



European Association for Palliative Care

Non Governmental Organisation (NGO) recognised by the Council of Europe

Recommendations on palliative care and treatment of older people with Alzheimer’s disease and other progressive dementias

The 11 domains and 57 recommendations including explanatory text

1. Applicability of palliative care

1.1 Dementia can realistically be regarded as a terminal condition. It can also be characterized as a chronic disease or, in connection with particular aspects, as a geriatric problem. However, recognizing its eventual terminal nature is the basis for anticipating future problems and an impetus to the provision of adequate palliative care.

Most dementias, such as Alzheimer’s disease, are inevitably progressive, life shortening, and ultimately lead to death even if patients may live for many years.¹⁻³ The perception of dementia as a terminal disease has been associated with greater comfort in patients dying with dementia.⁴

Some have suggested that labelling dementia care as palliative care might in itself result in improved patient care.⁵ The principles and practice of geriatric or gerontological medicine should also apply, because dementia, as a chronic condition, is often related to cerebrovascular and cardiovascular disease,⁶ albeit dementia also affects younger people. Whatever other models apply, a core element should be anticipating inevitable decline and death, and related to this, anticipating specific needs.

1.2 Improving quality of life, maintaining function and maximizing comfort, which are also goals of palliative care, can be considered appropriate in dementia throughout the disease trajectory, with the emphasis on particular goals changing over time.

Palliative care fits with dementia as a “disease not responsive to curative treatment”⁷ or a “life threatening illness,”⁸ because the dementia itself cannot be cured. It aims at “improving quality of life.”⁸ Quality of life is a broad notion and what constitutes quality of life will vary from person to person. The individual, especially in the early stages, as a matter of principle, should be regarded as best placed to define quality of life for him or herself.

As dementia becomes more severe, however, it becomes more reasonable to consider quality of life specifically as maintenance of function and maximization of comfort. These are potential goals of care even with mild dementia, and become the main goals of care with progressive dementia (Figure 1). Therefore, palliative care can be considered appropriate in dementia throughout the full disease trajectory, with emphasis on particular goals changing over time from diagnosis until after

death. Patients and families may have other specific and varying needs throughout the disease trajectory and such needs are well captured within a palliative (care) approach. There are few studies on the efficacy of palliative care in dementia,^{9,10} but there is some evidence from the U.S. that their system of hospice care (palliative care for terminally ill people with an expected survival of six months or less, and a benefit of several insurance programs) is beneficial in dementia mostly from the viewpoint of families.¹¹⁻¹⁴

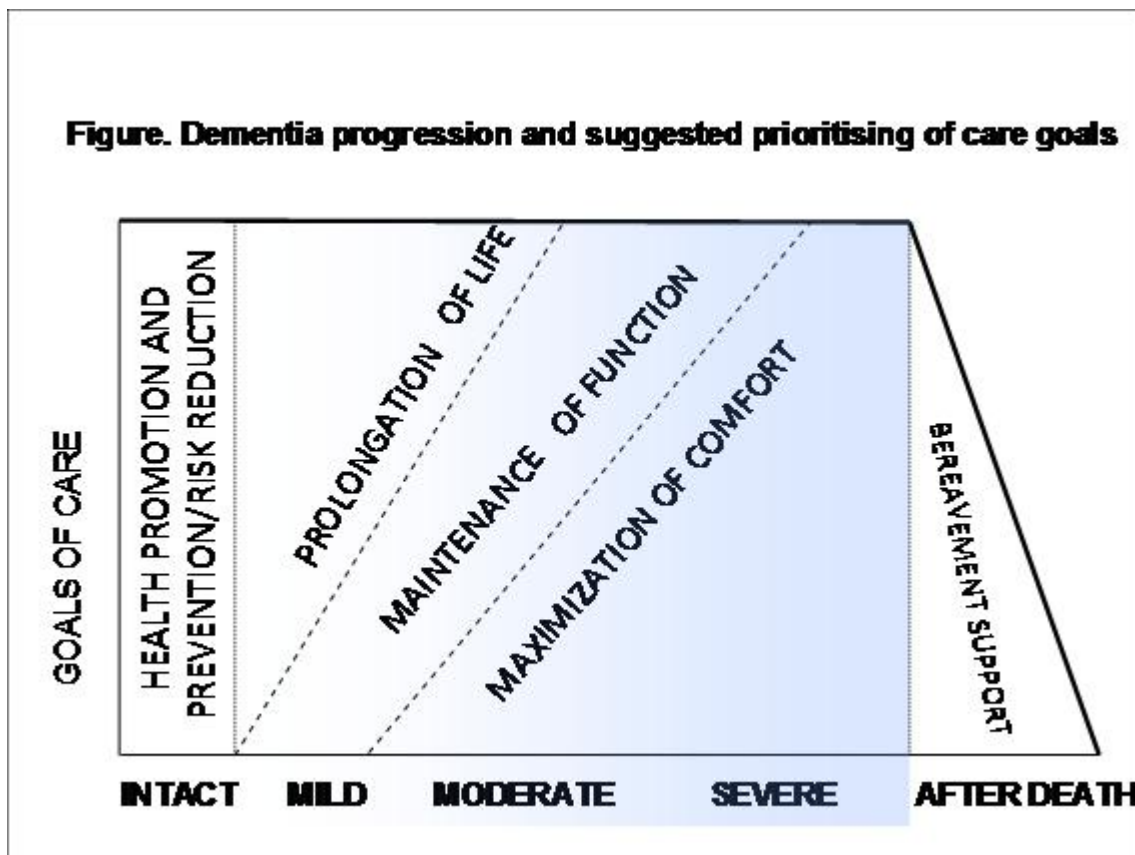


Figure 1. Dementia progression and suggested prioritising of care goals

Explanation: The figure represents a model of changing care goals and priorities throughout the course of the dementia. It suggests prioritising of care goals that may apply at the same time, but have variable relevance to different stages of dementia. More than one care goal may apply at the same time. For example, for a patient with moderate dementia, the three goals may apply simultaneously but maximisation of comfort and maintenance of function may be prioritised over prolongation of life.

As with any model, the visualization of care goals represents an abstraction of reality, and in practice will need tailoring to needs and preferences of patients and families. The figure does not directly relate to a palliative curative dichotomy. Nevertheless, the goals of maintenance of function which may include delaying of disease progression and maximization of comfort best represent a focus on quality of life and are therefore most compatible with palliative care.

Note also 9.6, while bereavement support is provided after death, families may need early and ongoing support for chronic or prolonged grief.

Of note, there was moderate agreement among experts on this recommendation (as opposed to high agreement for most other recommendations). The explanation was extended based on the feedback of the experts which indicated that it needed further clarification.

1.3 Palliative care for dementia should be conceived as having two aspects. The baseline is a palliative care approach. For patients with complex problems, specialist palliative care should be available.

A baseline palliative care approach^{7,15} always applies.^{16,17} Specialist palliative care is not included in the baseline approach, but this next step may be required, for example to assess and treat dyspnoea or pain or other symptoms. Specialist dementia care, e.g., to manage challenging behaviour, and guidance for families, is part of the baseline and should always be available.¹⁷

1.4 A palliative care approach refers to all treatment and care in dementia, including adequate treatment of behavioural and psychological symptoms of dementia, comorbid diseases, and (inter- or concurrent) health problems

Behavioural and psychological symptoms of dementia (BPSD) including behaviour that challenges caregivers such as agitation, or that may be a problem for the patient, such as apathy, are an important aspect of dementia. It may be related to other problems, such as cognitive impairment, depression, or pain.¹⁸⁻²¹ Often, such symptoms are also burdensome for families.²² The multidisciplinary palliative approach may be helpful in anticipating, assessing and managing problems. With challenging behaviour, integration of the specific expertise from the fields of geriatrics and dementia care specialists is recommended, with a significant role for (clinical) psychology.

Of note, a palliative approach does not aim to hasten death nor to prolong life, and therefore does not preclude treatment of health problems such as infections with antibiotics, because this may be the best way to resolve burdensome symptoms.

Note also 6.2, medication, and 11.3, collaboration

2. Person-centred care, communication and shared decision making

2.1 Perceived problems in caring for a patient with dementia should be viewed from the patient's perspective, applying the concept of person-centred care.

Attention to the holistic nature of palliative care overlaps with person-centred care in dementia.^{17,23,24} Person-centred care aims to acknowledge the personhood of people with dementia in all aspects of their care.^{25,26} This includes prioritising the relationship as much as care, and offering shared decision-making. The concept is particularly relevant to behaviour that challenges as part of behavioural and psychological symptoms of dementia for it suggests alternative interpretations are available, such as one that highlights the patient's coping with the consequences of disease.²⁷ Similarly, challenging behaviours can sometimes usefully be regarded as manifestations of unmet needs on the part of the patient,²⁸ although alternative physical and psychosocial factors should not be overlooked as causative or contributing factors. Person-centred care further implies that the patient is informed, insofar as this is possible using every means that might be helpful, about care and treatment, and that the degree to which a patient him- or herself can still be involved in the decision-making process is evaluated and acted upon.²⁹ For example, the use of covert administration of medication should be avoided; but if it is needed, it should be openly discussed with the family and team, and documented.³⁰

Note also 11.1, access to palliative care, and dignity

2.2 Shared decision making includes the patient and family caregiver as partners and is an appealing model that should be aimed for.

Patient and families (or significant others) should be involved in care and decision making from diagnosis, building up a relationship of trust. Shared decision making is frequently possible in mild dementia, and may also be feasible with moderate dementia with adaptation to the patient's cognitive performance. In more severe dementia, substitute (proxy) decision making is increasingly required. Nevertheless, some patients or families may have other wishes with regard to their roles in decision making; for example, some may wish the health care team to take decisions. Patients' and families' preferences regarding their roles in decision making should be elicited,^{31,32} and, if possible, the patient's preferences should act as a guide. In general families wish to be involved in end-of-life decision-making for incompetent patients, preferring group or consensual decision making involving multiple family members over individual substitute decision making.³³ In the ICU setting at the end of life, shared decision making has been associated with greater family satisfaction with communication.³⁴ Consultation with an ethicist or with a clinical ethics committee may be helpful in specific cases. The model of shared decision making is generally appealing, but should be put into practice in the context of local legal frameworks on health care decision making.

2.3 The health care team should ask for and address families' and patients' information needs on the course of the dementia trajectory, palliative care and involvement in care.

Studies have shown that many families have little understanding of the disease trajectory and health problems associated with dementia.^{35,36} In addition to preparing for their role as substitute decision makers and for a shared decision-making process, being prepared for death and what to expect at the end of life can be important for families' own wellbeing.³⁷ Information needs may, however, differ between ethnic groups, probably reflecting different views on death, dying and stigma. Dementia may specifically involve variable levels of stigma and shame, and family shame adds to caregiver burden.^{29,38-40}

Note also domain 9, family care and involvement

2.4 Responding to the patient's and family's specific and varying needs throughout the disease trajectory is paramount.

Along the disease trajectory, needs and priorities may change considerably. For example, practical support for the family caregiver may suffice to keep a patient with mild dementia at home, whereas in later stages, 24-hour supervision or help in managing challenging behaviour or symptoms may be needed.

2.5 Current or previously expressed preferences with regard to place of care should be honoured as a principle, but best interest, safety and family caregiver burden issues should also be given weight in decisions on place of care.

Palliative care addresses the needs of the patient wherever he or she is cared for, at home or in an institution⁷. Many may wish to die at home. It should be noted that preferences may change during a disease trajectory. For some, home is in an institutional long-term care setting, for others, it is the "next-best option."⁴¹ Care-dependent older people recognize that long-term care may be necessary or even better for people with dementia.⁴² Care cannot always be provided at home, for example, because challenging behaviour develops, or because caregiver burden or safety become issues. Nevertheless,

current or prior patient preferences with regard to place of care and death should always be considered, and require ongoing review. Importantly, patients and families should have access to high-quality support at home for a real choice.⁴³

2.6 Within the multidisciplinary team, patient and family issues should be discussed on a regular basis.

Attention to regular communication within the team is particularly important when people or the team caring for the patient are dispersed geographically, or when different services are involved, which often applies to home-care and residential settings. Families may also be invited to team meetings and telephone case conferences may be used as an alternative. Of note, a palliative approach can be adopted by a single professional category or even by an individual⁷ whereas specialist palliative care requires a multiprofessional and interdisciplinary team.

Note also 3.6, advance care planning, and domain 4, continuity of care

3. Setting care goals and advance planning

3.1 Prioritizing of explicit global care goals helps guide care and evaluate its appropriateness.

Prioritizing global, cross-health problem (non-disease specific) care goals is helpful in eliciting what is most important when making treatment decisions.^{44,45} Benefits of advance (care) planning in general include managing affairs while still able, ensuring that wishes are met, peace of mind, decreasing burden on loved ones, and keeping peace within the family.⁴⁶ It may also facilitate discussion on important sensitive issues including life prolongation, and at what cost.⁴⁷ General guidelines for family meetings in palliative care recommend clear structures of how to prepare, conduct, document, and follow-up family meetings.⁴⁸ Although a number of studies report that advance care planning results in, for example, lower hospitalization rates, evidence on effects of advance care planning on patient outcome is sparse,^{49,50} and an intervention study found no change in families of incompetent nursing home residents' satisfaction with care.⁵¹

3.2 Anticipating progression of the disease, advance care planning is proactive. This implies it should start as soon as the diagnosis is made, when the patient can still be actively involved and patient preferences, values, needs and beliefs can be elicited.

Advance care planning is frequently defined in terms of persons making decisions about their future health care should they become incapable of decision making. However, for frail elderly, often residing in long-term care, including patients with dementia, advance care planning is better defined in terms of an ongoing communication process between patient and/or family, and the health care team.^{47,52} In addition to writing up and making use of living wills, such advance care planning includes eliciting of preferences and values, as well as prioritizing care goals—assuming the patient agrees and can cope with this. The health care team may then just “plant the seed,”⁵³ or later, help translate care goals into appropriate treatment, because the course of the dementia varies between patients. At diagnosis, the decision making dimension is important in palliative care provision.⁵⁴ As a minimum, naming of a substitute decision maker at diagnosis is recommended. Advance care planning should start as soon as possible, but the optimal timing of initiating it may be highly individual as it is affected by a complexity of factors.^{55,56} Advance care planning may not be limited to end-of-life

situations, but care planning may refer to the full disease trajectory. Further, advance planning other than care planning is needed, such as advance financial planning.⁵⁷

3.3 Formats of advance care plans may vary in terms of preferences, the amount of detail required, and what is available in the specific setting for the individual.

Pre-structured models including a focus on specific treatment decisions or hypothetical scenarios may improve adherence to preferences in various populations.^{52,58,59} However, there is hardly any evidence for effects of one strategy over the other on patient outcomes and for dementia specifically. Currently, there is also insufficient evidence as to when and for whom this may be helpful. The practical use of living wills depends on the specific legal environment,^{60,61} and palliative and dementia care specialists should be aware of the specific legal framework in their own countries. Further, cautious interpretation of planning far ahead is needed because of limited opportunity to revisit with changing preferences.⁶²⁻⁶⁴ Finally, different perceptions with regard to advance care planning between ethnic or culturally diverse groups, such as possible stigmatization associated with a terminal disease, and different health literacy should be taken into account.⁶⁵⁻⁶⁷

3.4 In mild dementia, people need support in planning for the future.

Patients with mild dementia usually do not take the initiative to plan care ahead. They are primarily trying to cope with their condition and have a tendency to avoid thinking about the future. They may not realize the importance of advance planning until it is too late, or they may actively avoid pertinent discussions. Hence, and bearing in mind the limited “window of opportunity” with increasingly impaired competencies, advance care planning at this stage of the disease may not be pursued or may be overlooked. Possible interventions to stimulate and support people in this respect need prudent consideration of the ethical aspects and respect for patient’s choice if they should not wish to engage in advance care planning, especially given that there is variable readiness to engage in advance care planning in general.^{46,68-70} Nevertheless, patients should be explained, and may understand, the opportunity to plan for their future care.

3.5 In more severe dementia and when death approaches, the patient’s best interest may be increasingly served with a primary goal of maximization of comfort.

Maximization of comfort finally takes priority over maintenance of function and life prolongation (Figure). This may entail a focus on relieving symptoms, as well as promoting dignity and quality of life.

Of note, many patients do not live into the severe stages.^{71,72} Balancing end-of-life decision making in patients with moderate dementia may be complicated. Further, choosing appropriate care goals and tailoring care to dementia stages as conceptualized in the Figure requires some flexibility, considering that a core issue is that of monitoring deterioration and responding to the changing needs and wishes of the patient and family.

3.6 Advance care planning is a process and plans should be revisited with patient and family on a regular basis and following any significant change in health condition.

Evaluation of plans should be performed regularly, for example, every six months.⁵² It is also indicated where new health problems develop, if there has been deterioration, or where new treatments become available, and after invasive or possibly burdensome procedures such as hospitalization.⁵²

3.7 Care plans should be documented and stored in a way that permits access to all disciplines involved in any stage and through transfers.

Patient and family preferences, the treatment goals that take priority and any specific plans should be clearly documented. They should be available to the different disciplines of the health care team.^{48,52,73} The plans should be accessible immediately in case of emergency (Germany: “the Gottingen palliative emergency card”⁷⁴).

4. Continuity of care

4.1 Care should be continuous; there should be no interruption even with transfer.

Continuity of (palliative) care relates to care over time provided to individual patients. It comprises continuity of management, information, and relations,⁷⁵ and all may be important in dementia care at the end of life. That is, the first is especially important in chronic and complex diseases, the last two may be particularly relevant in care at the end of life, and mental health care is particularly served by continuity of relations.^{75,76} This is facilitated by adequate communication between the professional caregivers involved and by keeping patients and families informed. Preferably, at least one of the same professional caregivers is involved throughout the disease trajectory, which has great advantages with regard to knowing patient and family and facilitating continuity of communication.⁷⁷ Frequent transfers and high staff turnover may challenge this aspiration, but even then staff allocation must be considered prudently. Naming a key contact person in the family, for example, within 48 hours from admission⁷³ may facilitate the provision of continuous care if there is more than one substitute decision maker or if no substitute has yet been appointed.

4.2 Continuous care refers to care provided by all disciplines.

Continuity of care should be provided by the health care team including medical, nursing, psychological, social and spiritual disciplines, as well as by volunteers.

4.3 All patients should benefit from the early appointment of a central coordinator from within their care team.

Having a central coordinator is important even at the time when home care is not yet needed. In institutional settings, families’ knowing whom to contact is associated with a higher satisfaction with care.⁷⁸ The role of the central coordinator may be adopted by different disciplines, such as a physician, a nurse practitioner, a nurse, a social worker, or another non-clinical dementia advisor.

A central role in care for a physician or nurse practitioner (clinical nurse specialist, advanced practice nurse) has been shown to decrease hospitalization in frail elderly and dementia patients.^{79,80} In the Netherlands, nursing home residents with pneumonia and dementia are rarely hospitalized because they are treated in the nursing home by elderly care physicians who are on staff.⁸¹ Moreover, multi-disciplinary community care led by a nurse practitioner improved quality of care for patients and family and behavioural symptoms.⁸² Benefits of a nurse acting as case manager for dementia patients in community settings, however, is uncertain, because trials have not demonstrated effects on caregiver outcomes, patients’ quality of life, nor a reduction in terms of institutionalization, hospitalization, or costs.^{83,84}

4.4 Transfers between settings require communication on care plans between former and new professional caregivers and patient and families.

In particular transitions from home to institutional settings, such as a nursing home or a hospital, may necessarily involve changes to new professional caregivers. They should connect to patient and family shortly after admission, for example, within a few weeks from nursing home admission which is the standard in the Netherlands,⁸⁵ or within a few days from admission to a hospital. Additionally, the new professional caregivers should revisit care plans in consultation with former professional caregivers.

5. Prognostication and timely recognition of dying

5.1 Timely discussion of the terminal nature of the disease may enhance families' and patients' feelings of preparedness for the future.

Recognizing that dementia is a terminal condition, but that not all patients reach the severe stage and so will die with, although not necessarily from dementia, is an important mainstay for adequate care planning and provision of care and treatment. It is recommended that patients' and families' perceptions on prognosis and their willingness to discuss these issues should be explored, even in cases where patients and families are not inclined to initiate discussions themselves about this sensitive topic. However, if patients and families show clear signs of not wanting to have that discussion, for example when denial or hope is their psychological coping strategy, this wish should be respected. Cultural and individual sensitivities with regard to disclosure of prognosis, and also of diagnosis, should be considered prudently. More generally, skills in breaking bad news are required.^{65,66,86}

Note also domain 1, applicability of palliative care

5.2 Prognostication in dementia is challenging and mortality cannot be predicted accurately. However, combining clinical judgement and tools for mortality predictions can provide an indication which may facilitate discussion of prognosis.

Prognostication in non-malignant life-threatening disease including dementia is complex and a challenging task that in practice often relies on clinical judgment but is important for appropriate timing of care.⁸⁷⁻⁸⁹ The best prediction is achieved by combining clinical judgement with tools.⁹⁰⁻⁹² Tools to improve mortality predictions have been developed for and validated in patients with more severe, or "advanced dementia,"⁹³⁻⁹⁵ for mixed nursing home populations,⁹⁵⁻⁹⁷ and patients with dementia and pneumonia.⁹⁸ However, although identifying patients at low risk of death is possible, when a patient is going to die cannot be predicted accurately. Clinical impact has hardly been studied⁹⁹ and tools may have only limited usefulness in identifying those at moderate risk of dying (e.g., 20%, 40% and higher) in the next months.^{89,100} Dependency on others in terms of activities of daily living (ADL, e.g., eating, mobility dependency) is generally a strong mortality predictor.^{93,94,101,102} This is true for male gender as well,^{93,94,102-105} although older, small studies have neglected study of in particular gender as a potential predictor.^{106,107} The difficulty to identify those at high mortality risk underlines the need to consider the possibility of death with dementia even in the mild stage. Of note, both prognosis, to anticipate and help prepare families, and needs are important in the providing of palliative care.

Of note, there was moderate consensus among experts on this recommendation (as opposed to high consensus on other recommendations), because there were relatively many experts who agreed

“moderately” compared with “strongly.” Most critiques referred to concerns about the accuracy of mortality predictions. This is addressed, however, in the explanatory text, and we believe that a general discussion of prognosis is useful even if the prediction is not very accurate.

Note also domain 3, setting care goals and advance planning

6. Avoiding overly aggressive, burdensome or futile treatment

6.1 Transfer to the hospital and the associated risks and benefits should be considered prudently in relation to the care goals and taking into account also the stage of the dementia.

Transferring the patient from familiar surroundings to a hospital involves risks of decompensation with confusion or delirium; staff may not be equipped to deal with these problems.¹⁰⁸⁻¹¹⁰ However, hospitalization may be appropriate in mild or moderate dementia, balancing risks against the benefits of prolonging life or improving the quality of life (e.g. patients with a hip fracture). In severe dementia, hospitalization should be avoided. Further, in cases of pneumonia, it may not increase the chances of survival as has been shown in nursing home populations which included many patients with dementia.^{111,112} Survival in general,¹¹³ with specific health problems such as stroke¹¹⁴ and with hip fracture or pneumonia,¹¹⁵ is shorter for hospitalized patients with dementia compared with similar patients without dementia. Early work, although it did not consider dementia, already identified functional outcomes being worse for older persons with low ADL functioning and Mini-Mental State Examination (MMSE) scores.¹¹⁶

6.2 Medication for chronic conditions and comorbid diseases should be reviewed regularly in light of care goals, estimated life expectancy, and the effects and side effects of treatment.

Dementia is often associated with chronic conditions or comorbidities such as hypertension, heart disease, diabetes and osteoporosis. Providing guideline-adherent care to reach disease-specific targets for all these conditions would involve increasing the amount of medications. Polypharmacy or multiple drug regimens, however, increase the risk of adverse drug reaction and drug-to-drug interactions. It is also difficult to identify adverse effects in patients who are unable to communicate verbally. Finally, if there is dysphagia and resistance to taking medications, their continued administration can be burdensome.¹¹⁷⁻¹²⁰

Therefore, the goals of care should guide treatment in dementia (Figure). Prolongation of life may remain a priority, but if the patient is already near the end of life, the limited remaining life span mitigates the ability of many medications, such as lipid-lowering medication (statins), to meet this goal meaningfully. Similarly, some medications may be of limited benefit in those whose primary goal of care is to maintain their current functioning, because these patients already are severely impaired. For patients whose primary goal of care is maximization of comfort, it is reasonable to continue only medications that avoid or reduce suffering. In case of doubt, prescribing a potentially beneficial drug for a limited period of time only and then reassessing its future usefulness is recommended.^{117,121} A change in care goals should always be accompanied by an evaluation of the appropriateness of prescriptions. Future medication guidelines should discuss not only when to start but also when it is appropriate to stop the drug and monitoring of symptoms of withdrawal.

6.3 Restraints should be avoided whenever possible.

Mechanical restraints may increase patient's discomfort and its application offends the principle of respect for autonomy if applied without free and informed consent. Moreover, excessive use of restraints may add up to deprivation of liberty and violate the principle that the least restrictive environment and treatment appropriate to health needs and safety is required for people with mental illness.¹²²⁻¹²⁴ Therefore, they should, as a rule, be avoided.

Restraints for prolonged periods of time also increase the risk of a deterioration of cognitive and functional performance, falls, decreased social engagement, depression, agitation, pressure ulcers and contractures.¹²⁵⁻¹³⁰ The U.S. have effectively limited restraint use by strict regulations. Education of nurses only may have variable effectiveness.^{131,132} Mechanical restraints such as belts should be avoided whenever possible, and used only in exceptional circumstances,¹³³ and consistent with local regulations. If used, it should be regularly recorded, monitored and supervised.¹³³ Surveillance technology may replace mechanical restraints in some cases, but ethical issues such as privacy remain the subject of debate.¹³⁴

6.4 Hydration, preferably subcutaneous, may be provided if appropriate, such as in case of infection; it is inappropriate in the dying phase.

Older people with dementia are at increased risk of dehydration.¹³⁵ Hydration status affects survival in pneumonia.^{136,137} Subcutaneous rehydration (hypodermoclyses) may be less burdensome for confused patients, and recognising difference in practice, it may be provided more easily outside the hospital with similar effectiveness as intravenous rehydration, although there is not much evidence from clinical trials.^{138,139} Effects of hydration on, e.g., wound healing and decubitus ulcers are unclear.¹⁴⁰

In dying patients hydration is no longer necessary, and this needs to be tactfully and sympathetically explained to families. Attitude and communication of health care staff should do justice to possible cultural and religious sensitivities around withdrawal of hydration. Thirst can be managed with appropriate mouth care. Hydration may increase the risk of respiratory secretions, death rattle, and fluid retention, but evidence on indications in palliative populations is scarce.¹⁴¹

Of note, there was moderate agreement among experts on this recommendation (as opposed to high agreement for most other recommendations). This was mostly due to concerns about cultural and religious sensitivities and subcutaneous hydration not being routine practice in some countries, which are, however, addressed in the explanatory text.

6.5 Permanent enteral tube nutrition may not be beneficial and should as a rule be avoided in dementia; skilful hand feeding is preferred.

Observational studies suggest that tube feeding does not increase or decrease survival in dementia compared to hand feeding, although there is no conclusive evidence.¹⁴²⁻¹⁴⁵ There is also no conclusive evidence that enteral tube nutrition is effective in terms of improving quality of life, or leading to a better nutritional status or decreasing the risk of pressure sores. It may increase the risk of developing pneumonia. On the other hand, hand feeding increases social interactions and allows the taste of food to be enjoyed.¹⁴⁶ There is some evidence that high-calorie supplements and other oral feeding options, such as appetite stimulants, personal assistance with feeding, and modified foods, result in weight gain.¹⁴⁷ Although countries may differ in practice and family demand, an individually tailored support package, including prudent assessment, informing of families and shared decision making is paramount in all countries. Similar as with withdrawal of hydration (6.4), attitude and communication

of health care staff should do justice to possible cultural and religious sensitivities around providing of enteral tube feeding.

Of note, there was moderate agreement among experts on this recommendation (as opposed to high agreement for most other recommendations), when formulated as: “Permanent enteral tube nutrition may not increase survival and should as a rule be avoided in dementia; skilful hand feeding is preferred.” We have revised the recommendation slightly addressing comments that survival is not the main outcome addressed in palliative care. Some experts favoured individual decision making above general rules. We have addressed individualising of care, and addressing of sensitivities in the explanatory text.

6.6 Antibiotics may be appropriate in treating infections with the goal of increasing comfort by alleviating the symptoms of infection. Life-prolonging effects need to be considered, especially in case of treatment decisions around pneumonia.

Antibiotics may provide fast symptom relief in symptomatic urinary tract infections and burdensome bacterial infections, although there is little evidence specific to dementia. The evidence about effects of antibiotics on symptom relief in pneumonia is conflicting.¹⁴⁸⁻¹⁵⁰

Further, antibiotics may increase the chances of a prolonged life, but in patients with pneumonia and severe dementia, probably only in a minority of cases.^{137,151} Hydration status may be as or more important for life prolongation as antibiotics.^{136,137} Therefore, the effects of antibiotics in terms of life-prolongation, especially in pneumonia, are uncertain and need to be considered carefully taking into account other aspects relevant to decision making, such as ethical aspects regarding preferences and best interest.

7. Optimal treatment of symptoms and providing comfort

7.1 A holistic approach to treatment of symptoms is paramount because symptoms occur frequently and may be interrelated, or expressed differently (e.g., when pain is expressed as agitation).

Many patients suffer from pain, shortness of breath, and agitation/restlessness. Pain and shortness of breath increase towards the end of life. Patients are at risk of underdiagnosis and undertreatment, and also mistreatment with medication when non-pharmacological therapies should be preferred.^{1,53,87,152-154} Behaviour that challenges or behaviour that is a problem to the patient (behavioural and psychological symptoms of dementia, BPSD) should be dealt with together with physical symptoms, because behavioural symptoms are prominent and typical in dementia, and because they are interrelated. For example, providing pain relief may diminish agitation;¹⁵⁵ and changes in depressive symptoms¹⁵⁶ or in physical activity¹²⁹ may also change agitation levels. Therefore, behavioural change should trigger assessment,¹⁵⁴ and a trial of analgesics may be indicated¹⁵⁴ for distress for which no cause can be found.

Further, depressive symptoms are common throughout all stages of dementia, and depression and depressive symptoms are being under diagnosed and under treated.¹⁵⁷⁻¹⁵⁹ Diagnosing depression in patients with more severe dementia is challenging, but screening tools for depressive symptoms valid for dementia patients are available such as the Cornell Scale for Depression in Dementia, and adapted criteria for diagnosing depression in Alzheimer’s disease.^{160,161} The adapted criteria require different symptoms and different levels of symptoms, and some criteria for symptoms have been revised. For

example, concentration problems are not included, whereas additionally, social isolation or withdrawal is required, and there are revised criteria for loss of interest or pleasure.

7.2 Distinguishing between sources of discomfort (e.g., pain or being cold) in severe dementia is facilitated by integrating views of more caregivers.

Identifying a source of discomfort is facilitated by familiarity with the patient.¹⁶² Family and professional caregiver views may have to be integrated for the most accurate assessment.¹⁶³

7.3 Tools to assess pain, discomfort and behaviour should be used for screening and monitoring of patients with moderate and severe dementia, evaluating effectiveness of interventions.

Self assessment pain rating scales can often be used in mild and moderate dementia, but in severe dementia, should be supplemented by observation of body language and facial expression which may provide valid clues to patients being in pain.¹⁶⁴⁻¹⁶⁶ A variety of tools to assess pain in dementia have been developed and some tools have been tested in multiple studies with positive results, and have also provided cut off points suggesting the need for interventions.¹⁶⁷⁻¹⁷⁰ These include the Pain Assessment in Advanced Dementia (PAINAD) scale¹⁷¹ (cutoff for pain 2 of 10 points¹⁷²), the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC)¹⁷³ (cutoff for pain 4 of 24 of reduced-item PACSLAC¹⁷⁴), and Doloplus¹⁷⁵ (cutoff for pain 5 of 30¹⁷²). Some tools are rather complex to apply in practice. For instance, the Discomfort Scale-dementia of Alzheimer type (DS-DAT) integrates frequency, intensity and duration of behaviour in its rating of discomfort. It is, so far, the only well-validated tool to assess discomfort specifically in dementia.¹⁷⁶ Another tool has been developed for patients with communication difficulties more generally, but requires familiarity with the patient.^{177,178} Observation tools for discomfort and pain need to be applied when the environment does not cause distress; otherwise, pain tools may not be specific enough.^{176,177,179,180} Clinical assessment and judgement are, therefore, required in the assessment of possible pain.

For patients unable to self-report dyspnoea, including dementia patients, the Respiratory Distress Observation Scale (RDOS) is available.¹⁸¹ Among the most highly cited measures to assess challenging behaviour for use in research and practice, the best psychometric properties are ascribed to the Neuropsychiatry Inventory (NPI) and Behavioral Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD).^{182,183} These scales correlate with the Cohen-Mansfield Agitation Inventory (CMAI) which is also widely used and may be a good tool to assess agitation for clinical use and research. Some of the instruments require training.^{182,183} Further, tools specific to dementia may help the health care team and family caregivers detect delirium.^{184,185}

Although evidence is sparse, monitoring with tools may be helpful in particular with potentially distressing conditions near the end of life when some symptoms (pain and shortness of breath) tend to increase.¹⁵³ Familiarity with tools might help raise awareness to possible signs of distress. Tools may be used routinely,¹⁵⁴ in case of conditions that are commonly associated with discomfort or pain, and to evaluate effects of interventions.¹⁸⁶ Specific conditions, such as pneumonia, require attention to possible discomfort.¹⁸⁷ Other condition, such as peripheral vascular disease and musculoskeletal disorders should raise attentiveness to possible pain.¹⁸⁸

7.4 Both non-pharmacological and pharmacological treatment of physical symptoms, challenging behaviour, or discomfort should be pursued as needed.

Both pharmacological treatment and non-pharmacological treatment (with psychosocial interventions) of symptoms may be indicated.^{53,189} Psychosocial interventions, such as sitting with a patient, are first-line treatment.¹⁹⁰ Such interventions may be behaviour- emotion- or cognition oriented, including activities such as Snoezelen, therapies based on pleasant activities, reminiscence and therapies which may reduce depression and affect behaviour¹⁹¹⁻¹⁹⁵ although the evidence is limited.¹⁹⁶⁻²⁰⁰

A systematic step-wise approach to dealing with symptoms may help encourage psychosocial interventions as the appropriate first step, with pharmacological treatment only as needed. Nurses' employing such approaches may reduce the use of unnecessary medication and may improve patient's comfort.^{20,201} However, this should not impede the use of appropriate medical treatment of physical symptoms, for example the early use of opioids for treatment of pain or dyspnoea. End-of-life care pathways have the potential to improve symptom management in palliative populations, but high-quality studies are lacking.²⁰² Pharmacological treatment of pain may take into account general guidelines for pain in older persons²⁰³ as long as guidelines specific to pain in dementia are unavailable.

7.5 Nursing care is very important to ensure comfort in patients near death.

Nursing care, such as repositioning and moistening of lips, may ensure comfort. Several routine daily practices may be discontinued or modified, such as weighing, daily medications when the patient has difficulty swallowing or refuses them, and getting out of bed when death is imminent. To alleviate skin excoriation from incontinence, more frequent perineal care and skin hygiene is given, which involves regular washing and changing of incontinence supplies. Catheterization should be avoided as a rule. Pressure redistribution mattresses, perineal foam cleansers, and dry skin emollients have been shown to prevent pressure ulcers cost-effectively in long-term care settings, although this is not specific to dementia or the end of life.²⁰⁴ Ice chips and more frequent oral care can be provided to alleviate the discomfort of dry mouth from minimal oral intake.²⁰⁵ Use of Snoezelen may be integrated with usual care, music, warmth, etc. which may also be helpful if it suits the patient's wishes or style, although there has been little study in an end-of-life context.²⁰⁶

7.6 Specialist palliative care teams may support staff in long-term care settings in dealing with specific symptoms, while maintaining continuity of care. In managing behavioural symptoms, however, palliative care teams may need additional dementia care specialist expertise.

The integrated approach of treating symptoms is facilitated by the cooperation of dementia care and palliative care. Dementia care specialists should identify local palliative care specialists, whereas palliative care specialists and teams should seek local dementia care resources.²⁰⁷

Note also 10.2, core competencies, and 11.3, collaboration

8. Psychosocial and spiritual support

Note also domain 9 for support to family specifically.

8.1 In mild dementia, as also in the later stages, patients may be aware of their condition and patients and families may need emotional support.

The health care team should be attentive to possible coping problems, and input from social workers, psychologists, or people with similar expertise, preferably specialised in palliative care, may be needed.²⁰⁸

8.2 Spiritual caregiving in dementia should include at least assessment of religious affiliation and involvement, sources of support and spiritual wellbeing; in addition, referral to experienced spiritual counsellors such as those working in nursing homes may be appropriate.

Religious beliefs may affect the way patients experience dementia: patients with dementia and, importantly, their caregivers may benefit from spiritual support.^{5,209} Spiritual caregiving in dementia may be a neglected area²¹⁰ and there is little evidence to support specific interventions. A life review, if no longer possible for the patient, may help the family to come to terms and reflect on the relationships that have evolved.⁵⁴ Referral to experienced spiritual counsellors such as those working in nursing homes may be appropriate, but staff providing spiritual care may be appreciated.²¹¹ Of note, it is important that spiritual care is consistent with patient- and family-centred principles.

8.3 Religious activities, such as rituals, songs, and services may help the patient because these may be recognized even in severe dementia.

Visual symbols such as candles, menorahs, crucifix, rosaries, praying hands or a holy book, and sounds such as words of liturgy or recordings of church bells or shofar horns can also help by focusing or cueing patients with cognitive impairment.^{53,212-214} Nurses play an important role in signalling spiritual needs and providing of spiritual care.²¹⁵ Collaboration with professional spiritual caregivers, or having them as part of the team, and availability of visual symbols and other materials can facilitate spiritual care giving to patient and family.

8.4 For dying people, a comfortable environment is desirable.

Move to a private room may be needed early, avoiding transfer in a rush.²¹⁶ Volunteers may help in attending to the support needs of the patient. A loving and caring environment is required and is as important as it would be for people without dementia. Although not evidence-based, models for psychosocial care with severe dementia have been developed and may inspire or improve caregiving in dying patients with dementia. For example, Namaste Care has been developed specifically for people for whom participating in traditional activities is impossible. The program includes addressing of physical needs, but also a change to a soothing environment with staff paying attention to them, and offering activities and beverages, and monitoring of comfort.¹⁹²

Note also 7.4, non-pharmacological and pharmacological treatment

9. Family care and involvement

9.1 Families may suffer from caregiver burden, may struggle to combine caring with their other duties and may need social support.

Caregiving for a patient with dementia is especially burdensome^{22,40,154,217} and a variety of tools have been developed to assess caregiver burden.²¹⁸ Sources of burden and distress need to be identified. Families may struggle with various ethical issues.²¹⁹ Social support is important, for families are often struggling with depression and anxiety.¹¹⁰ Group and individual interventions may decrease caregiver depression²²⁰ or caregiver burden.²²¹ Respite care—services that allow for breaks in family caregiving –

can be beneficial for family caregivers although evidence is sparse,^{222,223} and may be offered even in earlier stages of dementia.

9.2 Families may need support throughout the trajectory, but especially upon diagnosis, when dealing with challenging behaviour, with health problems, with institutionalization, with a major decline in health, and when death is near.

Disclosure of diagnosis and prognosis is important to anticipate needs, but strategies should take into account family receptiveness and sensitivities. Dealing with challenging behaviour and (inter- or concurrent) health problems may involve difficult decision making. Institutionalization, although initially a relief to families, may involve new difficulties and often induces feelings of guilt. It does not, therefore, necessarily relieve caregiver burden.²²⁴ During the last 24 or 48 hours specifically, families need someone to explain what is happening to the patient, to minimize a family's distress.⁵³ *Note also 5.1, discussing of the terminal nature of dementia*

9.3 Families need education regarding the progressive course of the dementia and (palliative care) treatment options; this should be a continuous process addressing specific needs in different stages, examining family receptiveness.

The health care team can help a family through ongoing education and communication about the disease and how the patient is doing.^{53,110,154,225} Information is best provided in a stepwise fashion.^{226,227} Education may combine discussion with written or video materials and nurses and social workers may have an important role in this.²²⁸⁻²³⁴ Use of a family guide on comfort care²²⁹ has been accepted as best practice by WHO.²³⁵

9.4 Family involvement may be encouraged; many families may wish to be involved in care even when the patient is admitted to an institution providing long-term care.

Families may wish to continue their involvement in care after admission to an institution providing long-term care.^{224,236-238} Families' positive attitudes and high expectations of care actually increases the chances of them being satisfied with care,^{225,239} but high visiting frequencies and families providing significant hands-on care may also signal dissatisfaction and concerns about care.^{225,239,240} Families may need education on how best to communicate with the patient and help, for instance, with handfeeding.²⁰⁶ They should be taught how to perform comfort care.⁵³

9.5 Families need support in their new role as (future) proxy decision maker.

Families will need help to distinguish between previous patient wishes, inferred wishes based on the patient's values, their own wishes, and ideas about the patient's best interests,²⁴¹⁻²⁴⁴ as well as help to deal with feelings of distress and guilt when participating in decision making.^{29,35,36,230} Some families may prefer the health care team to take decisions.^{35,36}

Note also 2.3, information needs, and 3.1, prioritizing care goals

9.6 Professional caregivers should have an understanding of families' needs related to suffering from chronic or prolonged grief through the various stages, and with evident decline.

Chronic or prolonged grief, also called anticipatory or pre-grief, may occur with losses through the various stages of dementia. The health care team should support the family throughout their prolonged grieving process.⁵³ Chronic grief may increase with the severity of the dementia^{245,246} and remain

relatively stable for families of patients in the advanced stages.²⁴⁷ Chronic grief is associated with higher caregiver burden and caregiver depression and other unfavourable conditions.^{217,245,248}

9.7 Bereavement support should be offered.

Bereavement support can take various forms, such as convening of memorial services or individual contacts.^{53,249} As a minimum, a possible need for bereavement support should be assessed, and referral considered if needed. Of note, some families may also feel relieved after a long period of chronic grief.²³⁰

9.8 Following the death of the patient, family members should be allowed adequate time to adjust after often a long period of caring for the patient.

This implies, for example, that clearing the room of residence within just days after death should be avoided if possible. Further, an evaluation of the last phase of life may help families and also professional caregivers to improve care. Those family caregivers who are most heavily involved in care, those who have high levels of pre-loss depressive symptoms and burden, or those caring for a more cognitively impaired patient, are more likely to suffer from complicated grief post-loss.²⁵⁰

10. Education of the health care team

10.1 The health care team in its entirety, including allied health professionals and volunteers, need to have adequate skills in applying a palliative care approach to dementia.

Responsibilities may be shared within the health care team. Training, preferably on an ongoing or continual basis, may be necessary. Educational courses alone may not be sufficient in institutional settings, and organizational culture may need to be addressed as well.^{251,252}

10.2 Core competencies comprise all of the above listed domains (1 to 9). All competencies should be available within a health care team, and preferably all individual members of the team should be able to provide at least a baseline palliative care approach.

Some competencies are general, such as respecting the individual and empathic skills. Dementia specialists may need specific training in employing palliative care principles and advance care planning. Palliative care specialists may need to learn specifically about the course of dementia and timely recognition of dying, symptoms, goal-setting, palliative care measures and how to interact with patient and family more.⁵³ Further, spiritual caregivers, social workers, psychologists, occupational and art therapists, dieticians and other people working in or with the palliative or dementia care team should acquire basic training in palliative and dementia care. This will also facilitate collaboration across the health and social care interface. Special attention should be given to specific training of care workers/nurse aids in nursing homes in communication skills and symptom assessment.^{253,254}

It may be helpful to have a team member specialize in palliative care and take the lead to implement it, such as the champion or link nurse model.²⁵² Another strategy is for dementia care specialists to identify local palliative care specialists, and palliative care specialists to seek local dementia care resources.

11: Societal and ethical issues

11.1 Wherever patients reside, patients with dementia should have access to palliative care on the same footing as patients with other diseases which are unresponsive to curative treatment.

The patient's dignity should be preserved at all times. Based upon human rights and non-discrimination against people with dementia, dementia patients should have access to palliative care, with no more restrictions than other patients eligible to receive palliative care. Related to this, palliative care services should be adequately equipped to treat patients with dementia. Access should be monitored and backed up by national policies if required.^{16,29,87,123,255,256}

11.2 Family caregivers should have access to adequate support to combine caring for the patient with dementia with other duties.

Support should be available, in the shape of palliative care services, for families to combine care for the patient with other duties. This should include involvement of volunteers, availability of respite care, flexible working hours and "palliative care leave" for people caring for someone with dementia who is dying, and financial counselling. Inclusion of social workers in the health care team may facilitate this type of support, but other models should be able to provide the same services. This is becoming more important in Europe and elsewhere where long-term care needs in general are expected to double in the next few decades. Owing to aging societies and smaller families than previously, there will be a strong increase in the ratio of older people with dementia versus the generation potentially caring for them.^{257,258}

11.3 Collaboration between dementia and palliative care should be promoted.

Collaboration is highly important as indicated before, as it facilitates integrated treatment of physical and behavioural symptoms, and as a spin-off, will educate specialists from both sides. Local networks should therefore include dementia and palliative care specialist expertise. For example, multi-disciplinary palliative care teams available for consultancy or teams outreaching or visiting people where they reside may include both geriatricians and psychologists, and palliative care specialists.

11.4 Curricula for training of physicians and nurses at both undergraduate and postgraduate level, as part of continuing professional education, should include palliative care for patients with illness other than cancer.

Curricula for health care professionals including, but not limited to physicians and nurses should reflect differences in disease trajectory and concomitant differences in care needs of patient and family.

Note also domain 10 for education of the health care team

11.5 Professional caregivers should be motivated to work in dementia and palliative care and adequate funding for sufficient staffing is needed.

It may be challenging to attract, train, and maintain an adequate and skilled work force to provide compassionate care for people with complex long-term care needs.²⁵⁹ This is concerning, because staff shortage and turnover have been related to decreased quality of care in institutional settings.²⁶⁰⁻²⁶² Salary and working conditions should be sufficiently rewarding so as to reflect the value of the work carried out by people working in this domain.

11.6 Economic and systemic incentives should encourage excellent end-of-life care for patients with dementia.

Payment systems including health insurance systems should align incentives, and quality monitoring systems should include measures specific to dementia.¹⁵⁴

11.7 Awareness raising about palliative care in dementia is needed.

Family and professional caregivers of patients with dementia as well as the general public, may be insufficiently aware of the terminal nature of the dementia and the applicability of palliative care.^{35,36,154} As many people will either eventually develop dementia or deal with dementia in their environment, educating the general public may be worthwhile to raise awareness and preparedness for advance care planning.

11.8 National strategies for dementia, for palliative care, end-of-life care, and for long-term care should each include palliative care for dementia patients. Similarly, policy making on palliative care and long-term care settings should attend to dementia.

Policies, strategies and guidelines on palliative care should include dementia, and those on dementia should include palliative care, as this acknowledges the importance of high quality end-of-life care in dementia and raises awareness among policy makers. The UK national dementia strategy and End of Life Care Strategy^{263,264} address end-of-life care in dementia explicitly, but most other nations so far have not done so. Australia has issued national long-term care guidelines that include a paragraph on advanced dementia.²⁶⁵

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