

Medical-ethical guidelines: Care and treatment of people with dementia

Swiss Academy of Medical Sciences (SAMS)

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I. Preamble

The number of people with dementia¹ in Switzerland is currently around 150,000. The prevalence of this condition rises steeply after the age of 65. As a result of demographic changes, the number of people affected in Switzerland is thus expected to increase markedly over the coming decades.

The course of dementia – which frequently occurs in combination with chronic somatic and/or mental disorders (multimorbidity) – is often protracted and is difficult to predict. Cognitive impairments mean that self-determination and alleviation of symptoms are more difficult to achieve in everyday practice. People with severe dementia generally lack capacity, and decisions then have to be made by representatives on the basis of the patient's previously expressed or presumed wishes.

The management and care of patients may be complicated by disease-related behavioural disturbances.

The public, as well as the individuals affected, are fearful of the loss of independence and possible changes in personality associated with progressive dementia; in addition, people are often afraid of becoming a burden on their relatives² or society. Against this background, difficult decisions and significant ethical conflicts are not unusual – all the more so since life with dementia runs counter to guiding values, such as independence, productivity and rationality, which are central to our society.

The aim of these guidelines is to offer practical guidance for dealing with ethical conflict situations relating to the care and treatment of people with dementia. Specific issues are addressed which may ultimately arise for all those involved in dementia care, irrespective of the setting (domestic, hospital, residential) and professional group. Which of these ethical issues is the most salient will depend largely on the stage of the condition. Once the condition has been diagnosed, management should be based on the principles that are also applicable, for example, in palliative care: a focus on quality of life, equality of care, interprofessional collaboration and continuity, open and appropriate communication, support for decision-making processes, anticipation, a multidimensional approach³, and involvement of those close to the patient.⁴

These guidelines were prepared in cooperation with the Swiss Society of Gerontology (SGG SSG) as part of the National Dementia Strategy 2014–2019 (subproject 5.1: “Establishment of ethical guidelines”).⁵

II. Guidelines

1. Scope of the guidelines

The present guidelines are addressed to physicians⁶, nurses and therapists caring for patients with a persistent disease-related loss of cognitive abilities (dementia).

However, as topics falling outside the medical field are also covered, the guidelines may also, if necessary, provide a starting point for guidance for non-medical⁷ professions.⁸

2. Definition and stages of dementia

2.1. Dementia

The term “dementia” describes a syndrome which may be caused by various underlying diseases. The common feature is the occurrence of one or more cognitive deficits in various areas (attentional and executive functions, learning and memory, language, higher perceptual and motor functions, social cognition), which were not previously present and which persist even in the absence of delirium. These deficits lead to a reduced ability to perform (at least complex) daily activities and are generally accompanied by changes in social relationships and often fluctuating emotional and behavioural disturbances. A dementia syndrome may be due to neurodegenerative diseases (e.g. Alzheimer's disease, dementia with Lewy bodies/ Parkinson's disease dementia, frontotemporal dementia), but also to certain vascular diseases (vascular dementia), external insults (e.g. chronic alcohol abuse) and many other factors. Primary psychiatric disorders such as depression or psychoses are, by definition, not classified as dementia, even though they may give rise to similar symptoms in individual cases (particularly over the longer course).

2.2. Stages of dementia and stage-specific ethical issues

Dementia is generally a progressive condition. Various stages are distinguished, depending on the extent to which activities of daily living are impaired.⁹ The ethical issues raised by dementia vary according to the stage of the disease.

Mild cognitive and/or behavioural disturbances, especially at an advanced age, may possibly – but by no means necessarily – be harbingers or early signs of dementia. Here, the question arises to what extent screening or early diagnostic efforts should be intensified.

When the diagnosis of mild dementia has been confirmed, the focus is on helping the patient and relatives adapt to the new situation and expected future developments. The shared goal is to preserve the patient's independence for as long as possible. At this stage of dementia, patients themselves are often aware of their cognitive decline, which may lead to depressive symptoms or even a desire for suicide.

In moderate dementia, it becomes more difficult for the patient – even with support from relatives – to maintain activities of daily living. Increasingly, professional support is required (GP, domiciliary care service, etc.). Behavioural and emotional disturbances can become burdensome for people with dementia – and frequently even more so for their relatives. In addition to non-pharmacological interventions (e.g. adjustments to the environment, daily routines and communication), psychotropic drugs or measures restricting freedom of movement are commonly employed. Often, it is advisable for the patient to be transferred to a residential care institution.

In severe dementia, only minimal verbal communication is possible, relatives are often no longer recognised, and the patient generally requires assistance in all areas of daily life. Behavioural and emotional disturbances persist, but because of the patient's reduced vitality and mobility, these are often perceived by others as less distressing than in moderate dementia. The focus now increasingly shifts towards end-of-life issues (management of nutrition and hydration, possible withholding of life-extending measures, accompaniment of the dying patient).

3. Principles

3.1. *Respect for dignity*

Dignity is intrinsic to human beings and involves a fundamental right to respect. It is present irrespective of a person's physical, mental or psychological impairments. Thus, as it is not subject to conditions, it cannot be lost.

The dignity of people with dementia must always be respected and protected. In situations of infirmity and dependence – for example, in the case of progressive dementia – the risk of failing to respect the dignity of the person concerned is particularly acute.

For those who provide care and treatment for people with dementia, being guided by the principle of respect for dignity means, in particular:

- recognising each patient's uniqueness and treating them as individuals;
- in their behaviour and in any type of communication, taking account of the patients' particular vulnerability;
- treating them with respect, empathy and patience;
- taking their religious and cultural background seriously;
- not judging the value of their life by the conventional criteria of society, but acknowledging its intrinsic value.

Respecting people's dignity also entails respecting their claim to autonomy, even where the capacity for autonomy has been lost as a result of dementia.

3.2. *Respect for autonomy*

In exercising their self-determination, people with dementia are to be protected and supported as far as possible. To what extent self-determination is possible – for example, in choices concerning living arrangements and care or treatment – will depend not only on the social environment but also, crucially, on the stage of disease and any other coexisting conditions. While people in the early stages of dementia can generally be assumed to retain the capacity for self-determination, the progressive decline in cognitive functioning increasingly deprives patients of the ability to act autonomously. In advanced stages of dementia, autonomy is to be respected by enabling participation. This also includes giving appropriate consideration to non-verbal expressions of preferences and desires.

3.2.1. *Capacity*

A person with dementia who has capacity is entitled to refuse interventions that are medically indicated. Decisions concerning treatment which appear to be irrational do not in themselves justify an assumption of incapacity, although they may provide evidence thereof. An assessment of capacity for the specific decision-making process may then be required.

Not only cognitive but also emotional, motivational and volitional¹⁰ factors are relevant for the patient's capacity, comprising the following categories of mental abilities: (1) the ability to grasp at least the fundamental aspects of the decision-making situation, and to draw conclusions about possible consequences; (2) the ability to accord a personal and appropriate meaning to the decision-making situation; (3) the ability to make one's own, authentic decision; (4) the ability to communicate, justify and consistently defend this decision.

Capacity is always to be assessed in relation to a specific decision. In a person with dementia, it may be retained e.g. for straightforward interventions and everyday care measures, dietary preferences, etc., when it has already been lost for matters of greater complexity and significance (e.g. conclusion of a care agreement). In all cases, it should also be assessed whether a choice has been made voluntarily and in the absence of external pressure. If capacity is no longer present, the decision in question must be made by a representative on behalf of the person with dementia.

When capacity is assessed in people with dementia, any concomitant mental disorders (e.g. depression) also need to be taken into account. Also to be considered is the fact that people with dementia often display a lack of insight into their condition (anosognosia), which may in particular impair their capacity with regard to medical and care measures. An additional challenge is presented by the marked cognitive fluctuations that may accompany certain forms of dementia (e.g. Lewy body dementia, vascular dementia). In such cases, the time and setting chosen for the assessment of capacity should ensure, as far as possible, that the patient feels comfortable and is in the best possible state. Here, information provided by relatives or carers may be helpful.

3.2.2. *Patients lacking capacity*

In cases where capacity is lacking, so that the person with dementia can no longer make a decision on a specific matter in an autonomous manner, the patient's wishes and values remain of central importance for the relatives and care providers. If the patient's wishes have been expressed in the context of care planning, in an advance directive¹¹ or in a power of attorney, these are decisive for the treatment and care team. In the absence of any such document, the persons representing the patient¹² must make decisions in accordance with the latter's presumed wishes, i.e. as the patient would probably have decided if he or she had still been able to do so autonomously. Indications of presumed wishes may be provided by earlier (verbal) statements concerning wishes and values, as well as current desires, preferences and behaviour. In the absence of any indication of presumed wishes, decisions are to be guided by the patient's objective best interests. If there is any doubt in this regard, a decision is to be made in favour of preserving life.

3.2.3. *Participation*¹³

Participation (also known as "patient engagement") means being able – in spite of chronic illness or disability – to exercise control over one's own life through individual or collective activities. The principle of participation is also of great importance for people with dementia. In the early stages of dementia, patients can still formulate their wishes and needs themselves, but they require support in fulfilling them.

Possibilities for participation – irrespective of the degree of capacity of the person with dementia – are subject to a process of understanding and agreement between the patient, relatives and health professionals. This may consist of trying things out and/or involving relatives in discussions and negotiations. If verbal communication is restricted or no longer possible for the patient, it is essential to pay particular attention to non-verbal and paralinguistic (pitch, intonation, etc.) modes of expression. Important information about the patient's needs can be elicited by communicating in a straightforward manner and attending to non-verbal signals of well-being – positive (appetitive) responses – or discomfort – negative (aversive) responses. Thus, especially in advanced stages of dementia, the promotion and realisation of participation calls not only for expertise on the part of health professionals but also sufficient time and financial/structural resources.

3.3. *Quality of life/well-being*

Objective factors such as physical health, independence, social participation, meaningful daily activities, experiencing respect and appreciation, engagement in activities of daily living, and good living conditions are important requirements for a good quality of life in people with dementia. Ultimately, however, quality of life does not arise from these objective conditions, but from the subjective evaluation thereof. For this reason, a person-centred arrangement of the living environment, tailored to individual needs, is crucial for people with dementia.

Depending on the disease stage, the person with dementia can help to shape this living environment to a greater or lesser extent. Here, the mobilisation of resources which are still available can be stimulating, while being confront-

ed with one's own inability can impair the quality of life. As dementia progresses, the person concerned increasingly loses the capacity for looking ahead and planning. The present may become less significant, and the person's past experience may become the subjective present.

When patients are no longer able to express themselves, attentive supervision is required to ascertain what they are experiencing. This calls for both observation and empathy. The development of such relationships is essential to the effective management of people with dementia. Care personnel should also be aware of the risk of projecting their own prejudices and wishes. The quality of life of relatives and carers is often closely linked to that of the patient. It should be explicitly discussed and separately assessed.

Among the factors contributing to healthy human relationships are truthfulness and respect. Communication guided by the principle of truthfulness avoids the deliberate use of falsehoods to mislead and manipulate, even if this would be possible. A respectful manner preserves the quality of a relationship between partners on an equal footing, despite differences in their respective resources and ability to exert influence. Truthfulness and respect are also crucial fundamental attitudes in the management of people with dementia.

Here, however, the difficulty arises that people with severe dementia develop their own perception of reality. They then live in a world of their own, which for them is real, but which represents a different kind of reality than that of the world around them. Given this tension, the aim should be to respect the perception of reality which is peculiar to people with dementia rather than constantly correcting them by pointing out the "correct" reality of those who are not demented. When communicating with people with dementia, truthfulness and consideration require engagement with their perception of reality and the associated emotions – for example, through *validatory*¹⁴ methods of interaction.

3.5. *Quality of care and treatment*

Since, as dementia progresses, the ability to control one's own life is increasingly lost, quality of life is decisively influenced or determined by the quality of care. High-quality care supports a good quality of life. The aim of such care is to focus on the personhood of patients with dementia, enabling them to live their lives independently for as long as possible and to participate in social and cultural activities. Care of people with dementia should be guided by their individual biography and, at the same time, adapted to their current situation and remaining abilities. It thus preserves habits, enables patients to make decisions, and conveys acceptance and appreciation. Here, a major role is played by the organisation of daily life (e.g. activation programmes). Of crucial importance, however, is a person-centred, caring attitude on the part of caregivers and relatives towards people with dementia.

In the early stages of dementia, care is focused on helping the patient come to terms with the condition and providing support for independent living. In moderate dementia, providing support for activities of daily living and assisting autonomy become increasingly important. In severe dementia, involvement and thus participation of the patient in care measures, e.g. during meals, is more and more important. Participatory behaviour not only helps to maintain

functioning until the end of life, but also ensures that individual needs are taken into account and enables patients to experience self-efficacy in everyday life.

If the patient's capacity for verbal expression becomes severely limited, it is essential not only to review the care situation but also for caregivers and relatives to reflect critically on their own values and attitudes. They should repeatedly ask themselves whether their behaviour is genuinely guided by the needs and wishes of the care recipient, rather than their own. What is to be avoided in any case is that the actions of caregivers and relatives are determined by their fears – e.g. of the dying process and death. Observation and taking time for oneself are essential in providing dignified and respectful care for a patient with dementia as the end of life approaches.

Overall, the provision of appropriate care and treatment for people with dementia is extremely demanding. It calls for adequate numbers of well-trained professionals; at the same time, existing relationships (relatives) should be supported.

4. Decision-making processes

4.1. Communicating with people with dementia

The impairments in attention, memory, perception and capacity for verbal expression associated with dementia can make it much more difficult to communicate with the patient. Caregivers should therefore express themselves as clearly as possible, using short, simple sentences and maintaining eye contact. The focus should be on surviving cognitive abilities or daily activities rather than primarily on potential deficits.

The scope for communication depends largely on the type, stage and course of dementia. People with severe dementia are often no longer capable of verbal communication. However, they can generally perceive and appreciate non-verbal forms of expression (e.g. smiling, calm manner, gestures, gentle touching) in other people. Although the ability to express emotions remains intact until the end of life in people with dementia, their facial expressions and gestures are often less pronounced and may therefore be overlooked or misinterpreted by caregivers.

4.2. Advance care planning and advance directives¹⁵

Advance care planning (ACP) involves a process of discussion between patients (and possibly their relatives) and the health professionals concerned, in which strategies and treatment goals for anticipated situations are defined and subsequently adapted to the actual course of the disease. One aim of ACP is to ensure that the patient's perception of the disease, values, ideas and expectations of treatment, as well as spiritual needs, are ascertained before shared decision-making becomes impossible as a result of complications and/or an acute deterioration in the patient's state of health or consciousness. The measures to be taken in an emergency situation (e.g. if complications arise) should also be discussed. The discussions and the resultant decisions should be documented in writing and should be accessible to the professionals caring for the patient and to relatives. This documentation accompanies the patient on admission, discharge or transfer and is brought to the attention of the professionals responsible for further treatment.

In an acute situation, this can provide guidance and ease the burden on relatives.

Health professionals should, at an early stage, speak to patients diagnosed with dementia about the possibility of drawing up or updating an advance directive. The preparation of an advance directive is voluntary, and capacity is a prerequisite. If necessary, it must be carefully assessed. Relatives cannot prepare an advance directive on behalf of a patient lacking capacity.

If the patient lacks capacity and no directly applicable advance directive is available, the physician, in consultation with relatives or the authorised representative,¹⁶ will prepare a treatment plan. This should, if possible, be documented in writing and be updated if the need arises. In individual cases where a rapid decision is required and the representative cannot be contacted, the treatment plan provides valuable guidance for decision-making.

The right which every person has to refuse unwanted therapeutic interventions in an advance directive cannot be extended to cover care measures of all kinds. Thus, for example, an advance directive cannot stipulate that, in severe dementia, food or fluids should no longer be provided, in order to accelerate the process of dying, or that elementary care measures such as protection against cold or essential basic care should be discontinued, with the goal of succumbing to the consequences of inadequate care (e.g. due to hypothermia).¹⁷

4.3. Informed consent

Medical investigations (including establishment of a diagnosis) and treatments always require a medical indication and the patient's informed consent. The information provided must cover all the aspects that are relevant for the decision.

If a person with dementia lacks capacity, a decision is to be made by the legal representative. The latter must take into account the presumed wishes or, if these cannot be determined, the interests of the person concerned. Here, the person authorised to make the decision must be guided, not by their own outlook, experience and convictions, but by those of the person concerned. As far as possible, the person lacking capacity is to be involved in the decision-making process. If there is disagreement between different representatives, or if the representative's decision runs counter to the patient's presumed wishes or interests, then the Child and Adult Protection Authority (CAPA) is to be called in.

4.4. Decision-making within the treatment and care team

Particularly for patients with severe dementia, medical interventions and care measures often require an interprofessional decision-making process. Before such treatments or measures are proposed to a patient or representative, they should be discussed within the treatment and care team. The aim should be to arrive at a decision which can be supported by all concerned.

For difficult decisions, it may be helpful to seek ethics support.¹⁸ The application of explicit, structured ethical decision-making procedures enhances awareness and the quality of ethical reflection among those concerned and facilitates efforts to reach a consensus.

5. Areas of application

5.1. Diagnosis of dementia¹⁹

5.1.1. Dementia screening

Dementia screening in a strict sense is to be distinguished from routine screening of cognitive functions at healthcare institutions (e.g. hospitals, rehabilitation clinics, care centres).

At present, insufficient evidence is available for systematic dementia screening in asymptomatic individuals to be formally recommended. However, given the increased prevalence of dementia in people aged over 75–80, and the difficulties experienced by relatives and professional caregivers in identifying cognitive impairments, greater attention to this question is required in the case of elderly and very elderly persons. Early detection is essential if appropriate support measures are to be instituted for patients and their relatives.

Particularly important is knowledge of a patient's cognitive functions prior to a medical procedure – not only because of the need for decision-making (consent to medical treatment), but also because of the associated risk of delirium, the development of which can be effectively prevented or mitigated if the relevant risk factors are recognised in good time. For this reason, in elderly patients admitted to an emergency department, systematic screening of cognitive functions is recommended, possibly in conjunction with the screening of other functions, e.g. strength, walking ability and internal organ (kidney, heart, lung) function. Screening of cognitive functions does not in itself imply any further diagnostic dementia assessment, but is indicative of good treatment quality. Getting this message across calls for high-level communication skills on the part of the person conducting the examination: cognitive screening is often felt by patients to be degrading or disrespectful.

5.1.2. Diagnosis of dementia: timing, procedure, disclosure

Dementia should be diagnosed in a timely manner, with the aim of enabling patients and their relatives to access appropriate care and treatment. Early diagnosis and the use of pharmacological and non-pharmacological therapies can generally improve the quality of life of patients and their relatives, facilitate careful future planning (e.g. preparation of a power of attorney/advance directive), prevent crises and harmful consequences, and delay the need for care.

From a medical viewpoint, assessment of suspected dementia is indicated if the following symptoms are noticed by the patient, relatives or the attending physician or nurse:

- cognitive or behavioural disturbances;
- endangerment of oneself or others (e.g. car accidents, injuries).

The assessment can normally be carried out by a general practitioner. In younger patients and in unclear or complex situations, it should be carried out at a memory clinic or specialist practice. Patients with suspected dementia can, however, also be assessed at an acute hospital or – especially with more advanced symptoms – at a care home. In individual cases where life expectancy is limited or the pa-

tient is already dependent on care, it may be legitimate to forgo further diagnostic investigations.

In general, the assessment begins with the patient's own history and a physical examination. Subsequently, an informant history should be obtained. Depending on the situation, it may be advisable not to take this history in the patient's presence, so as to obtain conclusive information and avoid embarrassing the patient. After the history-taking, standardised cognitive testing is generally performed. If a disturbance of brain function is then suspected, imaging procedures (MRI or PET) are used to establish the cause. The determination of biomarkers and genetic testing are not indicated for routine diagnostic assessment.

If a patient who is judged to have capacity has evident symptoms of dementia but refuses to undergo further diagnostic investigations, this wish is essentially to be respected. It should, however, be borne in mind that a lack of insight into the condition (anosognosia) often forms part of dementia. If in this situation diagnostic measures and treatment are requested by relatives, consideration should also be given to their distress and need for information. In such cases, a round-table discussion involving all concerned may be helpful. If there is a risk of endangerment of self or others (e.g. driving, occupational responsibilities), notification of the authorities, or the employer, should be considered – with due regard for the provisions concerning confidentiality.

Attending physicians themselves may also be reluctant to carry out an assessment of suspected dementia, either because they wish to avoid confronting the patient with an unsatisfactory test result, or from a sense of inadequate self-efficacy, given the lack of therapeutic options available. In such cases, the patient – if so desired – should be referred to an appropriate institution.

Discussion of the diagnosis, once it has been established, is of crucial importance. For this discussion, the person with dementia should be accompanied by a close friend or relative, but whenever possible the information should be addressed directly to the patient. Disclosure of the diagnosis can trigger numerous emotions, and it is important that these should also be given adequate space and attention.

5.2. Appropriate care and treatment

5.2.1. Under- or overtreatment

People with dementia are among the groups at risk for undertreatment and/or unequal treatment within the health system.²⁰ This is partly attributable to a lack of interprofessional treatment decisions, and possibly also to cost-cutting efforts or covert rationing. The diagnosis-related flat-rate reimbursement system may also create perverse incentives. Particularly affected are people with dementia who show (sometimes severe) changes in social behaviour as a result of the condition. Management of this behaviour calls for specific skills, which make it possible to reduce situational risks of excessive strain and negative feelings. Also important in this connection for people with dementia is that delirium, or a delirious component, should always be recognised in good time, so that an overly pessimistic view of the prognosis is not taken from the outset, with potentially valuable diagnostic and therapeutic measures being withheld as a result.

On the other hand, overprovision of services can also occur, if, in advanced dementia, diagnostic or therapeutic measures are carried out which are no longer advisable in this situation – for example, the insertion of a PEG tube in severe dementia. The transfer of care home residents to hospital with medical conditions such as pneumonia or urinary tract infection usually neither reflects the patient's wishes nor is medically necessary. Early diagnosis and treatment of such conditions is also possible within the care home itself, if it has adequately trained nursing staff and well-integrated medical services. Also to be considered in such cases is the fact that hospitalisation is often more burdensome for people with dementia than for those who are cognitively intact. However, surgical problems such as a fractured neck of femur almost always necessitate hospitalisation, even in advanced dementia.

With regard to the question of transferring people with dementia to intensive care, it is particularly difficult to find a reasonable middle course between over- and undertreatment, especially in connection with delirium. The goals of such a transfer must be discussed and defined with the relatives and the treatment and care team.

5.2.2. Pain

For the assessment of pain, the patient – whenever possible – should be asked to provide a self-rating. Often, however, people with dementia are not able to verbalise or localise their pain, or to remember that they have suffered it. Evidence shows that, in dementia patients, pain is frequently not diagnosed and is undertreated. For this reason, systematic observation plays an important role. As pain may be expressed in the form of behavioural changes or disturbances, structured and (as far as possible) evidence-based instruments should be used to detect pain-induced behaviour. If there is a reasonable suspicion of pain, it is usually worthwhile to institute analgesic therapy while at the same time observing the patient's behaviour, so as to determine whether any improvement occurs in the behavioural symptoms.

5.2.3. Management of delirium

Delirium is a usually reversible acute confusional state, generally arising as a result of changes in the patient's physical condition and/or environmental factors. Delirium may manifest itself in a hyperactive or hypoactive form, with the latter being frequently overlooked. Pre-existing dementia is one of the main risk factors for the development of delirium. This makes prevention and early treatment of delirium all the more important in people with dementia.

Preventive measures include ensuring a peaceful, low-stress environment which remains as comprehensible as possible for the patient. Rapid turnover of care personnel is to be avoided. The patient's perceptual and communicative abilities should be supported (e.g. via a hearing aid, spectacles), and orientation is to be facilitated by appropriate measures. Attention should also be paid to adequate nutrition and hydration, oxygen provision, and excretion. Any pain should be treated.

If delirium occurs, the causes are to be investigated. Quite often, the assessment will reveal a previously unrecognised infection (e.g. of the urinary tract) or a metabolic disturbance which can be treated. In some patients, however, no

clear cause can be determined. In such cases, symptomatic treatment is indicated. Here, the emphasis is on non-pharmacological approaches, partly coinciding with the preventive measures. Coercive measures are to be avoided whenever possible, as they can exacerbate delirium. Medicines may be used, for example, to treat agitation.

Not only for the patient but also for the relatives, the occurrence of delirium is stressful and the changes in behaviour are difficult to understand. Appropriate information should be provided on the symptoms and course of the condition. The relatives should be instructed on how best to approach and communicate with the delirious patient (e.g. using short sentences and yes-or-no questions).

5.2.4. Multimorbidity and polypharmacy

Particularly in people of advanced age, dementia often occurs together with other chronic disorders (so-called multimorbidity). Treatment of the multimorbid patient never consists merely of the combination of treatments for each individual condition. Rather, based on the specific overall situation, an individual approach is to be adopted. Use of the various therapeutic measures and drugs is to be carefully weighed up so as to avoid overmedication, with drug interactions and potentiation of adverse effects (so-called polypharmacy).

As part of this assessment, the goals of treatment are to be defined in consultation with the patient, or the patient's representative. In mild and moderate dementia, the main aim is generally to maintain functioning for as long as possible. In more advanced stages, the emphasis is placed not only on preserving quality of life but also increasingly on alleviation of symptoms.

Decisions concerning treatments which are intended to improve the general medical prognosis – without directly improving functioning or alleviating symptoms – should be made on an individual basis, taking possible adverse effects and drug interactions into account. While, for example, the earliest possible control of cardiovascular risk factors (hypertension, diabetes mellitus, dyslipidaemia) also represents highly effective primary prevention of dementia, there is little evidence that such measures offer benefits in infirmity or advanced dementia.

5.2.5. Specific care pathways for people with dementia

Not so much dementia itself but its sequelae frequently give rise to acute medical problems or possibly emergency hospital admissions – for example, metabolic disturbances due to medication errors, infections caused by poor hygiene, dehydration, malnutrition, bone fractures due to falls, etc.

Although the requisite therapeutic measures for somatic problems of these kinds are generally instituted in hospital, what is frequently lacking is appropriate management of the underlying dementia. Often, this condition is not recognised or diagnosis is delayed. Necessary adjustments in communication and care are not undertaken. As a consequence, more serious – essentially avoidable – confusional states (delirium) may arise. These in turn impede or prevent the implementation of therapeutic measures planned for the somatic problems, leading to prolonged hospital stays, poor outcomes or rapid readmissions.

Here, geriatric, psychogeriatric or neurological consultation-liaison services and appropriate collaborations, e.g. with traumatology departments, or dedicated geriatric departments with an interprofessional geriatric team, offer a marked improvement. What may also be very helpful is the deployment of nurses specifically trained in dementia/delirium and in case management, who support the admission and discharge process for people with dementia. Ideally, prior to admission to an acute hospital, the patient's relatives should be contacted and preparatory discussions held. Booklets (e.g. produced by the Alzheimer's Association) provide useful guidance for relatives, explaining what information and personal items are important for the care team when a patient is admitted to hospital.

However, dementia-specific care pathways and networks are also important outside the hospital setting. An exclusive focus on the quality of care delivered by individual institutions or service providers cannot meet the specific needs of people with dementia. Integrated care approaches need to be strengthened, and, where necessary, dementia-specific care pathways established. These should be jointly developed and implemented – in a spirit of partnership – by health professionals, people with dementia and relatives.

5.2.6. *Early-onset dementia*

Dementia does not only affect the elderly: one in a thousand people aged between 45 and 65 suffer from a condition of this kind. Because symptoms such as altered personality traits, apathy, changes in emotional responses and language disturbances are not primarily associated with dementia in this age range, diagnosis is often delayed.

Younger people who are still working require comprehensive support at an early stage. During the period before the condition is recognised and diagnosed, there may often be persistent tensions at the workplace and sometimes also incorrect decisions with serious consequences. After the diagnosis has been established, remaining occupational options need to be rapidly assessed, and welfare planning (e.g. pension, financing of daily allowances) must also be addressed in good time. Within the circle of family and friends, symptoms of dementia can also lead to confusion, withdrawal by friends, breakdown of a partnership and isolation before the diagnosis makes the patient's behaviour explicable and thus comprehensible.

In early-onset dementia, therefore, the relatives should also receive particular attention and care. Strains in a marriage or partnership should be forestalled. Children require support in understanding and accepting a parent's dementia.

Partners of younger patients are often still working. For them, efforts to reconcile employment with caring for a family member, or the need to opt for one or the other, can be highly stressful. In addition, respite services are rarely designed for younger patients and represent an extra financial burden. Professional caregivers should seek to ensure that, alongside all the efforts made for the benefit of the patient, the welfare of the family as a whole is not neglected.

5.2.7. *Dementia in people with mental disabilities*

Dementia also affects people with mental disabilities. The symptoms do not fundamentally differ from those seen in other people with dementia. In people with trisomy-21

(Down's syndrome), dementia occurs much more frequently than in the general population and begins at a much earlier age. Here, changes in personality, emotional and psychotic symptoms, and late-onset epilepsy are particularly prominent, impairing the quality of life of patients and those close to them to a much greater extent than neurocognitive deficits.

In patients with mental disabilities, diagnosis is complicated by the lack of adapted screening and test instruments and often by inadequate documentation of baseline cognitive status.

Important for care and treatment is interprofessional collaboration between mental disability experts and health professionals. This becomes especially important as the focus of care gradually shifts away from developmental support andagogics towards validation and palliation.

If people with mental disabilities are living with their family at the onset of dementia, the challenge consists in adapting and intensifying respite and support services, since both more and different types of assistance are required. If care is provided by ageing parents, the growing need for support in care recipients is generally accompanied by declining energies in caregivers.

If care is provided at institutions for the mentally disabled, the increasing need for personal care, in particular – as well as difficulties in coping sympathetically with new behavioural symptoms – places significant demands on personnel and structural resources. At the same time, institutions offering long-term care for people with dementia remain inadequately prepared to admit people with mental disabilities, with regard to both their age and their specific needs.

The goal of providing care for as long as possible in a familiar environment can best be achieved if people who have previously lived with their family at home can be admitted, together with their parents, to mixed-ability accommodation for people with differing needs for assistance. People already living at an institution prior to the onset of dementia should be able to remain there if their particular needs can be met by the establishment of additional resources and skills within the institution. At any rate, efforts should be made to find the best possible solution for the individual patient, given the resources which are available or can be generated.

5.3. *Emotions and behaviour*

5.3.1. *Emotional and behavioural disturbances*

Dementia leads not only to cognitive and functional impairments, but very often also to emotional and behavioural disturbances, which are known as behavioural and psychological symptoms of dementia (BPSD) or as neuropsychiatric symptoms (NPS). These include delusions and hallucinations, agitation/aggression, wandering, sleep disturbances, disinhibition and irritability, but also depression and apathy.

These symptoms have a greater impact than the cognitive decline. They are inversely related to the patient's quality of life and can also place significant burdens on caregivers. They can lead to social isolation, neglect or even abuse. Particularly in the non-institutional setting, therefore, provision of support for relatives must be an integral part of

the care and treatment plan for dementia-related emotional and behavioural disturbances.

Specific knowledge and skills in the management of emotional and behavioural disturbances are prerequisites for the professional treatment and care of patients with dementia. An understanding of the biological, psychological, social and environmental factors that can cause and exacerbate such symptoms permits targeted care and treatment, adapted to the individual patient.²¹ In general, non-pharmacological care approaches take precedence over any pharmacological treatment. The aim is to understand the patient's life world and to adapt the care plan accordingly. Here, specific instruments should be used which enable step-by-step evaluation of emotional and behavioural disturbances and provide appropriate guidance. The use of medication often becomes unnecessary as a result or can be kept to a minimum.

5.3.2. Benevolent deception/deception in relation to medication

As a result of their condition, people with dementia cannot always correctly evaluate situations and interactions. This means that they are vulnerable and exposed to the risk of manipulation. The imbalance in power must not be exploited for personal advantage by those who interact with people with dementia – either relatives or professional caregivers. Nonetheless, failure to correct a misapprehension on the part of a person with dementia, or even active deception, may sometimes be justified if the motives are benevolent. Thus, for example, objectively false statements by a person with dementia are not corrected but deliberately allowed to stand. Instead, the caregiver will seek to comprehend the person's subjective assessment of the situation and to steer the interaction in such a way as to minimise conflicts between the subjective and the real world. Situations which could arouse disrespect can thus be prevented.

Similar considerations may also be relevant in answering the question of whether it is morally acceptable, in dementia care, to use objects that merely simulate reality (e.g. robotic pets, such as PARO the seal; a fake bus stop in a walled garden; a simulated railway carriage with videos of the countryside passing by). If such objects are appreciated by people with dementia and incorporated into their perception of reality, they need not be detrimental to truthfulness in the relations between caregivers and patients. What is crucial is that the intention is not to mislead people with dementia but to enable them to have positive experiences by rekindling memories and emotions. The use of such elements must not be designed to replace human care, but on the contrary should facilitate and intensify human interactions between caregivers and people with dementia.

Medication is sometimes given in the form of drops or as crushed tablets added to food or drink. In patients with severe dementia who are averse to swallowing tablets because of dysphagia, this can facilitate administration and is ethically unproblematic. However, if medication is concealed in order to administer a drug that would otherwise be specifically refused by the patient, then this is a case of benevolent deception and at the same time a coercive measure.²² In this situation, medication may only be concealed if the drugs are urgently required by the patient and less

intrusive measures have proved, or are likely to be, unsuccessful. In addition, the consent of the patient's representative is to be obtained; this does not apply in the case of emergency situations and (temporary) crisis interventions, such as may occur particularly in hospitalised patients with dementia. The legitimacy of the measure must be periodically reassessed.

5.3.3. Coercive measures²³

People with dementia can represent a danger to themselves and others for various reasons – frequently as a result of emotional and behavioural disturbances, confusion and falls. In such situations, coercive measures are sometimes used, generally in the form of restrictions on freedom of movement or the administration of sedative or neuroleptic drugs. Such measures are employed by nurses and physicians in the interests of safety, to prevent adverse consequences of behavioural disturbances, or to ensure the provision of medical care. However, interventions of this kind can sometimes have serious consequences for people with dementia. Coercive measures represent a serious infringement of personal rights. Therefore, they must not be ordered merely because the person concerned is disrupting hospital routine, or to facilitate the work of caregivers. Whenever possible, other, less intrusive measures must be used instead. Should coercive measures be required after all, they must be determined, applied, documented and regularly evaluated in accordance with interdisciplinary and interprofessional standards. In the case of measures restricting freedom of movement, the patient's representative must be informed. Coercive medical measures (administration of drugs) require the representative's consent, except in emergency situations and (temporary) crisis interventions, such as may occur particularly in hospitalised patients with dementia. The legitimacy of the measure must be periodically reassessed.

5.3.4. Involuntary committal

People with early-stage dementia generally still live in their accustomed home environment, possibly together with family members. In the later stages, the question of moving into a care home or specialised institution regularly arises. Here, various situations are to be distinguished.

If at this point the person with dementia still has capacity to conclude an agreement with the institution in question, and agrees to the move, then no further difficulties should arise. If capacity is lacking, then in principle the care agreement can be concluded by the person entitled to act as a representative in medical matters. However, such a placement must be necessary (i.e. medically indicated), proportionate to the degree of risk and always represent the least stressful option for the person concerned. If, in seeking a placement, the authorised representative appears not to be acting in the patient's best interests, then the CAPA should be contacted.

If the person with dementia whose care and treatment can no longer be provided in the accustomed home environment cannot be persuaded of the need to move into or remain at an institution, the CAPA should be called in. If appropriate, this authority can then order an involuntary committal. Depending on applicable cantonal law, provisional committal may also be ordered by a physician. It is, however, a prerequisite of involuntary committal that the

necessary treatment or care cannot be provided by any other means. When the decision is made, the burden on and protection of relatives should also be taken into consideration.

There are, however, also cases where relatives are opposed to the placement of a person with dementia in a care home, even though it is clearly no longer possible for appropriate care to be provided at home. In such cases, too, the CAPA should be notified of the risk to the person in question.

5.3.5. Procedure in the event of abuse

Abuse can take the form of physical or mental violence, neglect, or general exploitation of a position of power. People with dementia are often particularly at risk, as they are scarcely able to defend themselves or seek assistance. Caring for people with dementia is often extremely demanding, so that those concerned (relatives, but also professional caregivers) can easily feel overwhelmed – the most frequent reason for abuse.

Any signs of use of force, abuse or neglect observed by the care team should be carefully recorded in the medical file and in the care documentation, including details of the objective clinical findings (extent, localisation, appearance, etc.). Nurses and therapists who detect signs of violence must inform the responsible physician. If the patient is able to provide information on the background, the questions contained in the Elder Abuse Suspicion Index (EASI)²⁴ may be helpful.

The physician, nurses and therapists are to take the measures required to prevent any further abuse. In the home environment, it is often advisable, as a first step, to provide respite for the caregiver who is suspected of violence. Here, it is important to overcome what is often the shared social isolation of the victim and abuser. If necessary, and with the consent of the person concerned (or, if capacity is lacking, of the authorised representative), the CAPA should be called in. If consent cannot be obtained but such action is in the interests of the person concerned, exemption from the duty of confidentiality should be requested from the authorities and a notification of risk should be made.

Possible abuse by professional caregivers is a matter of particular concern. Such cases sometimes involve a number of victims over an extended period. Where such abuse is suspected, the responsible supervisory authority – and, if appropriate, the police – must be informed in a timely manner.

5.4. End-of-life decision-making

5.4.1. Withholding of life-extending measures

The decision as to whether life-extending measures are to be withheld in advanced dementia is guided by the patient's wishes or presumed wishes. Not infrequently, the withholding of such measures is requested in an advance directive.

If dementia is accompanied by significant somatic disorders (which is frequently the case, especially in older patients), then the spectrum of possible treatment-withholding decisions is broad. For example, in the presence of concomitant heart disease, it may be decided – in view of the progression of dementia – not to proceed with cardiac

surgery. By contrast, in dementia without significant comorbidity (frequently the case in younger patients in particular), options for withholding life-extending measures are generally restricted to the complications of advanced dementia.

People in advanced stages of dementia frequently contract pneumonia. Especially when this is a recurrent complication, the administration of antibiotics should not be the rule. Antibiotic therapy extends life only in a minority of these patients, and it is not clear whether it can improve well-being – and respiratory comfort in particular. Restraint should also be exercised because in these patients – owing to problems with adherence – there is a risk of development of resistance, and broad-spectrum antibiotics need to be prescribed.

The withholding of life-extending measures by no means signifies a reduction in medical care, but the focusing of care on effective alleviation of symptoms at the end of life.

5.4.2. Nutrition and hydration

In advanced dementia, oral intake of food and fluids is generally limited, leading to malnutrition. Possible causes, such as oropharyngeal pathology, are to be identified and treated. The eating process should be assessed so as to detect problems due to cognitive factors (e.g. agnosia – food is no longer recognised as such, and the patient chews the napkin instead) and take appropriate measures. Food intake may also be impeded by poor posture, especially in a bed or wheelchair. Dietary adjustments (e.g. favourite foods, earlier preferences, finger food and/or smooth food) should be considered.

In certain cases, however, restricted intake of food and fluids is associated with a general loss of vitality and will to live in advanced dementia. This is typically signalled by refusal of food offered (e.g. turning away of the head). This behaviour is to be accepted as a binding expression of wishes, and no pressure should be exerted (e.g. forcing a spoon into the patient's mouth). Different types of food and fluids should, however, be offered at different times throughout the day.

The insertion of a so-called PEG (percutaneous endoscopic gastrostomy) tube is not generally advisable in advanced dementia. Studies show that the patient's survival cannot thereby be improved at this stage of dementia. At the same time, the patient's quality of life may be severely impaired by – not infrequent – adverse effects and complications (e.g. reflux of feed; discomfort caused by the tube, accompanied by anxiety and agitation; increased risk of pressure ulcers).

Whether artificial hydration is indicated must be subject to interprofessional discussion in individual cases. There are no universally valid recommendations for patients with dementia. In each particular situation, the possible benefits (e.g. improved alertness) must be weighed up against adverse effects (e.g. risk of oedema). Such decisions must be regularly reviewed.

5.5. Management of the desire for suicide

People diagnosed with dementia may, in the early stages of the condition, express a wish to end their own life, either through suicide or assisted suicide.²⁵ Often, they wish to avoid a situation of complete dependence and disintegrated

tion of the personality induced by the disease. Frequently, a desire not to be a burden on others also plays a role. Empathetic disclosure of the diagnosis, combined with the offer of continued support and information on ways of coping with the disease, can help to diminish such fears. Any emotional problems or mental disorders (e.g. depression) contributing to the desire for suicide must be identified and, if necessary, treated. If the desire for suicide persists, it is legally permissible for a patient with capacity to opt for assisted suicide. The procedure for the physician is determined not only by the legal provisions but also by the relevant SAMS guidelines.²⁶ In people with dementia, the assessment of capacity in relation to a desire for suicide is particularly demanding.

6. Relatives

6.1. Relatives as informants and patients' representatives

When dementia is being diagnosed, relatives and other persons close to the patient already play an important role, since the impairment of daily living activities required for the diagnosis can only be determined on the basis of an informant history. In the subsequent course of dementia, relatives' knowledge is also of great importance in efforts to understand the patient's behaviour, recognise habits and identify needs.

The involvement of relatives in treatment decisions requires the consent of the person with dementia, as long as the latter has capacity. If this is no longer the case, the function of authorised representative is automatically assumed by certain relatives, provided that the person with dementia has not appointed a representative and no deputy has been appointed to act as a representative in medical matters (cf. Section 3.2.2).

The relatives' position as representatives may become problematic in cases where they give priority – consciously or unconsciously – to their own values and ideas. As a result, they may misinterpret or fail to recognise the needs of the patient, which may change as the disease progresses. In such cases, the treatment team must raise this issue and seek to resolve it through dialogue.

6.2. Relatives as caregivers

Relatives of people with dementia often provide extensive support and care over a period of years. The relatives may themselves be elderly, or still working, possibly also with parenting responsibilities, or it may be a child, adolescent or young adult caring for a family member with dementia. The physical, emotional and financial burdens associated with caregiving are substantial; family caregivers are often involved around the clock. Caregiving can thus become overwhelming, and the persons concerned risk becoming ill themselves. Professional dementia care therefore always also involves provision of care and support for relatives. Effective support for relatives often also leads to improvements in the emotional and behavioural disturbances of the person with dementia.

In individual cases, excessive strain and helplessness can lead to relatives neglecting the person they are caring for or using physical or mental violence. To prevent such situations arising, but also to provide assistance if abuse has already occurred, counselling services and self-help organ-

isations can offer support. For information on the procedure for professional caregivers in the event of abuse see Section 5.3.5.

6.3. Relatives as persons affected

Relatives are often skilled caregivers and, at the same time, are engaged in a process of leave taking. As the disease progresses, they find themselves on an emotional roller-coaster: depending on the situation, the person they are caring for may still seem to be the father or husband of earlier times and then appear no longer to have anything in common with the person they once loved. This gradual, protracted loss makes leave-taking all the more difficult and prolongs the mourning process.

Against this background, it is important not only that the person with dementia should receive the necessary care, but that relatives should also be given time and space for gradual leave taking, for a reassignment of roles and for the mourning process. The relatives' quality of life should be explicitly addressed.

7. Research involving people with dementia²⁷

If advances are to be made in dementia treatment and care, research projects involving people with dementia are indispensable. However, special attention must be paid to these patients' need for protection. Also to be considered in particular are the burdens associated with the research project, which can vary widely depending on the study design.

Capacity at the time of inclusion in the research project must be carefully assessed. Since physicians providing treatment often conduct research projects at the same time, the difference between the treatment on the one hand and the research project on the other must be clearly pointed out to the patients participating. If no direct benefit is to be expected from participation in the research project, this must be communicated to the patient. In the case of people with incipient or mild dementia, it must be ensured that they are not – for research purposes or with the aim of obtaining informed consent – informed about the nature and course of their disease to an extent which goes beyond what they find acceptable. In view of the frequently limited therapeutic options available, the patient must have the right not to be informed about certain matters.

People with advanced dementia who can no longer give their consent to participate in a research project must be involved as far as possible in the consent procedure. It should be borne in mind that the ability to revoke consent to participate in a research project is lost as the disease progresses. However, if the person concerned – through utterances or behaviour – exhibits opposition to participating or remaining in a study, then this must be taken into account.

The treating physician who raises the question of participation in a research project while the patient still has capacity should recommend that the patient's attitude to participating in research projects be included in the advance directive. Often, relatives are involved in a supporting role in the research project; for example, they have to ensure that the patient concerned complies with the requirements of the project (taking study medication, etc.). These individuals additionally receive separate informed consent documents.

Research projects with no expected direct benefit for the patient may only be carried out if they entail only minimal risks and burdens and are expected to yield substantial findings which could be beneficial for patients with dementia over the long term.

III. Footnotes

¹ In these guidelines, for the sake of comprehensibility, the term “dementia” (ICD-10) is used instead of “major neurocognitive disorder” (DSM-5).

² The term “relatives” is used to refer to persons close to the patient.

³ This encompasses the physical, mental, social and spiritual dimensions of the condition.

⁴ Cf. the National Guidelines on Palliative Care (available in French/German/Italian): <https://www.bag.admin.ch/bag/de/home/das-bag/publikationen/broschueren/publikationen-im-bereich-palliative-care/nationale-leitlinien-palliative-care.html>.

⁵ Cf. <https://www.bag.admin.ch/bag/en/home/strategie-und-politik/nationale-gesundheitsstrategien/nationale-demenzstrategie.html>

⁶ SAMS guidelines are addressed to healthcare professionals (physicians, nurses and therapists). On being incorporated into the Code of the Swiss Medical Association (FMH), SAMS guidelines become binding for all members of the FMH.

⁷ Hereafter, the term “medical” is used in a broad sense to refer to the activities of physicians, nurses and all other professionals providing therapy in the health sector.

⁸ The Swiss Society of Gerontology (SGG-SSG) plans to publish supplementary guidelines for professionals working in the field of agogics.

⁹ According to DSM-5, instrumental activities of daily living (IADL), such as housework or money management, are impaired in mild dementia. In moderate dementia, basic activities of daily living (BADL), such as eating or dressing, are also affected. In severe dementia, the patient is fully dependent on assistance.

¹⁰ The term “volitional factors” refers to the conscious, voluntary process of acting on goals and motives.

¹¹ Cf. National Advisory Commission on Biomedical Ethics, Opinion No. 17/2011 “Advance directives”.

¹² With regard to medical interventions, the following persons, in the following order, are entitled to act as representatives for the person lacking capacity: (1) persons appointed in an advance directive or power of attorney; (2) a duly authorised deputy; (3) a spouse or registered partner who shares the same household or regularly provides personal support for the person lacking capacity; (4) the person who shares the same household as and regularly provides personal support for the person lacking capacity; (5) the offspring, (6) the parents or (7) the siblings, if they regularly provide personal support for the person lacking capacity (Art. 378 Civil Code). For patients receiving medical treatment in connection with an involuntary committal, Art. 434 Civil Code is applicable.

¹³ Various definitions of the term “participation” exist, e.g. that of the International Classification of Functioning, Dis-

ability and Health (ICF): Participation is meant in the sense of control of one’s own life and involvement in major life areas, engagement in community, social and civic life.

¹⁴ “Validation” is a form of communication (verbal, non-verbal, paralinguistic) based on appreciation and empathy and guided by the needs of people with dementia. It involves seeing with their eyes, hearing with their ears, supporting their body rhythms and being receptive to their signals.

¹⁵ More comprehensive than the advance directive is the so-called power of attorney, in which non-medical matters may also be dealt with. Here, however, the formal requirements are more exacting. If a person with dementia is no longer capable of writing a power of attorney by hand, it may be prepared with the aid of an authenticating official.

¹⁶ Cf. Footnote 12.

¹⁷ Cf. National Advisory Commission on Biomedical Ethics, Opinion no. 17/2011, “Advance directives”, p. 7: “The patient’s usual diet, personal hygiene, exercise and other activities are always to be offered. An advance directive must not give instructions to the contrary.”

¹⁸ Cf. SAMS Recommendations: “Ethics support in medicine”.

¹⁹ Cf. Monsch AU et al. 2012.

²⁰ Cf. Albisser Schlegler H et al. 2007.

²¹ Cf. the guidelines jointly prepared by various Swiss professional associations: Savaskan et al. 2014.

²² Cf. SAMS Medical-ethical guidelines “Coercive measures in medicine”, Section 4.4.1 and Footnote 31.

²³ Cf. SAMS Medical-ethical guidelines “Coercive measures in medicine”, especially Section 4.4 (“Patients in long term care”), and Art. 383–385 Swiss Civil Code.

²⁴ Cf. Yaffe MJ et al. 2008.

²⁵ Cf. SAMS medical-ethical guidelines “End-of-life care” (in force 2004–2018) and “Management of dying and death” (forthcoming in 2018).

²⁶ Cf. SAMS medical-ethical guidelines “Management of dying and death” (forthcoming in 2018).

²⁷ Cf. SAMS, “Research with human subjects”. A manual for practitioners, Basel 2015.

IV. Information on the preparation of these guidelines

Mandate

In May 2014, the Central Ethics Committee (CEC) of the SAMS appointed a subcommittee to draw up medical-ethical guidelines on “Care and treatment of people with dementia”.

Sub-committee responsible

PD Dr Georg Bosshard, MAE, Geriatrics, Zurich (Chair)

Professor Regina Aebi-Müller, Law, Lucerne

PD Dr Klaus Bally, General Practice, Basel

Dr Stefanie Becker, SGG, Psychology, Yverdon

Dr Daniel Grob, Geriatrics, Rheinau

Professor Christian Kind, St Gallen (former CEC Chair)

Professor Andrea Koppitz, Long-term Care, Winterthur

Professor Sophie Pautex, Palliative Care, Geneva
 Dr Heinz Rügger, MAE, Ethics, Zurich
 Lic. iur. Michelle Salathé, MAE, SAMS, Bern
 Anja Ulrich, MNS, APN, Acute Care, Basel
 Professor Armin von Gunten, Psychiatry, Lausanne

Experts consulted

Professor Susanne Boshammer, Osnabrück
 Professor Raymond Koopmans, Nijmegen
 Professor Andreas Monsch, Basel

Consultation procedure

On 16 May 2017, the Senate of the SAMS approved a draft version of these guidelines to be submitted for consultation to professional associations, organisations and other interested parties. The comments received have been taken into account in the final version.

Approval

The final version of these guidelines was approved by the Senate of the SAMS on 16 November 2017.

Original versions

English version in the original layout available at <https://www.samw.ch/en/Publications/Medical-ethical-Guidelines.html>

German version available at <http://www.samw.ch/de/Ethik/Richtlinien/Aktuell-gueltige-Richtlinien.html>

French version available at <https://www.assm.ch/fr/Publications/Directives.html>

References

- Albisser Schlegler H, Reiter-Theil S. «Alter» und «Kosten» – Faktoren bei Therapieentscheidungen am Lebensende? Eine Analyse informeller Wissensstrukturen bei Ärzten und Pflegenden. *Ethik Med.* 2007;19(2):103–19. doi: <http://dx.doi.org/10.1007/s00481-006-0466-2>.
- Giordano S. Respect for equality and the treatment of the elderly: declarations of human rights and age-based rationing. *Camb Q Health Ethics.* 2005;14(1):83–92. doi: <http://dx.doi.org/10.1017/S0963180105050097>. PubMed.
- Mitchell SL, Teno JM, Kiely DK, Shaffer ML, Jones RN, Prigerson HG, et al. The clinical course of advanced dementia. *N Engl J Med.* 2009;361(16):1529–38. doi: <http://dx.doi.org/10.1056/NEJMoa0902234>. PubMed.
- Monsch, Büla, Hermelink, Kressig, Martensson, Mosimann, et al. Schweizer Expertengruppe. Konsensus 2012 zur Diagnostik und Therapie von Demenzzkranken in der Schweiz. *Praxis (Bern).* 2012;101(19):1239–49. doi: <http://dx.doi.org/10.1024/1661-8157/a001085>.
- National Advisory Commission on Biomedical Ethics (NEK-CNE). Advance directives – Ethical considerations concerning the new adult protection law with particular reference to dementia. Opinion No. 17/2011, Bern.
- Savaskan E, Bopp-Kistler I, Buerge M, Fischlin R, Georgescu D, Giardini U, et al. Empfehlungen zur Diagnostik und Therapie der behavioralen und psychologischen Symptome der Demenz (BPSD). *Praxis (Bern 1994).* 2014;103(3):135–48. doi: PubMed.
- van der Maaden T, Hendriks SA, de Vet HC, Zomerhuis MT, Smalbrugge M, Jansma EP, et al. Antibiotic use and associated factors in patients with dementia: a systematic review. *Drugs Aging.* 2015;32(1):43–56. doi: <http://dx.doi.org/10.1007/s40266-014-0223-z>. PubMed.
- van der Steen JT, Radbruch L, Hertogh CM, de Boer ME, Hughes JC, Larkin P, et al.; European Association for Palliative Care (EAPC). White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med.* 2014;28(3):197–209. doi: <http://dx.doi.org/10.1177/0269216313493685>. PubMed.
- Wettstein A. Betagtenmisshandlung: Empfehlungen zur Diagnostik und Therapie. *Prim Hosp Care.* 2016;16:391–4. [doi:].
- Yaffe MJ, Wolfson C, Lithwick M, Weiss D. Development and validation of a tool to improve physician identification of elder abuse: the Elder Abuse Suspicion Index (EASI). *J Elder Abuse Negl.* 2008;20(3):276–300. doi: <http://dx.doi.org/10.1080/08946560801973168>. PubMed.