regard it as their duty to care for their patients until they die, but they also lack confidence; that’s especially the case when it comes to spiritual, ethical and legal matters relating to palliative care.<sup>18</sup>

While various palliative care services are available in the cantons of St. Gallen and Vaud, and mobile palliative care teams are established in the canton of Ticino, other cantons, in particular in central Switzerland, are only just getting started.

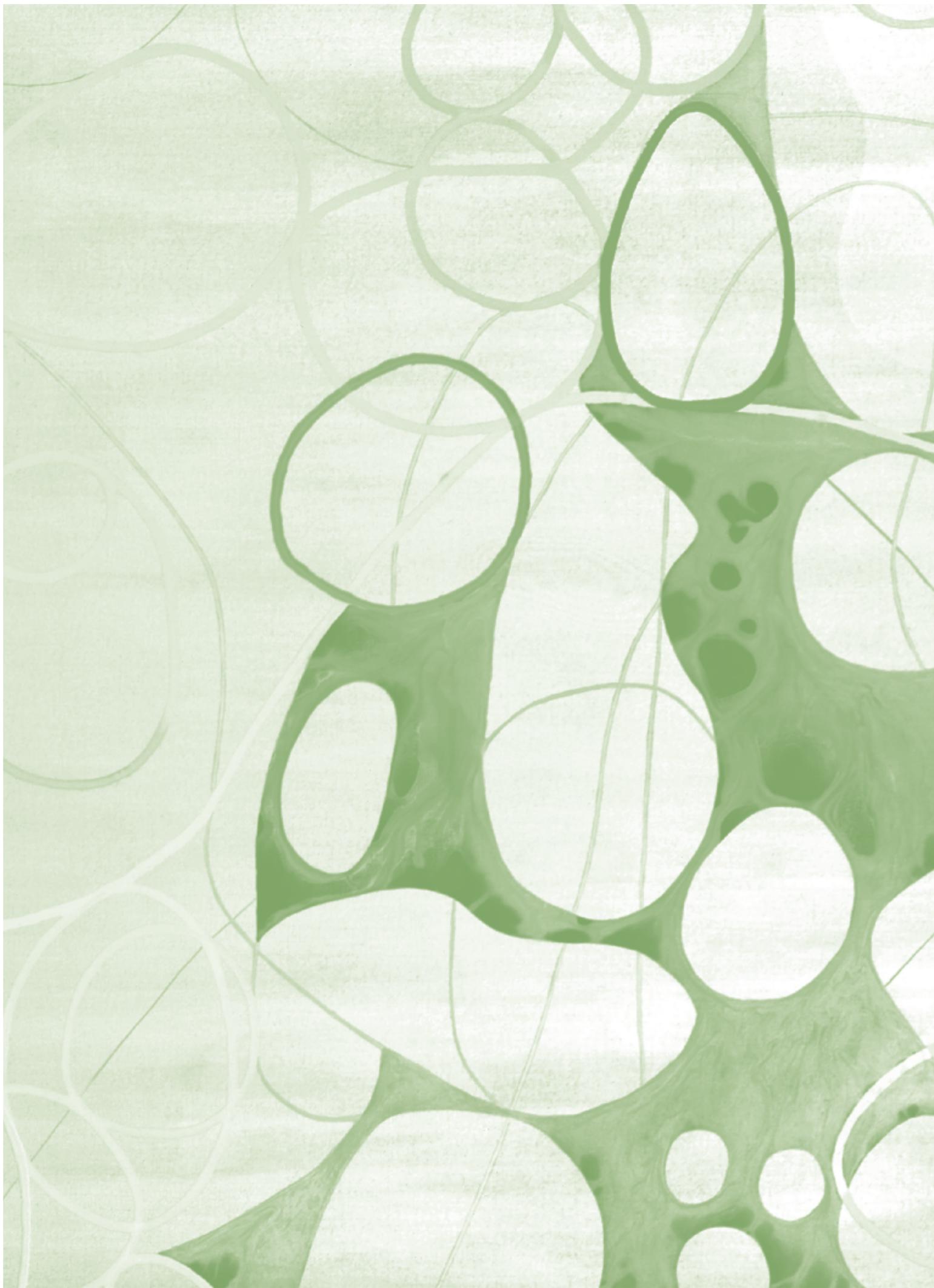
Training and continuing education for the various professions involved in primary care are necessary to ensure that palliative care is more widely and capably provided. Basic knowledge of the principles of palliative care as well as strategies for intervention should be incorporated into the training curriculum for health professionals. Specialisation and the acquisition of more detailed knowledge as part of continuing education should be provided. There are also gaps in the recruitment of specialised personnel.<sup>19</sup>

19 Janssens, Wolf, Wicki, Eychmüller

20 Lüddeckens

Palliative care also encompasses psychosocial and spiritual support for the dying. There are often family conflicts to be resolved or financial matters to be clarified. Care services and community-based services have a valuable role to play here. Apart from ecclesiastical-pastoral care, there are few alternative religious services, even though the need for alternative interpretations in the areas of disease, dying and death that differ from conventional religious beliefs is increasing. Such needs are being expressed not only by patients but also by specialists (see 2.5).<sup>20</sup> Sometimes the concerns of dying patients are attended to by the nursing staff or pastoral care workers – if they have the necessary skills and their help is accepted by the dying patient.

**RECOMMENDATION 2** *To ensure the best possible quality of life for those who are seriously ill or dying*  
*Having the best possible quality of life when dying is as important as curing diseases and extending life. Palliative (offering relief from pain) measures must be increasingly established alongside curative (having a healing effect) treatments. It is therefore imperative that palliative care – treatment that offers relief and physical comfort – be included in every area of education, training and continuing education for healthcare specialists.*





Results 2.2

## **DECISIONS AT THE END OF LIFE**

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Medical decisions

General practitioners

Transfer to the intensive care unit

Children and adolescents

Extremely premature babies

People with cognitive impairments

Surrogate decisions

## 2.2 DECISIONS AT THE END OF LIFE

**As a result of scientific and technical progress along with increasing prosperity, the more treatment possibilities there are available to those who are seriously ill or dying, the more frequently decisions will need to be made that influence and even steer the dying process.**

### MEDICAL DECISIONS

Today, the majority of deaths that are termed by physicians as not unexpected – so-called “non-sudden deaths”<sup>21</sup> – are preceded by medical decisions that may or may not result in a reduction of the remaining lifespan. These decisions are often difficult to take and subject to controversy. Little is known about: how the decisions are reached; who takes them; who else participated; and, with what intentions.

21 In cases of “sudden death” generally no more decisions can be taken.

22 “Medically assisted death” encompasses medical aid in committing suicide, intentional killing by a medical professional upon the express wish of an individual as well as deliberately ending a life without an express wish being formulated.

23 Puhan

24 The EURELD study, a similar study, was carried out in German-speaking Switzerland and in five further European countries in 2001.

According to an internationally established system, medical decisions at the end of life fall into three different categories:

1. *Active forms of aid in dying (known as medically assisted death); these involve the use of drugs with the clear intention of hastening death;*<sup>22</sup>
2. *Stopping or withholding treatment while accepting or intending a life-shortening effect;*
3. *Relief of pain and symptoms while accepting or in part intending a life-shortening effect.*

In four out of five “not-unexpected” deaths, physicians are responsible for taking one or more of these decisions. This was shown in a representative survey of physicians that explored the end-of-life decisions in 5328 deaths in 2013 and 2014.<sup>23</sup> In German-speaking Switzerland, the decision made most frequently was in favour of “stopping or withholding treatment while accepting or intending a life-shortening effect” – this was the case in 49 percent of the cases investigated. This decision was taken with significantly greater frequency compared to 12 years ago, when it was associated with 41 percent of deaths.<sup>24</sup> In three out of ten deaths, the decision was made to “relieve pain and symptoms while accepting or intending a life-shortening effect”. The frequency of this decision remained relatively unchanged compared to 2001.

For the above mentioned specific medical decisions at the end of life, it is necessary to differentiate “continuous deep sedation until death”, as that does not necessarily shorten life and therefore is not regarded as an aid in dying. Sedation here refers to medically inducing deep sleep until death occurs in order to control symptoms like pain, delirium, or difficult breathing that could not otherwise be controlled. According to one NRP 67 study,

this was the case in one in four “not-unexpected” deaths in 2013–2014, four times greater than in 2001.<sup>25</sup> The decision in favour of deep sedation is normally applied to patients whose treatment schemes are centred around relief from symptoms and pain.

In three-quarters of all deaths where the individual had a decision-making capacity, the physician discussed the decision with the patient.<sup>26</sup> Conversely, this also means that in one in four cases, the end of life decision was not discussed with the person involved although he or she was capable of making decisions. However, in half of those cases – representing about 10 percent of the total – the physicians did talk to the relatives, or were aware of the dying patient’s preferences with regard to life-extending measures.

25–26 Puhan

What justifies the exclusion of patient autonomy even when the dying patients have decision-making capacity? Why and in which situations do those responsible for treatment take decisions on behalf of the patient? The assumption is that some physicians simply missed the opportunity for a timely and open discussion with their patients about death and dying, or did not seek it out. Given how highly self-determination is valued by society and in the light of law on the protection of adults, this finding is striking and requires further clarification.

### **RECOMMENDATION 3** *To enforce principles of medical ethics*

*Even when capable of making decisions, patients are not always included in important end-of-life decisions. This contradicts current legislation as well as ethical principles. Institutions and professional associations need to take steps to promote policies which aim to ensure that self-determination is respected and promote the practice of shared and informed decision-making.*

Decisions in favour of medically assisted deaths, which include assisted suicide, were present in over 3 percent of the “not-unexpected” deaths investigated for the year 2013. What is more interesting than the absolute figure is how it has evolved: it has doubled since 2001, and is most likely set to increase in the coming years. Between 2013 and 2014, according to the Federal Statistical Office, the number of such cases increased by a quarter to 742, although this figure only includes those who took advantage of assisted death and were also resident in Switzerland.

Other NRP 67 projects dealt with the issue of decisions at the end of life. As expected, the results differ depending on the perspective of the interviewee: dying patients, relatives, and the various professional helpers all perceived the situation from their own point of

view when decisions had to be made. While decisions relating to the end of life are part of the daily work of healthcare professionals, for those who are dying and their relatives, they are unique and have an existential impact. Healthcare professionals can call on expertise and experience as well as having greater emotional distance. Relatives and friends, on the other hand, are directly affected by the experience of dying.

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### GENERAL PRACTITIONERS

General practitioners play a central role in the dying process. They have often known the person in question for many years, have treated them medically, and are aware of their family and social environment. General practitioners in all three parts of the country assign great importance to the inclusion of relatives when taking end-of-life decisions, as shown by a survey of 579 general practitioners across Switzerland.<sup>27</sup> General practitioners included relatives in almost every case; although in Ticino they included the family in only two-thirds of cases. The question whether the dying individual should be transferred to hospital or not often comes up. After admission to the hospital, many general practitioners have the impression of being included less frequently in subsequent decisions.

When general practitioners are confronted with ethical, legal, psychological or spiritual challenges while caring for the dying, particularly in the context of assisted suicide, they admit to being confronted by their own limitations. They are barely familiar with guidelines, or existing guidelines are not implemented. Interdisciplinary cooperation is similarly unsatisfactory, according to the respondents. They would like better training in palliative care and greater social recognition of their work.

Patients seeking assisted suicide often discuss this wish with their general practitioner. Between 2011 and 2013, almost 40 percent of the respondents were consulted about assisted suicide by one or two patients, and one-third consulted with three or more patients. More than half of these general practitioners experienced severe emotional distress on being approached with the request and directed patients to an assisted suicide organisation. Just one-fifth declared themselves prepared to provide the necessary guidance for a patient desiring to die.<sup>28</sup>

When a patient requests assisted suicide, general practitioners often find themselves in a dilemma. An analysis of group discussions with 90 general practitioners showed three types of reaction when confronted with this request: some set clear limits and, if necessary, terminated the discussion; others made every effort to understand the patient's point of view even when this contradicted their own views; and a third group attempted to negotiate the different beliefs and values with the patient. When this negotiation process succeeds, there is less of a burden on the physician and, in their view, the care provided improves.<sup>29</sup>

27–28 Bally

29 Liebig

### TRANSFER TO THE INTENSIVE CARE UNIT

Hospitals represent an important interface between internal medicine and intensive care. Under which circumstances and why are patients suffering from advanced disease transferred from an internal medicine ward to intensive care? According to the results of a study at the University Hospital Geneva, other factors in addition to clinical criteria play a role.<sup>30</sup> From the perspective of the physicians interviewed, determining factors included an evaluation of the indication for intensive medical treatment along with contextual factors (availability of personnel), an understanding of the patient's wishes, information provided by relatives, and finally, the quality of the communication between the physicians involved. Uncertainty arises particularly when the above mentioned criteria are not clearly met or fulfilled.

30–31 Escher

There are revealing aspects in the communication between physicians: Internists, for example, believe that intensive medicine specialists are ready to support them when taking difficult decisions and are fairly ready to take difficult life-and-death patient decisions. Intensive care specialists, in turn, acknowledge the extent of the internist's responsibilities and the fact that end-of-life decisions can overwhelm physicians, particularly if they are young and relatively inexperienced. Challenges arise when trying to discern the patient's wishes and the views of the family: these depend significantly on the empathy and willingness of the physicians involved, and their readiness to engage in complex and time-consuming discussions.<sup>31</sup>

#### **RECOMMENDATION 4** *To improve coordination and communication in hospitals*

*In hospitals, patients who are dying are often kept on different wards and treated and cared for by different staff members. Constant changes in personnel as well as a lack of coordination heighten fear and insecurity in those who are dying and can lead to conflict and poor decisions. Coordination and communication therefore urgently need to be improved.*

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## CHILDREN AND ADOLESCENTS

The U.N. convention on the rights of children states that children must be included in decisions that affect them. How does this apply to children and young people who are dying from cancer or other diseases? One NRP 67 study found that being involved in the process of taking difficult medical decisions was perceived as positive by the children and adolescents who participated in the study, although the readiness to be involved varied strongly as the disease progresses.<sup>32</sup> Parenting styles plus the maturity and personality of the children and adolescents influenced whether and how they were involved in shaping their medical treatment. Additional information was sometimes needed for underage patients if their consent was required for a potentially harrowing treatment that is considered to be appropriate by the adults. Parents and physicians were on occasion very divided. While physicians felt they have informed and involved the parents, the latter often held the opposite impression.

32 Elger

33–34 Berger

The reasoning of physicians working in paediatric oncology to involve children and young people as far as possible is based less on the idea of individual self-determination and more on the willingness to take their patients seriously so that they can be better helped (“relational autonomy”). Where children and young people are excluded from the decision-making process, their irrational fears and sense of isolation increase. There is a danger that they will be left alone with their fears.

The physicians interviewed felt their task is to preserve the children’s hope for survival. They feared that too negative a prognosis would weigh heavily on the family’s spirit. As they do not wish to raise false hopes, they themselves often feel under pressure and battle with self-doubt. While they do discuss issues of death, they always combine these conversations with the idea of not giving up the fight against cancer. They find hopeless situations in which they are unable to do anything more to save a patient very difficult.

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## EXTREMELY PREMATURE BABIES

When the life of an extremely premature baby, one that is born before the 28th week of pregnancy, is threatened, there are particularly difficult decisions to be made. This is illustrated by another NRP 67 study which looked at all 594 deaths that were documented over three years in Switzerland’s nine neonatal centres.<sup>33</sup> Only one-fifth of the deaths took place in the intensive care unit, while four-fifths of neonates died in the delivery room.<sup>34</sup> Of those who died in the delivery room, almost two-thirds were stillborn. One-third were alive at birth but died shortly afterwards. It is noticeable that birth was artificially induced in almost half of these children, after a decision had been taken in favour of terminating the pregnancy for medical reasons.

Interestingly, a sizeable proportion of these children survive a termination of pregnancy that is carried out late – in the sixth month – and, against expectations, are born alive. The legally permitted alternative would be foeticide but this appears to be uncommon in Switzerland. In all the deaths that occurred in the delivery room, the physicians took no measures to save the newborns and virtually no attempts were made at resuscitation.

Physicians and nursing staff in neonatal intensive care units rate the consideration of the anticipated low quality of life and suffering of extremely premature babies higher than the goal of enabling survival at any cost. This emerges clearly from one survey.<sup>35</sup> In the course of their professional lives, many physicians have opted to limit treatment in one or more cases. But only for a minority is the intentional ending of a life, a medically assisted death, acceptable. Two considerations are particularly difficult for physicians and nursing staff in these situations: their prognosis for the child's future quality of life, and their understanding and interpretation of the parents' attitudes.

A large proportion of the survey respondents felt that parents are not necessarily in the best position to decide what is best for a child who is born extremely prematurely. Two-thirds were of the opinion that both parties, the child and the parents, should be considered equally. A good third, however, reported that parental wishes and values should be the most important criteria in the decision-making process.<sup>36</sup>

A majority of citizens, predominantly Swiss Germans, believe – in contrast to physicians and nursing staff – that where opinions differ parents should have the last word.<sup>37</sup> In the Italian- and French-speaking parts, the decision is tilted in favour of the physicians. Medical treatment of extremely premature babies is viewed as basically positive, even if serious injuries to the child might ensue.

According to another NRP 67 study, the support offered to women who lose a child during pregnancy or birth is not optimal.<sup>38</sup> Care during and after birth is fragmented. Different specialists are responsible for communicating the diagnosis, providing support during the decision whether or not to terminate the pregnancy, accompanying the birth, and providing grief counselling in the tragic aftermath; these various functions are not adequately coordinated with each other.

35–37 Fauchère

38 Fleming

### PEOPLE WITH COGNITIVE IMPAIRMENTS <sup>39</sup>

Around 440 homes in Switzerland house people with disabilities. One-third of these institutions offer their residents the possibility of being cared for until the end of their life – as found in a representative survey of home managers.<sup>40</sup> A further third offer general care but exclude more specific care. Between 2008 and 2012, approximately half of 233 patients investigated remained in the residential home until death, almost all others died in hospitals, nursing homes or hospices, and some died with their families.

It is difficult for people with cognitive impairments to express themselves with respect to shaping the end of their life. In decisions affecting them, parents were consulted in three-quarter of the cases along with nursing staff and support services. Two-thirds of the patients were not involved in the decision-making process, even if they were judged to have a decision-making capacity, either partly or entirely. According to these findings, improvements also need to be made when caring for cognitively impaired people who are dying.

<sup>39</sup> People with dementia also suffer from cognitive impairments; this group is not covered in this chapter.

<sup>40</sup> Wicki

**RECOMMENDATION 5** *To address the needs of dying individuals who are particularly vulnerable at the end of life, the needs of particularly vulnerable individuals such as children, young people or those with cognitive disabilities should be given particular attention. It is important to create the necessary infrastructure for this and to make available the necessary professional resources.*

### SURROGATE DECISIONS

In discussions regarding difficult decisions at the end of life, considerable importance is given to the autonomy of the person involved. The prevailing belief is that self-determination should be ensured as far as possible. For this to succeed, healthcare staff, particularly physicians and nursing staff, have additional important responsibilities: they must inform patients, support their wishes, be attentive and exhibit empathy.

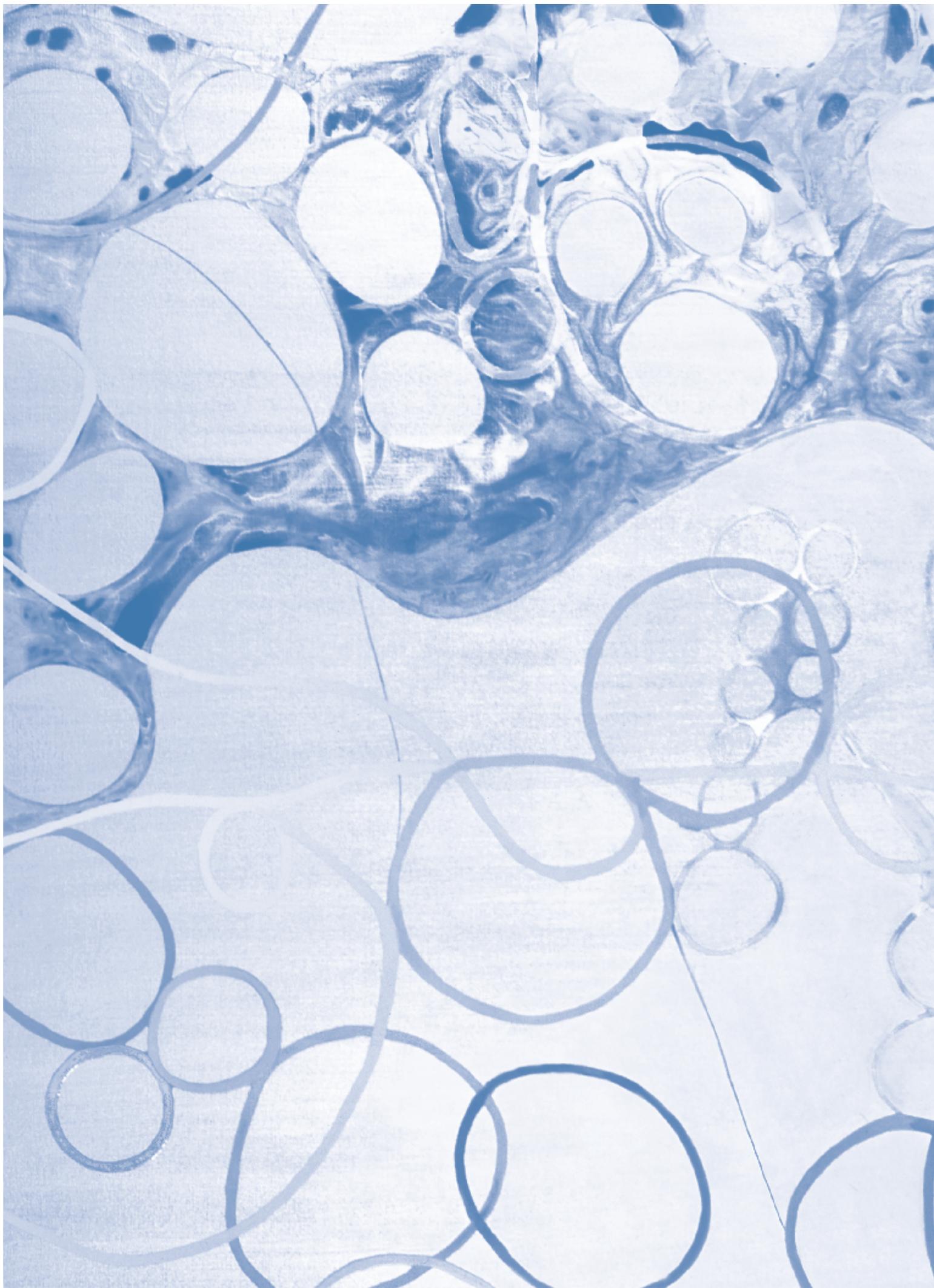
The contribution of advance directives, as they have been dealt with in the new adult protection law, is often unsatisfactory when physicians or relatives must take appropriate surrogate decisions for dying individuals who do not have a decision-making capacity. The advance directives are frequently not available in time, and it is often unclear whether they were written of the patient's own free will and in full knowledge of the consequences of the wishes expressed. It is not unusual that the wishes and requests expressed cannot be fulfilled or are contradictory.

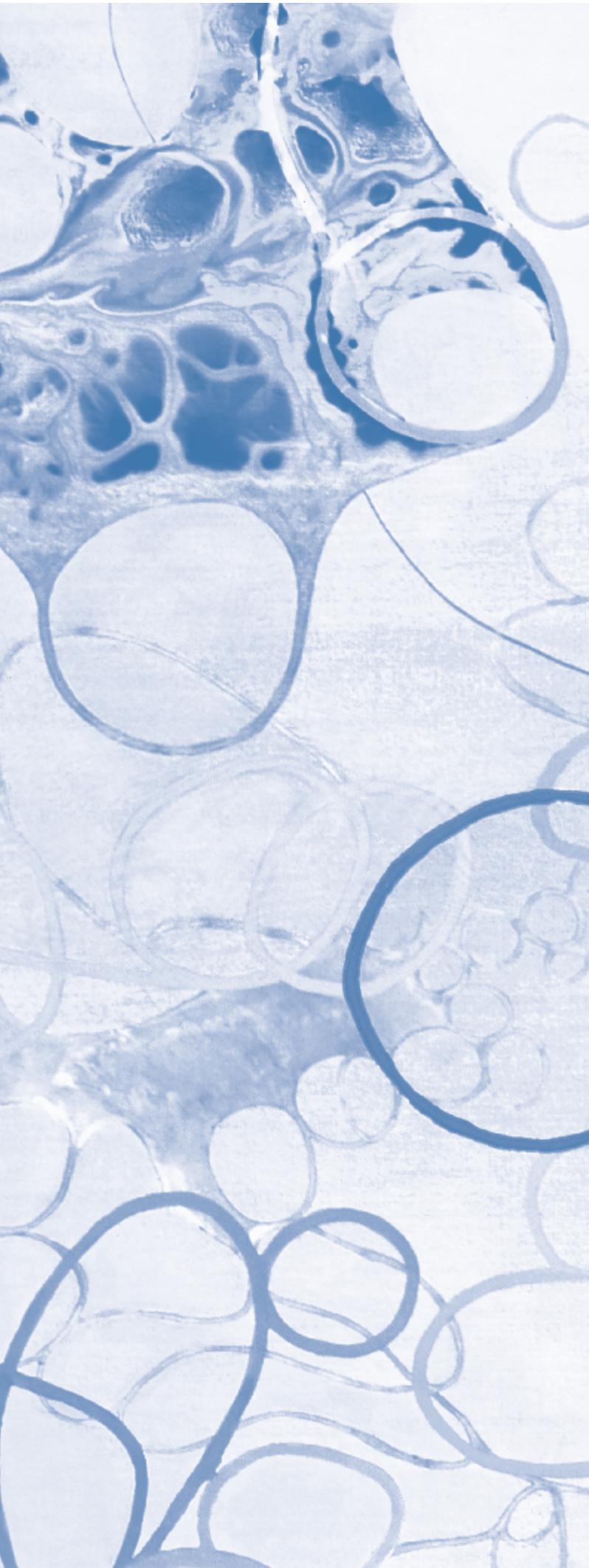
“Advance Care Planning” should help to improve this. It provides for continuous cooperation between patients, relatives and healthcare representatives: acting on the initiative of healthcare staff, patients discuss in due time their treatment expectations should they no longer be capable of participating in a decision – whether in an emergency or as part of the dying process – and which measures are to be followed. Ideally, a variety of situations will then be discussed; for example, whether or not the patient should be resuscitated in an emergency. The results of the discussion are recorded in an advance directive document. “Advance Care Planning” has been in use for a number of years in North America, several European countries and Australia, and the results have been positive. NRP 67 investigated “Advance Care Planning” in a university hospital.<sup>41</sup> It was shown that “Advance Care Planning” more frequently enables the fulfilment of patients’ wishes compared to the standard approach.

41 Krones

42 Stiefel

The limitations of physicians and nursing staff in the face of death and dying often prevent them from addressing important topics when talking to patients who are dying. Self-observation, creating awareness and reflection on one’s own values are therefore a precondition for helpful discussions.<sup>42</sup> One form of communication training for healthcare staff developed by an NRP 67 researcher focuses on those who are being treated: their everyday experiences in the clinical environment, their fears and thoughts, and the influence of the institutional context along with social values and norms. An important factor is recognising and overcoming practical resistance in everyday clinical practice, such as standardised procedures, lack of continuity in treatment, specialisation where responsibilities have not been assigned, or unrealistic expectations.





Results 2.3

## **PLACES AND WAYS TO DIE**

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Nursing homes

At home

Prison

Assisted suicide

## 2.3 PLACES AND WAYS TO DIE

**People die in various places. The conditions under which someone dies, plus the possibilities for influencing how one dies, also often vary significantly. Several NRP 67 projects looked at the various aspects of the places and the ways in which death occurs.**

### NURSING HOMES

Just about half of the residents of care homes are diagnosed with dementia, and one-quarter of those suffering from dementia are in permanent pain. Until now, relatively little research has been undertaken in Switzerland into how these patients experience this last phase of life, even though dementia-related diseases are the third most frequent cause of death today.

43 Monod

44 Gudat

45 Znoj

In a study of nursing homes in Canton Vaud, very aged residents experienced their conversations with researchers about death and dying as positive and providing a sense of relief.<sup>43</sup> Even individuals with mild dementia were able to comment. The desire to die soon is relatively widespread among nursing home residents: around one in five of those interviewed expressed the wish to die. Some were suffering from depression, while others were experiencing psychological stress or had unanswered existential questions.

The desire to die expressed by patients at the end of life is dynamic, complex and diverse – this is shown by a detailed analysis of conversations with 62 aging and very old dying patients, their relatives, nursing staff and physicians. The desire to die is often very carefully considered by dying patients, and justified on the basis of various physical and spiritual aspects, life situations and attitudes. This desire is always influenced by relationships with others, and it sometimes appears to be marked by contradictions. By listening closely, however, a better understanding can be gained. Some of those interviewed linked the desire to die with the idea of hastening death.<sup>44</sup>

According to one study with participative observation in a number of institutions, the ethnic origins of nursing home residents plays only the most minimal role in the acute phase of dying, and then only in situations of conflict.<sup>45</sup> Nursing home residents rarely volunteer their wishes in regard to the end of life. The fact that death and dying, as well as individual wishes regarding a good death are only peripherally discussed is associated, among other factors, with the fact that nursing homes see themselves primarily as places for living and not for dying.

Nonetheless, when someone dies in a nursing home, the nursing staff are often more closely involved in the dying process than physicians and relatives. They contribute to shaping the everyday life of the residents and spend the most time with them. Their own personal ideas of what constitutes a “good death” are correspondingly strongly affected.

It is not unusual for strong bonds to develop – this results in grief following the death of a resident. The time to process this grief is often unavailable in the daily nursing routine.

### AT HOME

The families that accompany a relative's death process at home face particular challenges.<sup>46</sup> Multiple stress factors and emotional overload often cause relatives to feel tired, isolated and not understood. They are confronted by the imminent loss of a loved one along with the accompanying feelings of grief, and must at the same time get on with daily life; the financial implications can also be burdensome. While there exist many support alternatives, they appear to be little known and poorly accessible. Switzerland has no standards on how businesses and employees should deal with such situations.<sup>47</sup> In dealing with the dual task of work and providing care, the tendency is to negotiate each situation individually. When they no longer know how to cope, family caregivers have to resort to taking sick leave.

One project looked at people who experienced the death of a parent at a young age and then made use of institutionalised assistance.<sup>48</sup> The early loss of a parent is experienced as a heavy blow that influences the transition into adulthood and can complicate it. Those affected do not always get the support they need from friends and family. Even institutional help does not always succeed here: there is a danger that it contributes to unresolved problems becoming even further entrenched.

#### **RECOMMENDATION 6** *To recognise the significance of the care provided by relatives and acknowledge their needs*

*Family caregivers can lighten the burden on the healthcare system, and in so doing, lessen the risk of inappropriate treatment for the dying. Political decisions on actions that take the financial, emotional and nursing pressure off family caregivers are required. In particular, measures are needed to reconcile paid employment and caregiving activities with, among others, employers. Any threat to pension or social security rights must be prevented.*

46 Sottas

47 Berthod

48 Schimmelmann

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## PRISON

The tendency towards longer prison sentences, an aging population, and the growing number of people in prison has resulted in a greater frequency of inmates dying in prison. Typically, death among inmates occurs according to three scenarios<sup>49</sup>:

1. *Following good behaviour and minimal risk of reoffending, inmates who are dying are released on parole to die in “freedom”.*
2. *Based on their poor condition, they are transferred to a specialised institution, such as a hospice, where they can receive visits from their family and die in “semi-freedom”.*
3. *Inmates who suffer a health crisis go into the prison hospital and die there in “unfreedom” – that is, while still interned.*

The possibilities at the end of life are largely restricted in prisons. Inmates have little say in their care at the end of life. This situation is due to the limited possibilities available or granted in prison or a correctional facility. These institutions are not equipped to deal with long-term care and are focussed more on confinement, surveillance and re-socialisation. In order to allow for people to die with dignity in prison, institutions must undergo a change in attitude to end-of-life treatment and adapt their infrastructure. Penal system policy needs to more actively include the subjects of aging, illness and involving inmates in end of life decisions<sup>50</sup>.

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## ASSISTED SUICIDE

It is broadly believed that people who make use of assisted suicide have reached this decision autonomously as a result of terminal illness or when suffering unbearable pain. From the philosophical point of view, however, autonomy encompasses more than this.<sup>51</sup> The criteria for autonomy are fulfilled if a person: a) decides “authentically”, that is, without pressure; and b) is “minimally competent”, meaning that he or she knows what he or she is deciding and associates it with his or her own values. The decision in favour of assisted suicide does not create an obligation for anyone to help the person concerned, but simply grants him/her permission to do so.

Who are the people who made use of assisted suicide? Between 1985 and 2013, a total of 3 666 assisted suicides were documented forensically.<sup>52</sup> The majority of those who chose assisted suicide, just about three-fifths, were women. At the time of their deaths, they were between 18 and 105 years old; the median age of 73 years shows that most of them were of advanced age. Among those over 65, the women were more likely to be widowed or divorced compared to the men. Half of those who wanted to end their life came from abroad. Approximately half of the Swiss citizens who wanted to end their life lived in the Canton Zurich; a quarter came from the area around Lake Geneva, and another quarter

49–50 Hostettler

51 Schaber

52 Bartsch

came from other areas in Switzerland. Assisted suicide is an urban phenomenon.

As a rule, these people were suffering from at least one severe illness: those from Switzerland from tumour-related illnesses and age-related diseases; those from abroad suffered more frequently from neurological diseases. Based on a review of the files, they had the following reasons for wanting to end their life (in descending order of importance): physical complaints, loss of important bodily functions, inadequate pain management, loss of quality of life, increasing need for care, desire for autonomy and death with dignity. In addition, weariness of life, care dependency, isolation, therapy-fatigue and the feeling of being a burden to others also played a critical role.

53 Bartsch

54 Rüttsche

New legal regulations on assisted suicide have been under discussion for years. Only half of all cases of suicide that were reported to the Federal Statistical Office between 1985 and 2013 were investigated forensically.<sup>53</sup> There was, therefore, no satisfactory legal control, and the protection of autonomy and right to life were inadequately regulated. One of the possibilities under discussion was that legislators should be restricted to procedural regulations: to evaluate decision-making capacity according to civil law as well as medical clarification and counselling; and, to fulfil the administrative requirements for assisted suicide and compliance with legal requirements (organisational and personal requirements, supervision and measures).<sup>54</sup>

**RECOMMENDATION 7** *To establish monitoring of decisions and practices at the end of life*

*Decisions and practices at the end of life have changed considerably in recent years. There are also regional and cultural differences. Little is known about how dying patients and their relatives are included in important decisions at the end of life. A monitoring system throughout Switzerland would make it possible to better recognise developments and implement the necessary measures.*





Results 2.4

## **ETHICAL, LEGAL AND POLITICAL QUESTIONS**

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Decision-making capacity

Autonomy and protection

Dealing with deep sedation

## 2.4 ETHICAL, LEGAL AND POLITICAL QUESTIONS

**Decisions taken at the end of life are frequently the subject of ethical reflections and legal regulation. Political debate, public discussion and scientific reflection are in particular required for this regulatory aspect.**

### DECISION-MAKING CAPACITY

When is someone nearing the end of his/her life no longer capable of making decisions? Answers to this question were relevant well before the new law on the protection of adults came into force.<sup>55</sup> This issue has now acquired central importance in terms of most patient rights and the determination of the patient's will. There are no standards to determine decision-making capacity; many physicians feel overwhelmed by this task or feel they lack the necessary expertise. Just finding consensus on a definition is problematic; the criteria in particular are controversial.

International guidelines have a bias towards cognitive aspects and tend to minimize the significance of emotional statements made by patients.<sup>56</sup> When determining a patient's decision-making capacity, the consequences of moral attitudes (for example, how controversial issues such as assisted suicide are assessed) and value orientation (for example, how certain physical disabilities are viewed) should be taken into consideration. If the significance of these is underestimated or ignored, there is a danger of paternalistic decision-making. For example, a physician may doubt a patient's decision-making capacity if the latter expresses, from the physician's point of view, a morally questionable wish.

When interpreting advance directives, emotional and normative-judgmental aspects – typically perceived as “irrational” – are only minimally taken into consideration. In connection with the NRP 67 results, the Swiss Academy of Medical Sciences is currently working on basic principles that should address the complexity of the issue of decision-making capacity, along with practical information as to how it can be approached in the medical and nursing context.<sup>57</sup> The researchers who dealt with the question of decision-making capacity are of the opinion that, in this regard, the law on the protection of adults does not currently need to be adapted.

### AUTONOMY AND PROTECTION

Regarding the question as to whether the adult protection law needs to be adapted, a NRP 67 jurisprudential study came to a different conclusion.<sup>58</sup> This study addressed the determination of the limitations on patient autonomy. As this final phase of life is often characterised by dependency, pain, and uncertainty, legislation that is exclusively oriented to the ideal of a well-adjusted patient is unrealistic. New legislative concepts need to be found that meet the ideal of patient autonomy as well as the needs of patients for protection

55–57 Biller-Andorno

58 Aebi-Müller

and care. Patient representatives are often overwhelmed and rely on the support of specialists when taking decisions. It is thus legally unclear whether the job of a patient representative is to represent the “presumed wishes” of the dying patient – a subjective parameter – or his or her objective interests, regardless of the representative’s own wishes. The law on the protection of adults currently lists both criteria without explaining how one pertains to the other.<sup>59</sup>

How such a new approach to and reformulation of the law on the protection of adults might look in clinical practice – for example, how the concept of the presumed will of a patient could be extended or replaced – needs to be explored in more depth. The study proposes the creation of a patient information law that would allow easier access for both patients and those treating them to statutory provisions. The law currently only recognises decision-making capacity and diminished responsibility. The introduction of intermediate steps could be considered.<sup>60</sup> A further legal change could be to permit Advance Care Planning with patient representatives in order to implement the “presumed will” of the severely ill and dying patient.<sup>61</sup> However, if it is only put into motion when the final steps of the process of dying have already begun, it is normally too late, either because the patient is no longer capable of making decisions or because emergency measures need to be taken that can no longer be fully discussed due to time pressures.

59–60 Aebi-Müller

61 Krones, Aebi-Müller

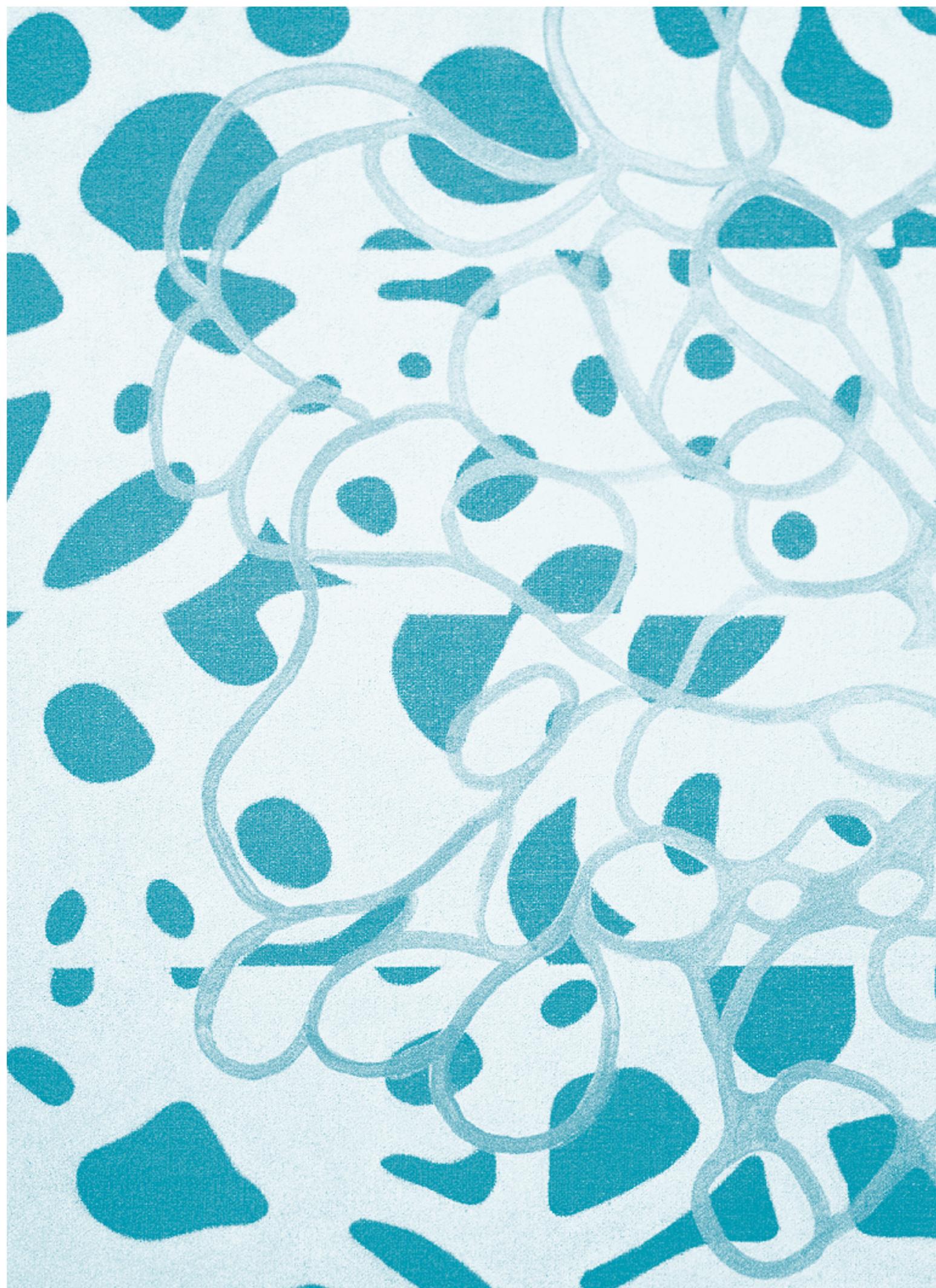
62 Puhan

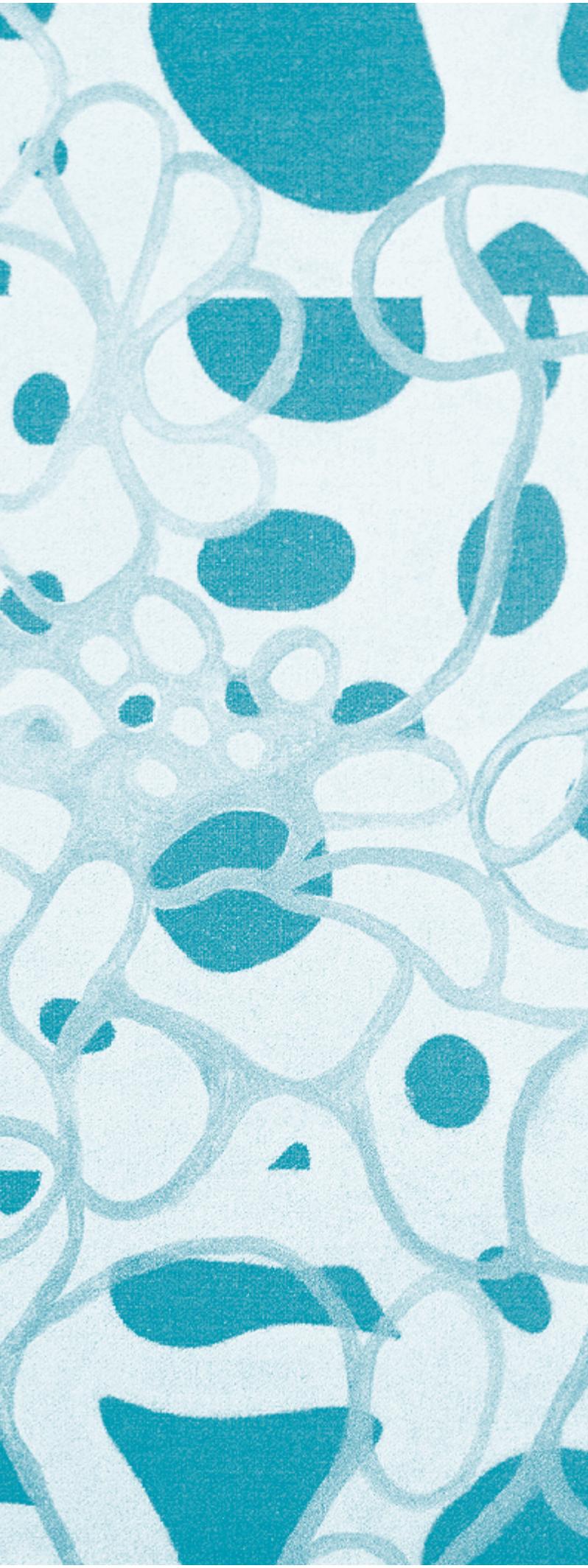
#### **RECOMMENDATION 8 To clarify the basic criteria of the adult protection law**

*Establishing whether a patient has no “decision-making capacity” has serious consequences for him or her. The criteria used must therefore be clarified precisely. The same applies to the criteria established in the adult protection law concerning “presumed will” and “objective interests” of the dying that also need to be respected. These provisions require more detailed clarification, the results of which are to be taken into consideration during a potential revision of this law.*

#### **DEALING WITH DEEP SEDATION**

Many patients die in a state of deep sedation.<sup>62</sup> As inducing unconsciousness that continues until the point of death is frequently accompanied by halting the intake of food and liquid, and the intention of the treating physicians might well be to deliberately end the life of a dying patient, sedation differs very little from other forms of assisted death. It is therefore necessary to determine which criteria should form the basis of such decisions and whether laws or regulation are needed.





Results 2.5

## **QUESTIONS OF MEANING, SYMBOLS AND IDEALS**

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Meaning and quality of life

Vivid experiences

Alternative religiosity

## 2.5 QUESTIONS OF MEANING, SYMBOLS AND IDEALS

**At the end of life, questions relating to the meaning of life and values frequently arise that were previously relegated to the background. The end of life has become a topic of public interest. There are, however, various principles and ideals on what constitutes a “good” as opposed to a “bad” death.**

### MEANING AND QUALITY OF LIFE

Although the ideal of self-determination in death has been accorded great significance, patients at the end of life can feel isolated as modern heterogeneous societies no longer share a general framework of spirituality. Attempts to communicate about meaning at the end of life and making choices when dying are familiar to palliative care, which clarifies the importance of spiritual aspects for modern medicine.

63 Borasio

64 Compare with Monod

65 Death narratives are stories that the dying tell about themselves in which they recount their situation and how they feel from a subjective point of view.

66 Gudat

From a survey of 200 dying patients, it emerges that spiritual wellbeing and having meaning in life positively influence the subjective experience of quality of life.<sup>63</sup> In this context, “spiritual wellbeing” acts like a protective shield against fear, depression and the wish to speed up the dying process. Correspondingly, dying patients who experience spiritual wellbeing less frequently express the wish to accelerate the dying process.<sup>64</sup>

Examination of death narratives<sup>65</sup> showed that people in palliative situations mention two aspects with particular regularity: the ideal of being able to accept their own death and the negative feeling of being a burden to others.<sup>66</sup> For those at the end of their life, “acceptance of death” is not always understood in the same way. It can be understood as a strategy of preparation for death. It can also be based on specific spiritual or moral precepts, or simply be a basic attitude towards life or destiny.

The feeling of being a burden to others often occurs in people who are seriously ill and is based in only a very limited fashion on the degree of care and support received. If a dying patient feels he or she is a burden on others, this can also be interpreted in various ways. It may mean that a patient worries about stopping others from sleeping or taking up too much of their private time. It can also include concerns about having become an emotional or financial burden on others. The feeling of being a burden to others is also linked to feelings of guilt, shame, anger and self-hate, and to feelings of worry or love for those to whom one is closest. This applies to the person who is sick as well as to his/her close family. Relatives seem to do everything within their might so that sick relatives do not feel they are a burden. Negatively perceived feelings like despair, hate or anger can reinforce the wish to die. And to further complicate matters, patients may also worry that expressing a wish to die will create another burden on their families.

An analysis of the notions of a good death, as expressed within the context of palliative care, also shows that factors such as self-determination, one's own wishes, control of pain and symptoms, maintenance of quality of life, leave-taking or reconciliation, communication and awareness are highly rated. Dying patients who reject these ideals are under pressure to justify themselves, while others cannot realize these ideals because they are children or suffering from dementia.

67 Bühler

**RECOMMENDATION 9** *To promote open discussion about death and dying in daily clinical practice and in care homes*

*An important condition of making a good decision or avoiding inappropriate medical treatment at the end of life is being able to speak openly about death and dying. In institutions, the foundations need to be laid for a culture of open discussion. This requires among others: the availability of suitable rooms for private discussion, recognising “narrative medicine and care”, and providing the time necessary for education and continuing education for the professionals involved to improve their skills in talking to the dying and their families.*

### VIVID EXPERIENCES

Another project confirmed the supposition that, when near death, images and narratives contribute to self-interpretation and self-orientation, and these can to a certain extent absorb the menacing loss of orientation and speech.<sup>67</sup> The frequency and meaning of vivid experiences on the part of dying patients in dreams, from waking and sleeping visions, or from near-death experiences are normally underestimated and are often perceived as a form of delirium in daily clinical practice. They are, for example, pathologised and regarded as a problem to be treated; rarely as an opportunity to be made use of.

In contrast, it was shown that such phenomena are, or at least can be, of great significance to those who are dying. That is why it is important to sensitise those who care for the dying to the variety of vivid experiences, and their significance to the dying and those close to them. This means creating space for these narratives in which the vivid experiences can be expressed and calmly listened to. As a rule, the dying individual interprets his or her own experiences so that no expertise is required in order to enable this space. These experiences as death approaches can be used as a positive resource,

whether to provide comfort, as a creative life-giving force, as a possibility to create some distance to one's own condition or to help in processing difficult experiences.<sup>68</sup>

### ALTERNATIVE RELIGIOSITY

The importance of alternative forms of religious ideas and practices<sup>69</sup> is increasing. The loosening of ties to the church and the emphasis on individuality are leading to the spread of new ideas concerning death and dying. Conventional, Christian-influenced ideals relating to a "good death" are disappearing. The dominant ideal of self-determination is leading to the aspiration of arranging and managing one's own death "spiritually".

68 Bühler

69 The term "Alternative forms" refers to ideas and practices that do not belong to the traditional repertoire of Christian and other religious communities.

70 Lüddeckens

Alternative religiosity and spirituality are widespread – as shown in studies undertaken in six institutions (four hospitals, one hospice, and one old people's nursing home, of which two are anthroposophical institutions) and interviews with dying patients, nursing staff, physicians, psychologists and pastoral care workers.<sup>70</sup> These ideas and healing practices are in part openly discussed and carried out. With some patients, however, they are only discussed in private conversation and carried out in secret if they represent a taboo subject in an institutional setting. While the range of ideas and practices observed is very broad, they reflect a common desire to enable a peaceful death.

Many of the employees interviewed would welcome seeing these practices dealt with more openly than is the case today in the majority of the institutions studied. Pastoral support from established religions is generally felt to provide relief, but only on the condition that the dying patient agrees to it, and that those offering this support have the necessary time and capabilities to deal with spiritual matters.

Unlike the other institutions under scrutiny, the anthroposophical institutions have a broad range of courses of action that can be called upon. The role of the physician is also perceived differently there: from the point of view of patients, physicians spend more time with them compared to other hospitals, and the personal connection between patients and physicians is also very strong. The openness of the anthroposophical medical fraternity to religion and spiritual matters are also perceived very positively by patients who are dying.

**RECOMMENDATION 10** *To strengthen whole-system care at the end of life*

*The quality of life of dying patients is influenced not only by physical limitations. During the final phase of life, social, mental and spiritual aspects – relating to the meaning of life and religiosity – are also significant. When caring for the dying and those close to them, all these aspects should be taken into consideration without patronising them or imposing particular ideals.*





Results 2.6

## **END-OF-LIFE RESEARCH**

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## 2.6 END-OF-LIFE RESEARCH

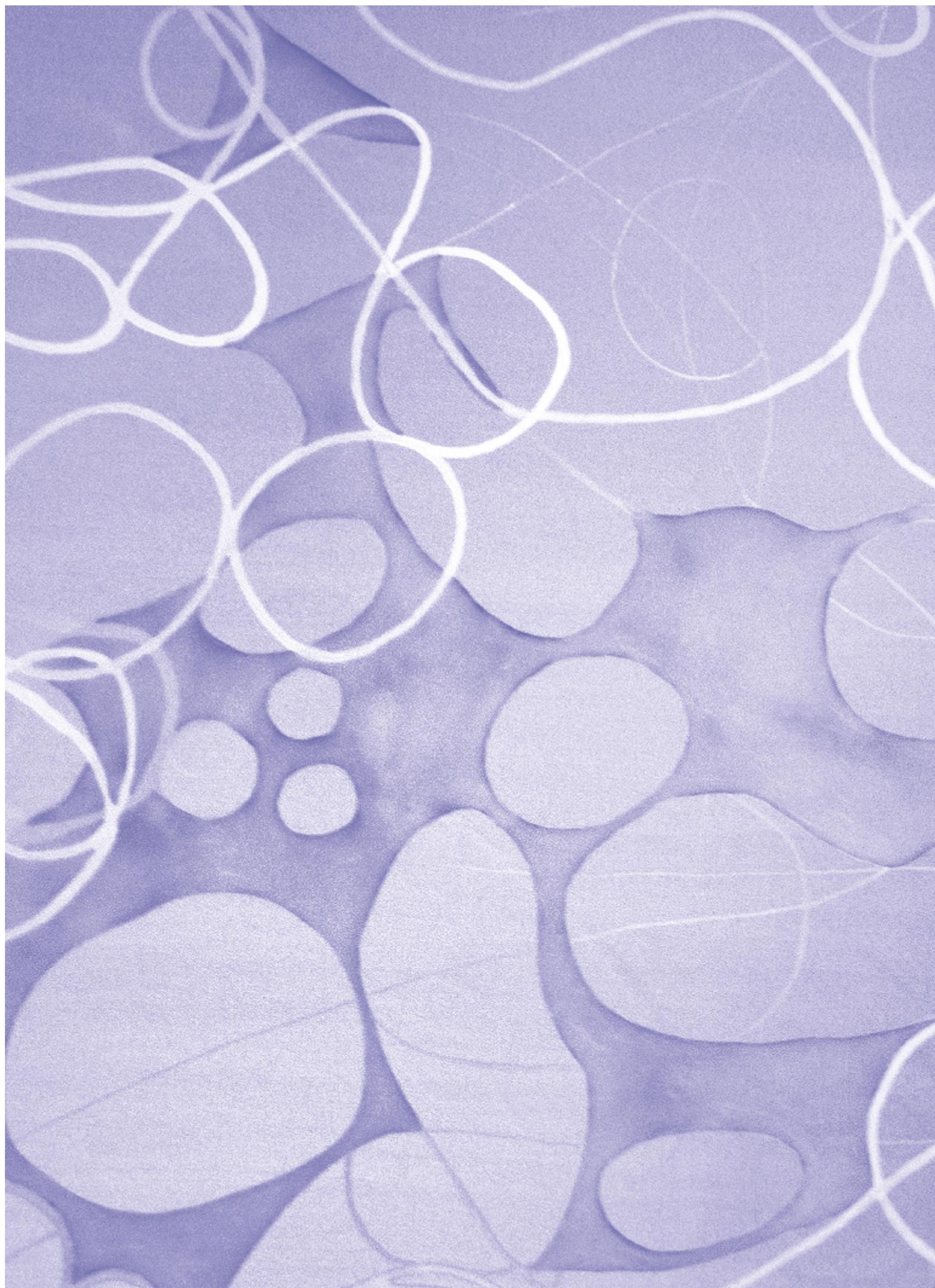
**In comparison with other European countries and North America, limited research has been conducted in Switzerland into the varied issues associated with the end of life. NRP 67 supported projects from various disciplines: medicine (epidemiology, neonatology, paediatrics, medical jurisprudence and palliative medicine, pneumology, geriatrics, psychiatry, and medical ethics), social work, health science, religion studies, law, sociology, anthropology, philosophy, theology, special education, health economics, and psychology. In doing so, the NRP is advancing the development of a research community.**

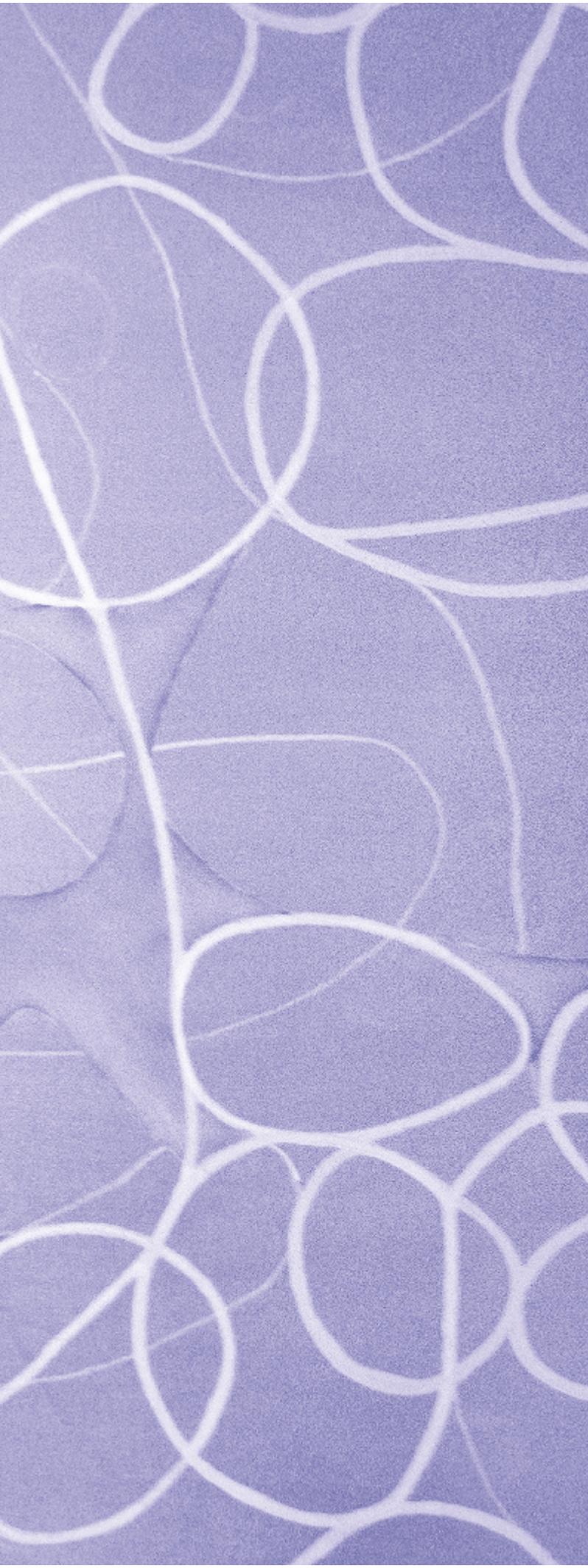
Three points should be noted:

- 1. NRP 67 researchers should continue to develop this knowledge as part of their career path. This means that the institutions responsible for supporting research should create the right conditions for researchers to use their expertise to formulate further projects and apply for grants.*
- 2. Establishing “end-of-life research” should first of all, in terms of content, focus on the influence of costs on difficult decisions and the quality of care at the end of life, and follow up on further questions relating to the fair distribution of resources at the end of life. Secondly, self-determination must be examined in greater depth in ethical and sociological terms with a focus on the distortion of the ideal of autonomy into social pressure, and also in legal terms by contributing in greater depth to the pending discussions on the law on protection of adults. Key words are: care planning, continuous deep sedation and assisted suicide. Thirdly, questions regarding education, training and continuing education as well as professionalization must be looked at in greater depth in terms of qualifying specialists and focussing on the educational system as well as sensitising the population.*
- 3. Special support must be given to research into palliative care. This refers to traditional research in medical sub-disciplines and other disciplines beyond medicine, such as nursing science, social work, psychology, philosophy and religious studies, and also to the trans- and post-disciplinary areas of science where researchers from various scientific disciplines work together closely across disciplines. With a view to developments in other high-wage countries around the world, it is safe to predict that this area of research will play a major role in the future.*

**RECOMMENDATION 11** *To recognise and establish end-of-life research*

*In the face of current and expected demographic changes, care for the dying is set to become much more important. Also, in recent years, an institutionalisation, professionalization, medicalisation and juridification of the end of life has been observed. For this reason, it is imperative to recognize and intensify end-of-life research. It contributes to understanding changes better, to assessing the consequences in terms of medical, political, economic and legal issues, and to promoting social engagement with the end of life.*





3.

## **RECOMMENDATIONS OF NRP 67 AT A GLANCE**

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## TO ENABLE DYING WITH DIGNITY SHOULD BE A FUNDAMENTAL SOCIETAL AIM

Society's most important goal in how we deal with dying should be to ensure that people die with dignity. Respecting the dignity of the dying means to respect individual freedom and self-determination, to protect human life that is particularly vulnerable, and to treat all those at the end of their life equally – regardless of social status and individual characteristics.

### RECOMMENDATION 1

#### ***To promote coordinated and cooperative care***

*The transition from one institution to another or back home is often difficult for people at the end of their life because cooperation between the services and responsible institutions is inadequate or poorly interconnected. In order to guarantee continuity of care and treatment, more coordinated regional networks need to be created and developed. In addition, referring physicians and relatives should be increasingly involved in the transitional phase. An alternative would be to establish broad-based institutions for basic care that integrate acute medicine, rehabilitation, geriatrics, psychiatry, and long-term and palliative care under one roof.*

### RECOMMENDATION 2

#### ***To ensure the best possible quality of life for those who are dying***

*Having the best possible quality of life when dying is as important as curing diseases and extending life. Palliative (offering relief) measures must be increasingly established alongside curative (having a healing effect) treatments. It is therefore imperative that palliative care – treatment that offers relief and physical comfort – be included in every area of education, training and continuing education for healthcare specialists.*

**RECOMMENDATION 3*****To enforce principles of medical ethics***

*Even when capable of making decisions, patients are not always included in important end-of-life decisions. This contradicts current legislation as well as ethical principles. Institutions and professional associations need to take steps to promote policies which aim to ensure that self-determination is respected and promote the practice of shared and informed decision-making.*

**RECOMMENDATION 4*****To improve coordination and communication in hospitals***

*In hospitals, patients who are dying are often kept on different wards and treated and cared for by different staff members. Constant changes in personnel as well as a lack of coordination heighten fear and insecurity in those who are dying and can lead to conflict and poor decisions. Coordination and communication therefore urgently need to be improved.*

**RECOMMENDATION 5*****To address the needs of dying individuals who are particularly vulnerable***

*At the end of life, the needs of particularly vulnerable individuals such as children, young people or those with cognitive disabilities should be given particular attention. It is important to create the necessary infrastructure for this and to make available the necessary professional resources.*

**RECOMMENDATION 6*****To recognise the significance of the care provided by relatives and acknowledge their needs***

*Family caregivers can lighten the burden on the healthcare system, and in so doing, lessen the risk of inappropriate treatment for the dying. Political decisions on actions that take the financial, emotional and nursing pressure off family caregivers are required. In particular, measures are needed to reconcile paid employment and care-giving activities with, among others, employers. Any threat to pension or social security rights must be prevented.*

**RECOMMENDATION 7*****To establish monitoring of decisions and practices at the end of life***

*Decisions and practices at the end of life have changed considerably in recent years. There are also regional and cultural differences. Little is known about how dying patients and their relatives are included in important decisions at the end of life. A monitoring system throughout Switzerland would make it possible to better recognise developments and implement the necessary measures.*

**RECOMMENDATION 8*****To clarify the basic criteria of the adult protection law***

*Establishing whether a patient has no “decision-making capacity” has serious consequences for him or her. The criteria used must therefore be clarified precisely. The same applies to the criteria established in the adult protection law concerning “presumed will” and “objective interests” of the dying that also need to be respected. These provisions require more detailed clarification, the results of which are to be taken into consideration during a potential revision of the adult protection law.*

**RECOMMENDATION 9*****To promote open discussion about death and dying in daily clinical practice and in homes***

*An important condition for making a good decision or avoiding inappropriate medical treatment at the end of life is being able to speak openly about death and dying. In institutions, the foundations need to be laid for a culture of open discussion. This requires among others: the availability of suitable rooms for private discussion, recognising “narrative medicine and care”, and providing the time necessary for education and continuing education for the professionals involved to improve their skills in talking to the dying and their families.*

**RECOMMENDATION 10*****To strengthen comprehensive care at the end of life***

*The quality of life of dying patients is influenced not only by physical limitations. During the final phase of life, social, mental and spiritual aspects – relating to the meaning of life and religiosity – are also significant. When caring for the dying and those close to them, all these aspects should be taken into consideration without patronising them or imposing particular ideals.*

**RECOMMENDATION 11*****To recognise and establish end-of-life research***

*In the face of current and expected demographic changes, care for the dying is set to become much more important. Also, in recent years, an institutionalisation, professionalization, medicalisation and juridification of the end of life has been observed. For this reason, it is imperative to recognize and intensify end-of-life research. It contributes to understanding changes better, to assessing the consequences in terms of medical, political, economic and legal issues, and to promoting social engagement with the end of life.*

## A PORTRAIT OF NRP 67

In recent years, dying has become a topic of public interest. Advance directives, palliative care, assisted suicide, caring for dying relatives or taking decisions about treatment at the end of life are issues that concern many individuals and institutions. Discussions on these topics are characterised by very different visions and ideals. NRP 67 contributes to a better understanding of this final phase of life. It identifies gaps in care, makes guidelines for decision-making available to patients and staff, and reflects on ethical implications. NRP 67 began in 2012 with funding of 15 million Swiss francs and closed in 2017.

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### FURTHER INFORMATION

Information on the findings of each project and their publications is available on the NRP 67 website: [www.nrp67.ch](http://www.nrp67.ch)

## THE NRP 67 RESEARCH PROJECTS

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### AEBI-MÜLLER

#### **Self-determination at the end of life**

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### BALLY

#### **Quality of end-of-life care from the perspective of general practitioners and family members**

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### BARTSCH

#### **Assisted suicide: developments over the last 30 years**

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## BECK

### **Priceless? The value of health care at the end of life**

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PD Dr. Viktor von Wyl, Institut für Epidemiologie, Biostatistik und Prävention, Universität Zürich

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## BERGER

### **End-of-life decisions for extremely preterm infants in Switzerland**

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### **Supporting a dying relative: between working and end-of-life care**

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### **Assessing decision-making incapacity at the end of life**

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### **Meaning in life, spirituality and personal values at the end of life**

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### **Imagination and communication of trust at the end of life**

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### **Regional differences in medical care at the end of life**

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### **End-of-life decision-making in paediatric oncology**

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## ESCHER

### Factors in intensive care unit admission decisions

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## EYCHMÜLLER

### Active preparation for the end of life with patients with advanced cancer:

#### A way to reduce stress and increase self-determination?

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## FAUCHÈRE

### Extremely preterm infants born at the limit of viability:

#### factors in decision-making

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### **Dying at the beginning of life**

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## GUDAT

### **The wish to die in persons with serious illness**

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### **Cost at the end of life from an economic perspective**

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### **Access to palliative care for patients with chronic obstructive pulmonary disease (COPD)**

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### **Pathways of end-of-life care of the elderly with multimorbidity**

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### **Alternative religiosity and its consequences at the end of life**

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## PUHAN

### **Medical end-of-life decisions: prevalence and trends in Switzerland**

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## RÜTSCHÉ

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### **Self-determined death? Assisted suicide and autonomy**

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## SCHIMMELMANN

### **Facing the loss of a parent – how is institutional support interiorised?**

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### **Family caregivers in critical end-of-life situations**

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### **Communication skills in end-of-life care**

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### **How do persons with advanced dementia experience the end of life?**

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## ZNOJ

### **End of life and diversity in nursing homes**

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