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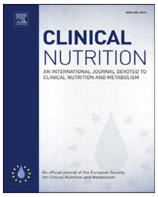

ESPEN Guideline

ESPEN guideline on nutrition and hydration in dementia – Update 2024

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SUMMARY

Background & aims: Dementia is accompanied by a variety of changes that result in an increased risk of malnutrition and low-intake dehydration. This guideline update aims to give evidence-based recommendations for nutritional care of persons with dementia in order to prevent and treat these syndromes.
Methods: The previous guideline version was reviewed and expanded in accordance with the standard operating procedure for ESPEN guidelines. Based on a systematic search in three databases, strength of evidence of appropriate literature was graded by use of the SIGN system. The original recommendations were reviewed and reformulated, and new recommendations were added, which all then underwent a consensus process.
Results: 40 recommendations for nutritional care of older persons with dementia were developed and agreed, seven at institutional level and 33 at individual level. As a prerequisite for good nutritional care, organizations caring for persons with dementia are recommended to employ sufficient qualified staff and offer attractive food and drinks with choice in a functional and appealing environment. Nutritional care should be based on a written care concept with standardized operating procedures. At the individual level, routine screening for malnutrition and dehydration, nutritional assessment and close monitoring are unquestionable. Oral nutrition may be supported by eliminating potential causes of malnutrition and dehydration, and adequate social and nursing support (including assistance, utensils, training and oral care). Oral nutritional supplements are recommended to improve nutritional status but not to correct cognitive impairment or prevent cognitive decline. Routine use of dementia-specific ONS, ketogenic diet, omega-3 fatty acid supplementation and appetite stimulating agents is not recommended. Enteral and parenteral nutrition and hydration are temporary options in patients with mild or moderate dementia, but not in severe dementia or in the terminal phase of life. In all stages of the disease, supporting food and drink intake and maintaining or improving nutrition and hydration status requires an individualized, comprehensive approach. Due to a lack of appropriate studies, most recommendations are good practice points.
Conclusion: Nutritional care should be an integral part of dementia management. Numerous interventions are available that should be implemented in daily practice. Future high-quality studies are needed to clarify the evidence.

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Abbreviations

AD	Alzheimer's disease
ADAS-Cog	Alzheimer's Disease Assessment Scale-Cognitive Subscale
ADL	Activities of Daily Living
AFBI	Aversive Feeding Behavior Inventory
BMI	Body Mass Index
EBS	Eating Behaviour Scale
EdFED-Q	Edinburgh Feeding Evaluation in Dementia Questionnaire
EN	Enteral Nutrition
GDS	Global Deterioration Scale
GLIM	Global Leadership Initiative on Malnutrition
KD	Ketogenic Diet
MA	Megestrol Acetate
MCI	Mild Cognitive Impairment
MCT	Medium Chain Triglycerides
MDS	Minimum Data Set
MMSE	Mini-Mental State Examination
MNA	Mini Nutritional Assessment
n3-PUFA	omega-3 Polyunsaturated Fatty Acid
ONS	Oral Nutritional Supplements
PEG	Percutaneous Endoscopic Gastrostomy
PN	Parenteral Nutrition
RCT	Randomized Controlled Trial
SOP	Standardized Operating Procedures
SR	Systematic Review

1. Introduction

1.1. Dementia

Dementia is a malignant and devastating clinical syndrome characterized by global cognitive impairment with a decline in memory and at least in one other cognitive domain, such as language, visuospatial, or executive function [1,2]. Many diseases can cause a dementia syndrome with Alzheimer's disease (AD), Lewy-body dementia, cerebrovascular dementia and mixed forms as the most common causes.

Worldwide, as a consequence of demographic changes, the prevalence of dementia is increasing. Estimates suggest that currently in the European region almost ten million people are affected and that these figures will almost double by 2050 [3].

The cognitive decline caused by dementia inevitably leads to functional losses and difficulties in communication and social interaction that become more and more serious as the severity of the condition increases [4,5]. In general, three broad levels of severity can be described. Early dementia where memory loss and disorientation are predominant, mild to moderate dementia with marked loss of function in instrumental activities of daily living and finally the severe stage of dementia with marked communication difficulties and reliance on others for basic activities of daily living (Table 1).

Dementia thus causes a high burden of suffering not only on affected persons, but also on their families and for societies [6,7].

1.2. Nutritional challenges

The many pathophysiological changes associated with dementia also affect eating and drinking (Table 2). A prominent clinical feature of dementia is weight loss, beginning even before diagnosis of the disease, and becoming more common with its progression [8–12]. Loss of smell, taste and appetite are typical in the early stages of dementia and are also associated with early weight loss. Disorders of orientation and attention may cause problems with shopping, storing and preparing food and result in a reduced variety and an unbalanced diet. As the disease progresses, the ability to concentrate on eating and drinking and to initiate and continue meals diminishes. Apraxia and agnosia jeopardize independence. Social relationships may be lost, so eating and drinking with others is reduced. Behavioral problems emerge and eating and drinking skills, namely the use of cutlery, are lost; eating and drinking may be literally forgotten. Agitation and hyperactivity may make mealtimes difficult and increase energy requirements. On the other hand, sedative effects of pharmacotherapy may reduce eating drive and dietary intake. Finally, swallowing disorders may develop, and ultimately eating and drinking may be completely rejected, often associated with great stress for relatives and carers and difficult ethical decision-making situations [13–24]. Thus, as the disease progresses, the prevalence of malnutrition increases [25].

In addition to these dementia-specific nutritional problems, in all stages of the disease, older persons with dementia may be affected by age-related impairments, disabilities and comorbidities (e.g. loss of appetite and thirst, chewing problems, depression, problems with continence) leading to reduced food and fluid intake and, as a result, to malnutrition and dehydration [26–28]. In long-term care institutions, based on 24 studies, a pooled prevalence of malnutrition of 27% and a combined pooled prevalence of malnutrition and risk of malnutrition of 80% was found in residents with dementia [29]. Low-intake dehydration is described in 20–30% of older people [30,31], and it is reasonable to assume a higher prevalence in persons with dementia, even if there is no specific data on this.

The serious consequences of insufficient food and fluid intake in older persons are well known and also well documented in persons with dementia, namely an increased risk of sarcopenia, frailty, morbidity and mortality [25,32–38]. Since many nutrients play an important role for brain structure and metabolism, nutritional deficiencies (including a lack of water) may impair cognitive abilities. Thus, malnutrition and dehydration may trigger a vicious circle of dementia leading to decreased food and fluid intake and deterioration of nutrition and hydration status, which itself contributes to acceleration of dementia (Fig. 1).

In addition, due to the great social and emotional importance of eating and drinking, problems in this regard are extremely stressful for persons with dementia, their relatives and carers [39,40]. It has been shown in longitudinal studies that caregiver burden increases the risk of adverse eating behavior [41] as well as the risk of weight loss [10,42] in patients with AD.

1.3. Rationale for the guideline and aims

In summary, nutritional problems are part of the increasingly common dementia syndrome, and put those affected at high risk of developing malnutrition and dehydration. Malnutrition and dehydration are associated with poor outcome, contribute to disease

Table 1
Stages of cognitive dysfunction and dementia.

	Normal	MCI	Early dementia	Mild to moderate dementia	Severe dementia
Memory	No memory loss or slight inconsistent forgetfulness	Consistent slight forgetfulness; partial recollection of events; objective memory deficit when interviewed	Moderate memory loss; more marked for recent events; memory loss interferes with every day activities	Severe memory loss; only highly learned material retained; new material rapidly lost	Severe memory loss; only fragments remain; finally unable to communicate verbally
Orientation	Fully oriented	Fully oriented except for slight difficulty with time relationship	Moderate difficulty with time relationship; oriented for place in known environment; may have geographic disorientation elsewhere	Severe difficulty with time relationships; usually disoriented to time and often to place	Oriented to person only
Judgment & problem solving	Solves everyday problems; handles business and finances well; judgment good in relation to past performance	Slight impairment in solving problems, similarities and differences	Moderate difficulty in handling problems; similarities and differences, social judgment usually maintained	Severely impaired in handling problems, similarities and differences; social judgment usually impaired	Unable to make judgments or solve problems
Social activities	Independent function at usual level, shopping, volunteer and social groups	Slight impairment	Unable to function independently at these activities although may still be engaged in some; appears normal to casual inspection	No independent function outside home; well enough to be taken to functions outside home	No independent function outside home; too ill to be taken to functions outside home
Home and hobbies	Life at home, hobbies and intellectual interests well maintained	Life at home, hobbies, and intellectual interests slightly impaired	Mild but definite impairment of function at home; more difficult chores abandoned; more complicated hobbies and interests abandoned	Only simple chores preserved; very restricted interests, poorly maintained	No significant function in home
Personal care	Fully capable of self-care	Fully capable of self-care	Needs prompting	Requires assistance in basic ADL; may become incontinent	Dependency in basic ADL; incontinent
Affect	Normal	Some denial as defense; mild anxiety	Denial is dominant; emotional blunting; withdrawal	Delusions; anxiety and agitation; repetitive obsessive behavior	Disturbed diurnal rhythm; delusions
CDR Scale	0	0–0.5	1–2	2–3	3
GDS-Reisberg Stage	1–2	3	4	5–6	6–7

ADL = activities of daily living, CDR = Clinical Dementia Rating (copyrighted instrument of the Alzheimer's Diseases Research Center, Washington University, St. Missouri, USA) [4], GDS = Global Deterioration Scale [5], MCI = mild cognitive impairment.

Table 2
Dementia-related disorders affecting nutrition in different disease stages.

Dementia-related disorder	Stage of dementia
Olfactory and taste disorders	Preclinical and early
Attention deficit	Mild to moderate
Impaired executive functions	Mild to moderate
Impaired decision-making ability	Mild to moderate
Dyspraxia[a]	Moderate to severe
Agnosia[b]	Moderate to severe
Behavioral problems	Moderate to severe
Agitation, wandering	Moderate to severe
Oropharyngeal dysphagia	Moderate to severe
Refusal to eat	Severe

[a] Coordination disorder, loss of eating skills.

[b] Loss of ability to recognize objects or comprehend the meaning of objects, which means that food may not be distinguished from non-food and that eating utensils are not recognized as what they are.

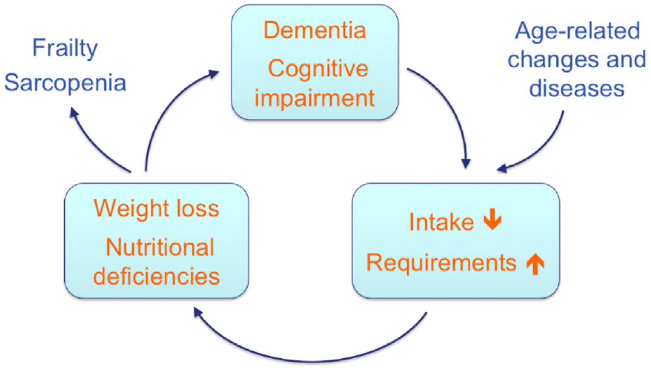

Fig. 1. Vicious circle of nutritional deficiencies and dementia.

progression and increase caregiver burden, which in turn may aggravate nutritional problems.

A range of interventions is available to counteract these problems. Disrupting the vicious circle of malnutrition and cognitive decline may support affected persons and decrease the burden of this devastating syndrome. Regarding the limited effects of pharmacological interventions, non-pharmacological strategies like nutritional interventions are of particular interest as part of disease management.

In 2015, ESPEN Guidelines on Nutrition in Dementia were published for the first time [43] with the aim to summarize the available evidence in this regard. The increasing relevance of the topic and the ongoing publication of new scientific findings make it necessary to update the existing guideline. Furthermore, there has been a greater awareness of the specific problem of dehydration in recent years.

Thus, this guideline update aims to provide current evidence-based recommendations for nutritional care of persons with dementia and answer the overarching question of which interventions are effective in preventing and treating malnutrition and dehydration.

2. Methods

2.1. General methodology

The present guideline is an updated version of the “ESPEN Guideline on Nutrition in Dementia” published in 2015 by Volkert et al. [43]. It was developed according to the standard operating procedure for ESPEN guidelines [44] by a multinational expert group representing different professions including physicians (TF, RW), dietitian researchers (AMB, GFI, LH, HK, JP, ER, MS) and a nutrition scientist (DV) which was founded in autumn 2021 and has since then worked closely together in regular online meetings.

The first development step of this guideline was to check the original PICO questions for further applicability and extension. PICO questions are designed to address specific **p**atient groups (or **p**roblems), **i**nterventions, **c**ompare different interventions, and be **o**utcome-related [44]. To answer the updated PICO questions (for details see below, “special aspects”), a literature search that covered the period since the last guideline was performed to identify suitable meta-analyses, systematic reviews (SRs), and primary studies (for details see below, “search strategy”). Each PICO question was allocated to two experts for the respective topics, and 40 recommendations answering the PICO questions were formulated. To evaluate the literature, the AMSTAR 2 checklist [45] was used for SRs, the Cochrane risk of bias tool [46] for RCTs, the Newcastle–Ottawa scale [47] for cohort studies and cross-sectional studies, and a checklist from the National Heart, Lung, and Blood Institute (NIH) for pre-post studies [48]. The AMSTAR 2 checklist was slightly modified; items 2 and 7 were classified as non-critical because, due to the nature of the field of this guideline, they are rarely fulfilled, which would lead to unjustified critically low quality in very many cases. Supporting the recommendations, the working group added commentaries to explain their basis and background.

Grades of recommendation were determined according to the levels of evidence assigned (Table 3). In some cases, a downgrading of the recommendation was necessary based on Table 3, e. g. due to limited quality of primary studies included in a SR or meta-analysis which is described in the commentaries accompanying the respective recommendations.

The wording of the recommendations reflects the grades of recommendations: level A is indicated by the use of the word “shall”, level B by the word “should” and level 0 by the word “can” or “may”. Good practice points (GPP) are based on experts' (i.e. the authors') opinions due to the lack of studies for the respective PICO questions, the choice of wording was open and not predetermined here.

Overall, when assessing the evidence, it must be recognized that persons with dementia are an extremely vulnerable group, especially in advanced stages, and research is extremely difficult to conduct. Obtaining consent, randomization of individuals within shared living and eating areas, successful implementation of certain interventions and blinding are just some of the existing hurdles. Control groups without intervention are not ethically justifiable in many situations. Consequently, well designed high-quality studies are rare in the field of nutrition and dementia, and many recommendations are graded GPP. This, however, does not mean that these issues are any less important or relevant. The experience and unanimous, convinced opinion of the experts is a valuable substitute in these situations.

Between 21st June and 23rd July 2023, the recommendations were voted on online (Delphi round) using the guideline-services.com platform. All ESPEN members were invited to agree or disagree with the recommendations and to provide comments. In addition to the recommendations, current drafts of the commentaries were made available to the participants on that occasion. Thirty-eight recommendations reached an agreement >90% (indicating a strong consensus, see Table 4) and were directly passed. Two recommendations reached an agreement of >75–90%, and were thus subsequently revised based on the comments, and voted on again during a consensus conference that took place during the ESPEN congress in Lyon on 13th September 2023. Eight recommendations that originally had received more than 90% agreement were also voted again during the consensus conference due to significant changes in wording following the online feedback. One new recommendation was added based on comments issued during the Delphi round and one recommendation was deleted, thus, ten recommendations were voted on during the consensus conference. At the consensus conference, all recommendations but three received an agreement >90%. During the finalization of the comments, four recommendations (19, 34, 36, and 38) had to be subsequently amended due to further interpretations by the expert panel; these amendments were adopted unanimously by the group. The final guideline contains 40 recommendations. To support the recommendations and the assigned grades of recommendation, the ESPEN guideline office created evidence tables of relevant meta-analyses, SRs, (randomized) controlled trials, and cohort studies. These evidence tables are available online as supplemental material (Appendix A) to this guideline.

2.2. Special aspects

The present guideline update addresses nutritional care of persons with dementia. In accordance with the ESPEN Guidelines on Definitions and Terminology [50], ***nutritional care*** includes all

Table 4
Classification of the strength of consensus.

Strong consensus	Agreement of >90% of the participants
Consensus	Agreement of >75–90% of the participants
Majority agreement	Agreement of >50–75% of the participants
No consensus	Agreement of <50% of the participants

According to the AWMF methodology [49].

Table 3
Definition of grades of recommendation [44].

A	At least one meta-analysis, SR, or RCT rated as 1++, and directly applicable to the target population; or A body of evidence consisting principally of studies rated as 1+, directly applicable to the target population, and demonstrating overall consistency of results
B	A body of evidence including studies rated as 2++, directly applicable to the target population; or A body of evidence including studies rated as 2+, directly applicable to the target population and demonstrating overall consistency of results; or and demonstrating overall consistency of results; or Extrapolated evidence from studies rated as 1++ or 1+
0	Evidence level 3 or 4; or Extrapolated evidence from studies rated as 2++ or 2+
GPP	Good practice points/expert consensus: Recommended best practice based on the clinical experience of the guideline development group

RCT, randomized controlled trial, SR, systematic review.

measures to support adequate nutrition and hydration for preventive as well as therapeutic purposes.

The guideline update is based on the PICO characteristics summarized in Table 5.

Literature about persons with all types and stages of dementia from all health care settings was included, independent of age. Literature focusing on individuals with mild cognitive impairment (MCI) or no cognitive impairment (addressing prevention of dementia) was excluded. No distinction was made between different types and stages of dementia because there is hardly any specific literature available to date. Studies in nursing homes referring to the general nursing home populations not restricted to residents with dementia were only taken into account if there were no dementia-specific studies available. In addition to persons with dementia, organizations caring for persons with dementia and their staff were also considered for the first part of the recommendations. ***Organizations caring for persons with dementia*** are all facilities offering food and drinks, e.g. hospitals, residential and semi-residential care institutions but also home care service and providers of congregate meals and meal delivery. Unless otherwise stated, the recommendations apply to all health care settings. Although most of the studies were conducted in institutions, there is no reason to assume that the effectiveness of certain measures on people receiving care at home or in the various types of institutions are fundamentally different.

With regard to interventions, the whole range of possible measures that can contribute to the prevention and treatment of malnutrition and dehydration was considered except supplementation of single micronutrients and other single bioactive substances and herbal products.

In this context, it is important to note that dehydration refers specifically to ***low-intake*** *(or hypertonic)* ***dehydration***, which is caused by insufficient water intake and is widespread in older people due to the reduced sensation of thirst in old age. Other types of dehydration (iso- and hypotonic) are not addressed as they are caused by illness and only indirectly associated with nutrition [51].

In terms of comparators and outcomes, a broad spectrum of options was taken into account, too (Table 5). Papers that exclusively focused on brain biomarkers or brain imaging were excluded.

We would also like to mention that the recommendations are of a very general nature, but there are always well-founded exceptions and individual decisions must be made in each case.

Finally, we also refer to the ESPEN Guideline on Clinical Nutrition and Hydration in Geriatrics [52,53], which overall has relevance also for persons with dementia.

2.3. Search strategy

Literature was searched in the databases Medline, Embase and Cochrane Library (for SRs and trials) on 12th June 2022 from 2014 to the search date. Search terms for dementia and older people, malnutrition and dehydration, numerous interventions and publication type (meta-analyses, SRs, randomized controlled trials (RCTs)) were combined and non-human studies excluded in complex searches using truncation, indexing terms and Boolean operators. The complete search strategies can be viewed on reasonable request.

The search resulted in 8484 references. After elimination of duplicates 6074 titles and abstracts were screened in duplicate using the Covidence systematic review tool (www.covidence.org). 378 full-texts were assessed for eligibility and finally 163 references included. Furthermore, all references that were available to the authors or that were found while reading the literature were taken into account. The topic of oral care was not yet included in the search strategy, as it was identified as a priority area for consideration during the preparation of the guideline. An updated search was carried out to identify the relevant literature for inclusion on this topic.

Table 5
PICO characteristics of the present guideline.

Population	– persons with dementia (all types and stages, excluding mild cognitive impairment) – in all health care settings
Intervention	– all interventions to support adequate nutrition and/or hydration
Comparator	– standard care, placebo or other nutritional intervention
Outcomes	– dietary intake and nutritional status – clinical and functional course – quality of life, well-being – survival

2.4. Outline of the guideline

The 2024 guideline update consists of 40 recommendations derived from 31 PICO questions. It is divided into two parts, addressing four topics at the institutional and five at the individual level:

1. Institutional level
   - 1.1. Quality assurance of nutritional care
   - 1.2. Staff
   - 1.3. Environment
   - 1.4. Food and drink provision
2. Individual level
   - 2.1. Screening, assessment and monitoring
   - 2.2. Strategies to support oral nutrition and hydration
   - 2.3. Oral nutritional interventions
   - 2.4. Enteral and parenteral nutrition and hydration
   - 2.5. Individualized, comprehensive approach

3. Recommendations

3.1. Recommendations at institutional level

3.1.1. Quality assurance of nutritional care

Should organizations caring for persons with dementia establish a nutritional care concept and standardized operating procedures to support nutrition in persons with dementia?

Recommendation 1

A nutritional care concept should be used in all organizations providing care to persons with dementia to promote adequate and appropriate nutrition and hydration.

Grade of recommendation GPP – strong consensus (100% agreement)

Commentary

In view of the high risk of persons with dementia for malnutrition and dehydration, a nutritional care concept, which is defined here as a framework for nutrition and hydration care with the perspective that nutritional care is vital to the overall care of persons with dementia.

To ensure this prioritization of nutritional care, the concept should be available in written form and contain all ideas about the importance and implementation of the care, regarding nutrition as well as hydration. It must be in harmony with the overall philosophy of the organization and be based on basic ethical and care principles and the general state of knowledge. It requires leadership but also an explicit commitment to interdisciplinary cooperation between all professional groups involved in the provision of nutritional care.

Further, a relationship- and person-centered approach is an important component of nutritional care, that must be captured in the concept [54]. This approach puts the person with dementia at the center of care and recognizes the importance of relationships between the person affected, their relatives, and the multidisciplinary team in providing optimal care, especially in long-term care arrangements (e.g., nursing homes, home care).

It is the general aim of the nutritional care concept to promote adequate and appropriate nutrition and hydration, where “adequate” means that food and fluid provision meet the individual nutritional requirements and needs of the persons with dementia, while “appropriate” indicates that food and fluid provision is adapted to the individual preferences (e.g. culturally appropriate) and resources (e.g., considering eating capacity).

Recommendation 2

Standardized operating procedures for nutritional care shall be used to assign responsibility and accountability for adequate nutritional care in the organization.

Grade of recommendation GPP — strong consensus (100% agreement)

Commentary

In all organizations providing care to persons with dementia, standardized operating procedures (SOPs) to meet the nutrition and hydration needs must be established to guide practice in caring for these persons. These SOPs are intended to provide general orientation and a common basis for all persons involved in nutritional care, but also enable individual requirements and preferences to be taken into account.

SOPs for nutrition and hydration care should include the procedures for the procurement, production and distribution of food and drinks (see recommendations #6, #7), but also for systematic screening and nutritional assessment (see #8—#11), and all strategies to prevent and treat malnutrition and dehydration (see #12—40). In addition to describing the activities and processes, responsibilities of the professional groups involved and accountability must also be clearly indicated.

We are not aware of any trial examining the benefits of SOPs for nutrition and hydration care of persons with dementia, but SOPs are good clinical practice and commonly used for quality assurance of care.

3.1.2. *Staff*

3.1.2.1. Qualified staff. Should food and fluid intake in persons with dementia be supported by adequate levels of qualified staff?

Recommendation 3

Organizations caring for persons with dementia should employ sufficient qualified staff for supporting food and fluid provision and intake to ensure adequate nutritional care for all persons with dementia, including those who require eating and drinking assistance.

Grade of recommendation GPP — strong consensus (100% agreement)

Commentary

Persons with dementia experience physical, mental and behavioral changes that can impact food and fluid intake and therefore need support at different levels and from people of different professions who are familiar with these changes and associated challenges and know about suitable interventions.

Cooking staff must be knowledgeable regarding the specific nutritional issues and needs of persons with dementia, specifically, the requirement for different solid and fluid textures (see #26) and use of nutrient-dense ingredients and foods (see #25). Menu-planners for nursing homes and hospitals need sufficient time to plan and prepare high-quality menus, and for long-term care specifically, revise these menus regularly (see #7).

Further, sufficient staff to meet the eating and drinking support needs of persons with dementia who need assistance at meals and snacks is required. This support also includes staff time to regularly offer suitable drinks (see #19), supervise mealtimes and build personal relationships [54] (see #16). The need for eating support can vary from day to day and meal to meal, necessitating flexibility in staffing levels and time for meals to accommodate these changes. Sufficient staff during meals and snacks to appropriately support residents is also needed to ensure safety as well as dignity of the persons with dementia, and extends to sufficient staff to assist persons with dementia with using the toilet, so that fluid intake is not curbed to avoid incontinence. Towards the end of life, almost all residents with dementia will require some level of eating and drinking assistance and toilet support.

Thus, sufficient qualified staff are needed in organizations to adequately provide persons with dementia with high-quality food and drinks and appropriate support with eating and drinking.

Although some observational and quasi-experimental studies describe an association between lacking feeding assistance and low food intake, and positive effects of increased nursing time during meals on eating behavior, dietary intake and nutritional status [43,55], the overall evidence is very limited.

Some evidence from the hospital [56,57] and nursing home sector [58,59] suggests that trained volunteers and non-nursing staff can provide effective support with eating. For persons with dementia, only one small pre-post study about volunteers' assistance at mealtimes for seven hospitalized patients in a rehabilitation unit reports increased energy intake at lunch and increased BMI [60]. Despite this very limited direct evidence, eating support by volunteers could also be an option for persons with dementia, provided that they are well trained (see #5).

3.1.2.2. Education of caregivers. Should food and fluid intake in persons with dementia be supported by education of their caregivers?

Recommendation 4

All health care professionals should be educated on nutritional care issues to ensure awareness and skills to promote adequate food and fluid intake of persons with dementia.

Grade of recommendation B – strong consensus (100% agreement)

Commentary

Health care professionals, first and foremost nursing and caring staff but also, for example, house keepers, kitchen workers, therapists and doctors, are essential formal caregivers for persons with dementia, who are also responsible for nutritional care.

Nutritional care for persons with dementia requires awareness, knowledge and skills to provide adequate food and fluids, recognize nutritional problems, deal with the day-to-day challenges around eating and drinking that persons with dementia face and initiate adequate interventions to prevent and treat malnutrition and dehydration, including appropriate assisting strategies and managing the dining environment [61].

Training needs have been identified in a systematic scoping review, based on eleven predominantly qualitative trials about staff's confidence, competence or knowledge regarding managing mealtime difficulties in persons with dementia [61].

The effects of education and training of formal caregivers are addressed in several SRs about interventions to support nutrition in persons with dementia [61–70] which refer to 13 original studies [55,71–82]. More than half of these studies also include other interventions, e.g. change in food provision, environmental modifications or provision of oral nutritional supplements (ONS), so that the effects cannot be attributed to the education alone. Two cluster-randomized controlled trials [55,73], two cluster controlled trials [78,81] and two pre-post studies [80,82] had their focus on staff training. Eating assistance skills training or supporting self-feeding was the focus of six studies, but covered topics and education modes vary widely, likewise the duration and intensity of the education. Also, various professional groups are addressed individually or combined.

Positive outcomes were reported in most of the studies, e.g. improved dietary intake and nutritional status, increased self-feeding and decreased food refusal, but outcomes were very diverse and sometimes contradictory. When assessed [55,73,82], higher levels of knowledge or improved attitudes post-training were reported consistently.

Overall, research in this area is rather difficult to conduct, and training effects are difficult to verify due to the complexity of influencing factors (e.g. eating challenges) and very individual resources (of persons with dementia as well as of caregivers) and occurring problems. Moreover, training effects depend very much on baseline knowledge and attitudes before the training, which may also vary.

Nevertheless, existing studies provide promising evidence that education has positive effects on the knowledge and skills of staff and thus can promote food and fluid intake of persons with dementia. Education and skill training for staff is a necessary component of the multicomponent nutrition care concept that is needed to optimize nutrition of persons with dementia (see #40).

Training can be in-person, as well as web-based [55], providing greater flexibility for care staff. Further, it must be noted that updates and continuous learning should be incorporated into ongoing training for staff and also for volunteers. Yet, staff training cannot overcome insufficient staff time for the essential activity of nutritional care.

Recommendation 5

Informal caregivers should be offered education on nutritional care issues to ensure awareness and skills to optimize food and fluid intake of persons with dementia.

Grade of recommendation B – strong consensus (100% agreement)

Commentary

Informal caregivers, including family members, friends, neighbors and other volunteers, play a central role in supporting persons living with dementia, whether they live in the community or in a care organization. Due to their close contact with the person with dementia, they are able to identify changes in capacity for food-related activities, such as planning meals, grocery shopping and cooking-related tasks. As the dementia progresses, they can also identify changes in eating, drinking and swallowing capacity and should be able to ensure that food and fluid is consumed as well as possible, considering the eating challenges that may occur in persons with dementia, especially towards the end of life.

Thus, educating informal caregivers on these nutritional care issues will raise their awareness, provide the appropriate knowledge and skills and encourage prompt treatment and adequate intake. The goal of this education is to meet the nutritional requirements, but also promote pleasurable eating and drinking experiences for both, the informal caregiver and the person with dementia.

The effects of informal caregiver education are addressed in several SRs about supporting nutrition in persons with dementia [62,63,65–67,83]. These reviews refer to a total of eight different trials, including four (cluster) RCTs [84–87]. Sometimes the person with dementia was involved in the educational program. Group sessions with potential follow-up with a health professional, and individual sessions with a dietitian were also used in these interventions with varying content of the sessions. Also, decision aids on feeding options at the end of life were considered. As a result of the intervention, improved intake, nutritional status and health related quality of life, and decreased dependency and decisional conflicts have been reported, but results are not consistent, leading to a downgrade of the grade of recommendation.

In summary, education of informal caregivers and persons with dementia is a promising intervention, although further research is needed, especially to address challenges with more progressed cognitive impairment.

3.1.3. Environment

Should food and fluid intake in persons with dementia be supported by an adequate dining environment?

Recommendation 6

Meals and drinks should be provided in a functional dining room with an atmosphere that stimulates eating and drinking to support adequate dietary intake of persons with dementia.

Grade of recommendation GPP – strong consensus (100% agreement)

Commentary

Environmental factors play an important role for the atmosphere during mealtimes, including location and furniture, lighting, sounds, smells, accessibility of food and other persons present. All these factors influence the ambience during the meal and are known to influence food and fluid intake [88].

The question of whether changes in the environment affect food and drink intake of persons with dementia was addressed in several SRs [62–64,67,89–91] and summarized in an overview of SRs [92]. Environmental modifications are defined and categorized differently in theses SRs but generally include lighting and contrast (overall addressed in three trials), more home-like environment (two trials), music played during mealtimes (six trials), a fish aquarium in the dining area (one pre-post study), food service changes (e.g. help-yourself-meals, serving directly at the table) (seven trials) and social modifications (e.g. shared mealtime with others) (three trials).

As a result of these modifications, improvements in eating behavior, increased interactions and communication among residents, more active eating participation, increased independence and finally increased dietary intake have been described. However, the results are not consistent. Underlying studies are generally small, uncontrolled and very heterogenous with regard to type of intervention, outcome, follow-up etc.; therefore, the available evidence is mostly rated as critically low.

Nevertheless, there are positive examples, and it seems reasonable that institutions caring for persons with dementia provide a room that allows communal eating and drinking. This room should be easily accessible and have enough space for aids (i.e. wheel-chairs, walking frames) and for additional persons to eat and drink together (i.e. relatives, staff). Further, the atmosphere – including e.g. sounds, smells and food service – should be inviting and encourage eating and drinking. Distractions should be avoided as far as possible as this may negatively affect dietary intake.

Since favorable factors promoting dietary intake are individual, the environment and the conditions during mealtimes should be designed together with the persons involved. Individual needs – with regard to environment as well as eating company – must be taken into account as far as possible (see also #15 about shared mealtimes).

3.1.4. Food and drink provision

Should food and fluid intake of persons with dementia be supported by attractive and varied choice of foods and drinks?

Recommendation 7

Organizations caring for persons with dementia shall offer attractive food and fluid with choice of food, snacks and drinks to support adequate dietary intake of persons with dementia.

Grade of recommendation GPP – strong consensus (100% agreement)

Commentary

As part of their care, hospitals and long-term care institutions in many parts of the world are obliged to provide food and beverages that meet the needs of their beneficiaries. Evidence-based recommendations regarding the organization of food catering in institutions (including nursing homes) and regarding the management of diet supply to reduce the risk of malnutrition and achieve good nutritional care are given in the ESPEN Guideline on Hospital Nutrition [93]. According to this guideline, institutions shall have a structured institutional food facility and meal delivery system, shall use high-quality and sustainable food ingredients and offer meal choice and between-meals snacks [93]. Especially in long-term care, menus must be revised regularly to avoid boredom and take advantage of seasonal products. The large research gap in this area is emphasized [93] and applies specifically to catering for persons with dementia.

Due to the high risk of malnutrition in persons with dementia, it is however particularly important for this target group to offer appealing meals and a variety of attractive food, snacks and drinks with the option to choose in order to support adequate food and fluid intake. Furthermore, the wide range of nutritional problems and very individual needs require flexibility to adapt the food and fluid offers to the respective needs and abilities (see #19, #25 and #26). In this regard, close cooperation of kitchen, dietetic and nursing staff is required.

In many countries, guidelines for kitchen managers of nursing homes are available (e.g. [94–96]). Organizations caring for persons with dementia, must pay particular attention to this issue.

3.2. Recommendations at individual level

3.2.1. Screening, assessment and monitoring

Should persons with dementia be screened for malnutrition and dehydration?

Recommendation 8

Persons with dementia shall routinely be screened for malnutrition and dehydration with validated tools to identify those with malnutrition and/or dehydration.

Grade of recommendation GPP – strong consensus (100% agreement)

Commentary

Systematic screening is the first step in the process of nutritional care. It allows early detection of persons with malnutrition and/or dehydration and of persons at risk of either problem. In view of the high risk of malnutrition and dehydration in persons with dementia, routine screening should be established in all health care settings and performed in all persons *at the time dementia is diagnosed*, independent of specific other diagnosis and including also overweight and obese persons.

As nutritional problems may occur in all stages of the disease, may differ from person to person and vary across the different dementia types, *regular* screening is important to identify persons who are not at risk at the time of diagnosis but develop nutritional problems in the course of the disease. Thus, in all settings, screening should be repeated at regular intervals, e.g. every three months, and additionally if changes in general health, eating/drinking ability or eating/drinking behavior occur. In case of acute health problems closer supervision of the nutritional situation is required.

There are no specific screening tools for persons with dementia, but tools used should be validated and preferably specific to an older adult population. For malnutrition (risk), the Mini Nutritional Assessment (MNA) short-form [97] is widely used also for persons with dementia, although the questions should be answered by care-givers rather than by those affected [98]. Screening for low-intake dehydration should ideally be performed by measuring or calculating serum osmolality, keeping in mind that normal osmolality does not rule out other forms of dehydration [52].

As there are no differences in the screening process between persons with and without dementia, we also refer to the corresponding recommendations in the ESPEN Guideline on Clinical Nutrition and Hydration in Geriatrics [52].

In addition to malnutrition and dehydration screening, screening for dysphagia can also be useful, particularly in advanced stages of the disease where this problem is prevalent. In this regard we refer to the ESPEN Guideline on Clinical Nutrition in Neurology [99].

What are the consequences of a positive screening result?

Recommendation 9

A positive screening shall be followed by systematic assessment, individualized intervention to reduce the risk and treat malnutrition and/or dehydration, monitoring and corresponding adjustment of interventions.

Grade of recommendation GPP — strong consensus (95% agreement)

Commentary

As for persons without dementia, an abnormal screening result must be followed by individual assessment, which should include nutritional status, food and drink intake for several days, nutritional requirements, and individual preferences and needs. Importantly, modifiable causes of malnutrition and/or dehydration, which can also be completely independent of the dementia process, e.g. chewing problems or adverse effects of medications, must be systematically clarified.

In persons with dementia, specifically *in moderate to severe stages of the disease*, existing eating/drinking problems and behavioral symptoms must be systematically recorded. For this purpose, specific tools have been developed:

- The Aversive Feeding Behavior Inventory (AFBI) [100], also known as “Blandford Scale”, looks at potential causes of eating problems particularly in persons in advanced stages of the disease. This tool still needs validation, nevertheless it can be helpful to deal with such problems in everyday care.
- The Edinburgh Feeding Evaluation in Dementia Questionnaire (EdFED-Q) [22] is a validated tool supporting the recognition of problems with eating and drinking and helps developing an appropriate multidimensional intervention plan.
- The Eating Behaviour Scale (EBS) [101] measures the ability to eat independently and can therefore be used to judge the need for support during meals.

This comprehensive nutritional assessment should lead directly to the formulation of **individual treatment goals** and derivation of a nutrition care plan with **adequate interventions**, that should be tailored to the individual problems, needs and resources and initiated immediately.

Whenever nutritional treatment is initiated, the process should be monitored closely by follow-up evaluations and documentation. Where required, interventions should be adapted.

For the diagnosis of malnutrition, we refer to the Global Leadership Initiative on Malnutrition (GLIM) criteria [102], for the diagnosis of dehydration to the ESPEN Guideline on Clinical Nutrition and Hydration in Geriatrics [52].

In summary, especially for persons with dementia, nutritional screening and assessment must be integral parts of the comprehensive geriatric assessment and care process. They are indispensable prerequisites for the implementation of strategies to prevent or minimize malnutrition and dehydration and their serious consequences.

However, it must be noted that a formal, standardized approach in persons with severe dementia can be burdensome for caregivers and patients and bring more harm than good (see also #37). In this situation, the focus should be placed on informal identification of individual needs and problems, with the aim of enabling optimal personalized palliative care and provide appropriate support for eating and drinking.

Should body weight be monitored in persons with dementia?

Recommendation 10

Body weight should be routinely monitored and documented in every person with dementia.

Grade of recommendation GPP — strong consensus (100% agreement)

Commentary

Weight loss is a prominent clinical feature of dementia, which may occur even before dementia is diagnosed. It becomes more common as the disease progresses and affects nearly half of the patients with mild to moderate forms of AD [8–10,12,103,104].

Since weight loss is the most important sign of malnutrition and its prevention is crucial for maintenance of general health, body weight should be measured at least once a month. If weight loss occurs, this should be changed to once a week.

Regular, routine weight assessment enables detection of body weight changes and appropriate countermeasures at an early stage should thus be part of the regular management of the disease.

Body weight should be measured under the same conditions (time of day, clothing defecation, urination) and using the same scale. When interpreting the results, changes in total body water must be taken into account. In acute care hospitals, where dehydration as well as water retention are widespread, a closer control of body weight is necessary.

If weight loss is detected, the causes must be investigated and appropriate countermeasures initiated (see #9).

As already stated before (see #9), in persons with severe dementia, assessment and monitoring of weight could create unnecessary burden for caregivers and patients. In this situation, nutritional status and individual needs should be clinically assessed and carefully observed as basis for individualized palliative care.

If possible, in addition to body weight, calf or mid upper arm circumference and handgrip strength can be determined and provide information about muscle mass and function and their development [105].

Should individual habits and preferences be considered in persons with dementia?

Recommendation 11

In all persons with dementia, individual habits, preferences, abilities and behaviors around eating and drinking shall be assessed and considered as far as possible.

Grade of recommendation GPP — strong consensus (100% agreement)

Commentary

Even though individual preferences and needs are integral part of the nutritional assessment (see #9), a separate recommendation is dedicated to this topic due to its importance in the care of persons with dementia.

Following the principles of person- and relationship-centered care, all interventions must be in line with the habits, wishes and preferences of the person receiving care, which requires knowledge of these [54]. Specifically, preferences and dislikes regarding food and drinks but also crockery and cutlery, meal structure and meal companions should be taken into account.

An eating and drinking biography can be a valuable tool in this respect which also takes into account cultural and religious traditions.

Knowledge of personal impairments, remaining abilities, skills and resources around eating and drinking as well as specific behaviors or behavioral symptoms that affect eating and drinking is key to being able to tailor aids and personal support accordingly.

Finally, knowledge of preferences regarding enteral nutrition (EN) and parenteral nutrition (PN) is relevant when treatment decisions are required in this regard (see #34–39).

3.2.2. Strategies to support oral nutrition and hydration

3.2.2.1. Elimination of potential causes of malnutrition and dehydration. *Should potential causes of malnutrition and dehydration be eliminated in persons with dementia?*

Recommendation 12

In persons with dementia, probable causes of malnutrition and dehydration shall be identified and managed as far as possible.

Grade of recommendation GPP — strong consensus (100% agreement)

Commentary

Besides dementia-specific changes affecting nutrition, such as impaired appetite regulation, attention disorders and behavioral symptoms (see Introduction), a variety of factors independent of dementia can contribute to insufficient food and fluid intake, malnutrition and dehydration, e.g. chewing problems, pain, acute disease or side effects of medications [28].

Thus, a cause-oriented approach is essential for effective prevention and treatment.

After identifying possible causes as an inherent part of the nutritional assessment (see #9), measures to manage the causes in the best possible way are a central part of the care plan. While most symptoms of dementia are difficult to influence, other causes are easier to treat and eliminate, e.g. by adequate oral care, dental or medical treatment. Dietary restrictions can usually be easily omitted (see #13) and medication can often be modified to reduce adverse side effects on nutrition and hydration (see #14). If it is not possible to eliminate the causes, compensatory strategies can often be adopted to support eating and drinking, e.g. texture-modification of food and fluids in case of severe dysphagia. For more examples, please see Table 6.

Since causes are varied and differ from person to person, individualized approaches are essential, which in addition should be part of the overall nutritional care plan (see also #40).

Interventions should however only be taken as long as it is clinically appropriate. If a potentially helpful intervention is associated with appreciable burden and risks (e.g. complex dental treatment or surgical intervention in frail patient with severe dementia), potential benefits and risks of the intervention for the patient have to be weighed against the potential benefits of improved nutrition.

Should dietary restrictions be avoided in persons with dementia?

Recommendation 13

In persons with dementia, dietary restrictions that may limit food and/or fluid intake are potentially harmful and shall be avoided.

Grade of recommendation GPP — strong consensus (94% agreement)

Table 6
Potential causes of malnutrition and dehydration in older persons with dementia and possible management strategies.

Potential causes	Interventions
Chewing problems	* Oral care * Dental treatment * Texture modification
Swallowing problems	* Swallowing evaluation * Swallowing training * Texture modification
Xerostomia	* Check medication for adverse side effects, remove or change medication if possible * Ensure adequate fluid intake * Use mouth rinse and gel
Mobility limitations	* Physiotherapy * Group exercise * Accompanied walking * Support to go to the toilet in time * Resistance training * Support with shopping and cooking * Meals on wheels
Disability of the upper limbs	* Support with meal preparation, eating and drinking * Special eating and/or drinking utensils
Psychiatric disorders (e.g. depressive mood, depression, anxiety)	* Adequate medical treatment * Eating with others, shared meals * Pleasant eating environment and meal ambience * Group activities, occupational therapy * Soothing sounds, music

Table 6 (*continued*)

Potential causes	Interventions
	* Verbal prompting, remember to eat and drink
Acute disease, (chronic) pain	* Adequate medical treatment
Adverse effects of medications (e.g. xerostomia, nausea, apathy)	* Check medications (see above) * Reduce or replace medications
Social problems (e.g. lacking support, family conflict)	* Support with shopping and meal preparation * Meals on wheels, shared meals * Offers to talk, conflict resolution

Commentary

Dietary restrictions – defined as any limitation on the type, quantity or consistency of certain foods or food groups – may limit food choice and pleasure to eat and thus bear the risk of limiting dietary intake. They are one potential cause of malnutrition and therefore generally not recommended for persons with malnutrition or at risk of malnutrition [52,93,106]. In addition, the benefits of special diets in old age and particularly in persons with dementia are uncertain [107]. Furthermore, there is no convincing evidence that a specific diet significantly slows down the progression of dementia (see also #21, #30).

Thus, in view of the high risk and prevalence of malnutrition and dehydration, dietary restrictions should generally be avoided as far as possible, especially for persons with dementia. Also, fasting periods due to diagnostic procedures or surgery bear the risk of worsening nutritional status and should be minimized.

However, there are justified exceptions. In case of food intolerances, the incompatible foods must of course be omitted. Also, patient-desired restrictions, e. g. for cultural or religious reasons, must be respected. In case of severe dysphagia, restrictions regarding food and fluid consistency may be appropriate to enable safe swallowing (see #26), and in cases of specific pronounced illnesses, e. g. severe kidney failure or severe obesity-related health problems, dietary restrictions may also be justified. However, the potential benefits and possible risks, namely the development of malnutrition and reduction of quality of life, must be carefully weighed up in each individual case.

A generally healthy diet can be supported by dietary counselling (see #21).

Should medication with adverse effects on nutrition be avoided in persons with dementia?

Recommendation 14

In persons with dementia, a medication review should be performed by a qualified practitioner to minimize adverse drug effects on food and fluid intake.

Grade of recommendation GPP – strong consensus (97% agreement)

Commentary

While many medications may affect cognitive function as well as appetite and nutritional intake, it is important to review the medication of persons with dementia in this regard. The medication review should be performed by an experienced physician or pharmacist at the first diagnosis of dementia, whenever there is a change in the clinical situation, and at least every twelve months. If the medication review concludes that a certain drug should be stopped or the dosage should be lowered, risks and advantages should be balanced and discussed with the patient and/or proxies.

Patients are frequently not aware of medication side-effects on appetite, because appetite usually declines continuously and gradually, from unnoticed to more severe loss of appetite, nausea and vomiting. However, even slight changes may lead to marked weight loss over longer periods of time. In addition, drug-induced taste and smell disorders as well as disturbed gastrointestinal motility may play a role. Furthermore, attention and activity at mealtimes as well as the urge to eat and drink may be reduced by sedatives, limiting food and fluid intake.

The potential impact of medication on nutritional intake and nutritional status is generally not well studied and there is very little data on persons with dementia. A robust association between polypharmacy and malnutrition has been demonstrated in the general older population [108,109], indicating that drugs may play a role in the development of malnutrition. Poorly investigated and mainly based on anecdotal experience, medications that occasionally affect appetite are opioids, sedatives, digoxin, metformin, antibiotics and nonsteroidal anti-inflammatory drugs [110]. However, nearly all drugs may affect individual patients, depending on dosage, body weight, renal function, co-medication and individual vulnerability. It is therefore important to assess the temporal relationship between the change in medication and the occurrence of changes in appetite and body weight.

In addition to these general considerations, a dementia-specific issue must be addressed. Patients on cholinesterase inhibitors, approved and frequently used for the treatment of dementia, experience a slightly increased risk of weight loss compared to matched controls [111]. This does not appear to be relevant for the majority of patients with dementia [112]. However, individual patients with increased vulnerability may experience severe weight loss if taking cholinesterase inhibitors [113].

In the field of fluid balance, older persons in general experience less thirst, leading to a marked vulnerability for dehydration [114]. Due to the cognitive changes, loss of thirst is often aggravated in persons with dementia, which can be worsened particularly by sedatives. Excessive fluid losses due to diuretics are also frequent [115]. If patients develop dementia, get older and/or lose weight, a previously adequate diuretic medication may become inadequate. Therefore, the indication and dosing of a diuretic medication should be checked and adjusted in every person with dementia at risk of dehydration.

3.2.2.2. Social support. *Should persons with dementia be encouraged to share their mealtimes with others?*

Recommendation 15

Persons with dementia should be encouraged to share their eating and drinking occasions with others to improve quality of life.

Grade of recommendation GPP – strong consensus (94% agreement)

Commentary

It is generally known and has been observed in healthy adults and also in older home health service recipients and older hospitalized patients that eating in company stimulates dietary intake [52]. The value of social interactions in general is also emphasized for persons with dementia [116,117], but no studies were identified comparing older persons with dementia eating with others or eating alone with regard to food and fluid intake.

Several SRs about mealtime interventions in persons with dementia include social aspects around eating and interactions between residents [62–64,66,67,89,91] and between carers and residents [90]. In particular, a controlled trial in two French special care units for persons with severe dementia is repeatedly highlighted [62–64,66,67,89,91] with eight residents having family-style meals together with staff on one unit compared to ten residents in another unit eating without staff. Significant weight gain in the intervention group and weight loss in the control group are reported, along with improvements in autonomy, interactions and enjoyment of meals [74].

Further, implementation of a breakfast club [118], a reminiscence cooking therapy [119] and changing the mode of meal delivery from prepared plates to family-style meals [71] are considered in this context in some SRs [63,89,91] with the conclusion in one review [91] that studies with a strong social element around eating and drinking, despite small sample sizes and low quality, provide consistent evidence for improvements in quality of life. Among 56 interventions indirectly supporting food and drink intake in persons with dementia, Bunn et al. identified meals with caregivers, family-style meals and a breakfast club as promising interventions which need to be tested in future high-quality trials [63].

Clearly, meal, snack and drink times provide the opportunity to interact with others, and it seems likely that shared eating and drinking occasions can support meaningful engagement with food and drink (as well as with other persons) and may have a positive effect on quality of life also or especially for persons with dementia. Thus, shared mealtimes should generally be encouraged and actively supported by care staff.

Maltais et al. reported improvement in nutritional status of 47 nursing home residents with dementia who were cluster-randomized to a social activity or an exercise intervention with 2 one-hour sessions per week for 24 weeks. Findings suggest that social interaction may be nutritionally beneficial even outside the context of eating and drinking [120].

Of course, there may be persons who prefer eating alone and situations, where taking their meals separately is more appropriate, e.g. if very agitated persons would bring great unrest into the dining room. Thus, as with all other interventions, the decision should be based on a person-centered approach and each individuals own choice (see also recommendation #14 in [52]).

3.2.2.3. Nursing and care activities to support eating and drinking. Should food and fluid intake of persons with dementia be supported by nursing and care activities?

Recommendation 16

> Persons with dementia and impaired eating and/or drinking ability should be offered support and assistance during eating and/or drinking occasions based on individual preferences and capacity to support adequate food and fluid intake.
>
> Grade of recommendation GPP – strong consensus (100% agreement)

Commentary

With progressing disease and decreasing ability to remember to eat and drink, to recognize food and beverages and to eat and drink independently, eating and drinking support and help becomes necessary, regardless of the nutritional status of the person with dementia. This support includes measures that enable an individual to eat and drink and can take the form of supervision, verbal encouragement, partial eating assistance, and ultimately, hand-assisting with all eating and drinking, where the caring person provides all food and fluids to the person with dementia. It may also include positioning at the table, provision of assistive tools and assistance with cutting the food into smaller pieces [50].

The role of nursing assistance is included in several SRs about interventions to support nutritional intake of persons with dementia [62,65–67,77,90,91]. In these reviews, nursing assistance is differently defined and often part of a multicomponent intervention. Different studies are considered which are not always restricted to persons with dementia and mostly with high risk of bias, so that not clear conclusion can be drawn. Overall, RCTs on this topic would be unethical since adequate support cannot be withheld from a person in need of assistance to eat and drink.

Three hand-feeding techniques to assist nursing home residents with dementia to eat were however recently compared in a RCT. All three techniques were found to be viable options to increase intake, and can be used based on the individual preferences and response from those being assisted [121].

As no other new studies have been published since the first publication of the guideline in 2015, we also refer to the corresponding chapter in the previous version of this guideline, where some observational and quasi-experimental studies supporting our recommendation are mentioned [43]. It was also emphasized there how important emotional support and specific behavioral and communication strategies are, especially in the advanced stages of the disease.

Interactions between carer and persons with dementia during mealtime care are the focus of a SR [90]. Based on 18 studies the authors came to the conclusion, that mealtime care should be individually tailored and enable persons with dementia to promote their autonomy and independence. Further, the importance of knowing residents' preferences and focusing on the individual rather than the task to build relationship and social connection is stressed. Finally, the special challenge of responding carefully and skillfully to food refusal is highlighted [90].

Overall, although scientific evidence is limited, food and fluid intake has to be supervised, encouraged and supported by adequate care and nursing activities, such as verbal encouragements, cutting food into small pieces, offering drinks frequently etc. These interventions should both compensate for existing deficits and promote independence as far as possible. Assistance should be provided in all stages of the disease and in all health care settings according to individual needs and resources in a manner that is safe and preserves the dignity of the affected person.

Support with eating may also be provided by family members, volunteers and helpers if there is a shortage of professionals, provided that they are appropriately trained (see #5).

Recommendation 17

> Persons with dementia and impaired eating and/or drinking ability should be offered appropriate eating and/or drinking utensils to support independence.
>
> Grade of recommendation GPP – strong consensus (94% agreement)

Commentary

Many frail older persons – including persons with dementia – are experiencing difficulties in lifting and handling eating and drinking equipment due to underlying conditions such as muscle weakness, arthritis or tremors. As long as individuals are still able to eat and drink and recognize its necessity, but have physical limitations in eating and drinking, physical aids can be useful and complement personal support. Although the offer of assistive tools is part of the support with eating and drinking (see #16), we believe that this aspect deserves its own recommendation, as it is often neglected.

Available evidence regarding the effects of eating and drinking utensils for persons with dementia is very limited.

Two small non-randomized studies suggest that colored tableware can increase food and liquid intake of persons with dementia [122,123], probably especially of persons who are limited in their ability to see objects well.

In a small RCT with 45 participants with dementia or MCI from care homes and hospitals, consumption of ONS when served in a glass or beaker was compared to a straw inserted into the container and higher intake reported with a drinking vessel. On the other hand, ONS served in a glass or beaker were more often not consumed, leading to the conclusion that both options are suitable [124].

In a mixed nursing home population, it has been found that some drinking vessels used in nursing homes may be difficult for residents to handle and that improving the design of drinking vessels according to the residents' preferences, has the potential to increase fluid intake without increasing staff workload (pre-post design) [125]. This probably also applies to persons with dementia.

Overall, a variety of different eating and drinking aids are available for different impairments which should be used according to individual limitation and resources. Ideally, an occupational therapist should be involved in supporting the decision about which utensils and aids best support eating and drinking independence in an individual.

Recommendation 18

Persons with dementia and impaired eating and/or drinking ability should be offered training to maintain or improve eating and/or drinking ability.

Grade of Recommendation B – strong consensus (94% agreement)

Commentary

As the disease progresses, persons with dementia may forget how to eat and drink and have to be reminded and supported (see #16, #19).

The question of whether targeted, individualized training can maintain independence in eating and drinking and support adequate nutrition was examined in five controlled studies by a working group from Taiwan [126–130], which were included in several SRs [62–66,68,131] in varying numbers and combinations.

In these trials, spaced retrieval, errorless learning and/or Montessori based activities with three training sessions per week for 24 weeks had positive effects on eating ability, measured by the EdFED Scale. Results regarding food intake and nutritional status were inconsistent [126–130].

In another trial (not included in SRs) from the same Taiwanese group, spaced retrieval memory training alone (n = 46) and combined with Montessori activities (n = 49) with 30 sessions over a 6-week period improved hyperphagic behavior of residents from eight special dementia care units [132]. As well, in a RCT with 85 hospitalized persons with AD in China, sensory stimulation and eating training guided by Montessori methods improved eating capacity and reduced eating difficulties [133].

Furthermore, a one-to-one hand exercise training program (30 min three times weekly for six months) compared to usual care was also effective for improving eating behavior (EdFED) and skills (autonomous eating, coordination, accuracy) in a RCT with 60 residents with AD from a Chinese nursing home [134].

Overall, there seems to be beneficial effects of eating training on eating behavior and skills which might have a positive impact on nutrition. Due to limited and overall low-quality evidence, the level of recommendation is downgraded from A to B.

Recommendation 19

Persons with dementia and (risk of) malnutrition and dehydration should be frequently offered drinks, additional snacks and/or finger food to facilitate food and fluid intake.

Grade of recommendation GPP – strong consensus (100% agreement)

Commentary

In addition to providing adequate assistance to support eating and drinking, a central task of nursing and caring is to provide and offer food and drinks. Persons with dementia and malnutrition or at risk of malnutrition need special attention and support in this regard to facilitate food and fluid intake.

The literature search identified two SRs assessing the effect of additional snacks and finger foods.

Abdelhamid et al. describe two non-randomized trials examining the use of finger foods [91]. One evaluated six months of a finger food menu for twelve cognitively impaired residents with poor dietary intake and limited use of cutlery, finding weight-loss stopped in ten out of twelve participants and eating independence improved (though no numbers or statistical analysis were provided) [76]. The other assessed effects of increased finger food provision on weight and food consumption of 43 care center residents with AD [135]. The number of finger foods offered was only slightly increased. The proportion of food eaten also slightly increased but no effect on body weight was observed.

Bunn et al. also included one of the above mentioned studies about finger foods [76] in their SR [63]. In addition, one study offering finger food [136] and one study offering additional snacks [137] as part of comprehensive mealtime interventions are described where the effects of finger foods and snacks however be separated from the other intervention components. One study using a glass-door refrigerator filled with snacks accessible at all times and additional time for meals reported an increased the body mass index (BMI) after twelve weeks in 40 persons with dementia [60]. Based on this before-after study, constantly accessible snacks and additional time for meals are described as promising intervention needing high-quality reassessment [63].

In a feasibility study (pre-post design), the offer of two finger foods daily in addition to the regular diet slightly increased dietary intake of 15 nursing home residents with dementia, without significant compensation during the main meals [138].

Apparently, no studies have assessed the beneficial effect of providing additional drinks to persons with dementia. However, among frail older care home residents, supporting pleasure in drinking through provision of a choice of pleasant drinks, appears to increase fluid intake [137,139–141] which can also be assumed for persons with dementia.

Despite very limited directly relevant scientific evidence, we recommend frequent offer of appropriate drinks, additional snacks and/or finger food to facilitate food and fluid intake of persons with dementia and (risk of) malnutrition and dehydration, given minimal expense and no risk of harm but potential positive effects.

Recommendation 20

Persons with dementia should be offered routine oral care to optimize food and drink intake.

Grade of Recommendation GPP — strong consensus (95% agreement)

Commentary

Good oral health is a fundamental prerequisite for adequate nutrition. Persons with dementia are at higher risk of poor oral health than those with better cognition, having fewer natural teeth, more dental plaque and caries, lower salivary flow and more oral soft tissue problems like gingival bleeding or periodontitis/stomatitis [142–144]. This appears to be associated with reduced toothbrushing, flossing and infrequent dental visits.

Few studies examined the effect of oral care interventions in persons with dementia [145,146], in mixed nursing home populations [147–149] or in persons with mild dementia or MCI [150]. Some improvement of preventive oral care behaviors and swallowing function, oral and denture hygiene and oral health parameters are reported in these studies.

Nutritional status was only addressed in a small uncontrolled trial in 40 nursing home residents, where a tooth brushing intervention by a dental nurse every three weeks for six months did not affect nutritional status (measured by MNA) in the subgroup of 25 residents with dementia [148].

We are not aware of any study examining the effect of oral care interventions on dietary intake in persons with dementia.

In summary, there is scant evidence. Nevertheless, it seems reasonable to assume that supporting oral care in those with dementia is likely to improve oral health as an important prerequisite for adequate dietary intake. Oral care in the narrower sense means cleaning the teeth, oral cavity, and dentures, but in a broader sense includes all measures to maintain oral functions, e.g. also dental treatment and swallowing training [151]. This may even have wider health impacts, e.g. prevention of pneumonia, as reported from mixed nursing home populations [152,153] and of other common diseases including cardio- and cerebrovascular diseases and even cognitive decline [151,154,155].

Reported trials have implemented oral brushing ranging in frequency from five minutes of brushing after every meal to brushing once every three weeks. Brushing once or twice daily, in line with guidelines for the general population, is appropriate to implement. Ideally, oral care is carried out by a specially trained person and also includes regular visits to the dentist.

3.2.2.4. Dietary counselling. Should persons with dementia be offered individual dietary counselling?

Recommendation 21

Persons with dementia and/or their informal caregivers should be offered individual dietary counselling by a nutrition expert to optimize dietary intake of the person with dementia.

Grade of Recommendation B — strong consensus (94% agreement)

Commentary

Dietary counseling by a health care professional is a key option in nutrition therapy and a core skill and activity of nutrition experts (e.g. dietitians) to guide patients in implementing an adequate diet. As there is no evidence that a special diet significantly slows down the progression of dementia, a generally healthy, varied diet is also recommended for persons with dementia. Of paramount importance, however, is the appropriate management of individual nutritional problems and the best possible assurance of adequate nutrition and hydration to prevent weight loss and dehydration.

No guideline or SR about the effects of dietary counselling for persons with dementia was identified, but two primary studies [87,156], both with participant-caregiver dyads living in the community.

In an RCT of low quality and high risk of bias the effects of tailored nutritional guidance by a nutritionist with quarterly home visits were compared to a written guide about nutrition for older adults. 78 persons with AD living with a spouse completed the study, 40 in the intervention and 38 in the control group, with a mean BMI of 26 ± 4 kg/m^2 and a mean mini-mental state examination (MMSE) 19.5 ± 6 points. 40% were at risk for malnutrition, nobody was malnourished. Changes in body weight after one year (primary outcome) were not statistically different between the groups, but changes in protein intake and health related quality of life and the rate of falls were significantly better in the intervention group [87].

In a quasi-experimental pre-post study, also rated as low quality and high risk of bias, targeted dietary recommendations in person, by mail and telephone contacts at three to six week intervals for 34 dyads were compared to leaflets with general information on food and eating for 33 control-dyads. The participants had early-stage AD, their nutrition risk and appetite were described as moderate. After six months, fat intake increased significantly, and energy, protein, and calcium intake tended to increase in participants in the intervention group while intake was unchanged in the control group. In both groups BMI was stable and grip strength decreased [156].

Thus, the evidence is very limited but nevertheless, due to the high risk of malnutrition and dehydration associated with the progression of the disease, it seems appropriate to support persons with dementia and their relatives with dietary advice. Counselling should also be provided preventatively and carried out by a nutrition expert to ensure the required quality (see also ESPEN Guideline on Clinical Nutrition and Hydration in Geriatrics [52]).

3.2.2.5. Appetite stimulation. *Should persons with dementia receive appetite stimulating drugs?*

Recommendation 22

Drugs to stimulate appetite or weight gain should NOT be used in persons with dementia.

Grade of recommendation GPP – consensus (89% agreement)

Commentary

Generally, drugs that stimulate appetite (orexigenic drugs) might be helpful for patients with persistently reduced appetite to stimulate eating, increase dietary intake and maintain or improve nutritional status. Various agents, mainly cannabinoids, antidepressants, megestrol acetate and neuroleptics, have been tested in various patient groups suffering from anorexia and weight loss, including older patients and long-term residents [157–160].

At this point, only three small placebo-controlled trials have investigated the effect of cannabinoids on weight change or caloric intake in patients with dementia, one with parallel and two with cross-over design, with a total of 100 participants. In a Cochrane Review about the effects of cannabinoids in the treatment of dementia, based on these three trials, no significant effect on body weight, BMI or energy intake was found [161].

Mirtazapine and other antidepressant drugs have been reported to cause weight gain as a side effect [162]. However, there are no placebo-controlled trials on persons with dementia. One small retrospective non-controlled open label study in 22 participants with dementia given a daily dose of 30 mg mirtazapine reported a mean weight gain of 1.9 kg after three months and 2.1 kg after six months, with about 80% of patients experiencing weight gain [163]. Therefore, mirtazapine could potentially play a beneficial role when dementia patients with weight loss and depression require treatment with antidepressants. However, for the indication of weight loss without depression, its use cannot be recommended.

The effects of megestrol acetate (MA) were tested in two studies in nursing home residents with weight loss or at risk of weight loss, however only 41% the samples in both studies had dementia [164,165]. Whereas in one of the studies (RCT, n = 69) positive effects on appetite and body weight were reported [164], no effect on body weight was found in the other (no control group, n = 17) [165]. In hospitalized older subjects, also no effect on body weight was observed in an open label study in 16 patients with different daily doses of MA [166]. In older hospitalized patients with recent functional decline, 800 mg MA per day attenuated the beneficial effects of twelve week resistance training, reflected in smaller gains or even deterioration in muscle strength and functional performance compared to placebo [167]. However, no trial was performed exclusively in dementia patients. Therefore, no conclusive recommendation can be given for this patient group.

Neuroleptics, prescribed in various psychiatric diseases, are reported to induce weight gain as an adverse drug effect in patients of all age groups, with olanzapine demonstrating the highest weight gain [168]. However, no prospective randomized study has yet been performed in persons with dementia. A chart review of 90 nursing home residents with dementia showed no significant increase in body weight after the introduction of a neuroleptic drug [169].

In conclusion, the evidence for the use of drugs as appetite stimulants in patients with dementia is very limited. Dronabinol, antidepressants, MA and neuroleptics were tested only in small trials with weak methodology and not always focused on dementia patients, and did not achieve consistent effects. For all mentioned substances, various, potentially harmful, side effects must be taken into account and balanced against the very uncertain benefits for appetite and body weight. Consequently, the use of appetite stimulants cannot be recommended for persons with dementia and reduced appetite. Further research is required.

Should persons with dementia receive other potential appetite stimulants (e.g. alcoholic drinks, herbal products)?

Recommendation 23

Non-pharmacological agents advertised as appetite stimulants should NOT be offered to promote food intake of persons with dementia.

Grade of recommendation GPP – consensus (87% agreement)

Commentary

Numerous non-drug products are advertised to stimulate appetite, among them alcoholic drinks and herbal extracts, referred to here as non-pharmacological agents.

Alcohol is known to increase energy intake, including the energy from alcohol, in the general healthy population [170,171]. However, there are no trials investigating its effect on appetite or unintended weight loss either in older persons or especially in persons with dementia. Given the increased risk of falls in persons with dementia [172] and the fact that alcohol increases the risk of falls in the general population [173], alcohol consumption should not be recommended in persons with dementia and (risk of) malnutrition.

The administration of a specific herbal product to persons with dementia and loss of appetite is only mentioned in an anecdotical case report of six patients without clear effects [174]. Even outside the area of dementia, the literature about appetite stimulating herbal products is more than scarce. Therefore, the administration of herbal products cannot be recommended.

Should persons with dementia receive flavor enhanced food?

Recommendation 24

Flavor enhancing additives should NOT routinely be used to promote food intake in persons with dementia.

Grade of recommendation GPP – majority agreement (73% agreement)

Commentary

The perception of taste and smell decreases with age and is often significantly impaired in persons with dementia. Reduced odor perception is observed early in the course of neurodegenerative disease and even serves as an additional diagnostic marker [175].

Two small studies have examined the effect of food odor exposure on appetite and nutritional intake in persons with dementia. Odorizing the dining room of three French AD units with a meat odor before lunch increased meat and vegetable intake of the 32 residents at this meal, but the effect could not be replicated two weeks later [176]. In four Dutch nursing homes, after twelve weeks of food odor dispersion prior to the main meals, no clinically relevant changes in appetite, nutritional intake and body weight were observed in the 45 residents with dementia compared to a four week control period before [177].

In mixed nursing home populations, sprinkling flavor enhancers over the cooked meals of 36 residents for 16 weeks appeared to be effective regarding energy intake and body weight compared to a control group of 31 residents [178], however, in a randomized study in 83 nursing homes residents no effect of 16 weeks of flavor enhancement on dietary intake and nutritional status was found [179]. No study on the effectiveness of flavor enhancement was performed in patients with dementia.

Therefore, odor stimulation and flavor enhancement cannot be systematically recommended for the prevention or treatment of malnutrition of persons with dementia. However, taste is very subjective and the addition of spices and other flavor enhancers according to individual preferences may increase enjoyment and nutritional intake in some individuals and may therefore be used depending on individual preferences.

3.2.3. Oral nutritional interventions

3.2.3.1. Food and drink modification. Should food and/or drinks be modified for persons with dementia, e.g. fortified, texture-modified?

Recommendation 25

Persons with dementia and (risk of) malnutrition should be offered fortified foods and drinks to increase energy and protein intake.

Grade of recommendation B — strong consensus (97% agreement)

Commentary

Many older persons and especially persons with dementia are limited in their ability to consume sufficient amounts of energy, protein and micronutrients. Generally, food and drink fortification (or enrichment) by using natural foods (e.g. oil, cream, full cream milk, nuts, butter, eggs) or specific nutrient preparations (e.g. maltodextrin, protein powder) offers the possibility to increase energy and protein density of meals and beverages and thus enables an increased intake by eating similar amounts of food [52].

Unfortunately, there are no dementia-specific studies on this topic. Four SRs based on up to ten RCTs in different populations, mostly in nursing homes, consistently conclude that energy and protein intake can be increased by food fortification [180–183]. In nursing home residents with malnutrition or at risk of malnutrition weight gain is reported as a result of the enrichment [182].

Since there is no reason to assume different effects, the evidence is extrapolated to persons with dementia but downgraded from A to B.

Overall, food fortification should be based on a varied, individualized diet (see #7) and be part of a comprehensive nutrition care approach combining all individually appropriate measures to optimize food and fluid intake and meet the requirements for energy, protein and all essential nutrients as best as possible and individually appropriate (see #40).

Please see also the ESPEN Guideline on Clinical Nutrition and Hydration in Geriatrics, #20 [52].

Recommendation 26

For persons with dementia and signs of oropharyngeal dysphagia and/or chewing problems texture-modified, fortified foods and drinks should be considered as a compensatory strategy in parallel to treatment of dysphagia and chewing problems to support adequate food and fluid intake.

Grade of recommendation GPP — strong consensus (94% agreement)

Commentary

Individuals with dementia are often affected by chewing and swallowing disorders, especially in the advanced stages of the disease. As a compensatory strategy, in parallel with the treatment of the underlying problems, the consistency of foods and drinks can be modified to support eating, drinking and safe swallowing.

Two SRs highlight the lack of studies examining the effects of modifying the consistency of food and fluids specifically in persons with dysphagia and dementia [184,185]. Only two related studies about the effects of fluid modification on aspiration and adverse events were identified, both with a high risk of bias and inconclusive results [184].

As texture-modified diets are usually associated with reduced food and fluid intake [185–187], fortification seems a reasonable strategy to support adequate intake despite hardly any scientific evidence (in general as well as dementia-specific). Please see also the ESPEN Guideline on Clinical Nutrition and Hydration in Geriatrics, #22 [52].

In one small RCT the effects of a nutritionally complete formula diet based on lyophilized foods was studied in 53 patients with advanced AD in need of semi-solid or liquid diets. An increase in body weight compared to a control group receiving dietary advice was reported after three months, but there were no effects on mental function and adverse events [188].

Overall, it is very difficult to achieve sufficient energy, nutrient and especially fluid intake with consistency-modified foods and drinks. Therefore, the diet of persons with dementia and dysphagia and/or chewing problems must be individually adapted, appealing and well monitored. The safe consistency, i.e. the consistency without risk of aspiration, should be tested by a speech and language therapist before thickeners or texture-modified meals are used. In addition, the so called “water protocol” with the permission to drink clear water between meals may be an option if thickened fluids are not accepted or tolerated [189].

As texture modifications can also reduce nutritional quality, nutritional intake and quality of life [190], texture modification should be performed as much a necessary for a safe swallow but as rarely as possible, to support sufficient intake. Given the uncertainty about immediate and long-term effects of modifying the consistency of food and drinks for swallowing difficulties in dementia [184], restrictions should be handled very cautiously (see #13) and the affected persons closely monitored clinically.

Generally, oropharyngeal dysphagia should be managed by a multidisciplinary team and its treatment should be based on the diagnosis of dysphagia severity and pattern and include different strategies [191,192]. For more detailed information about nutrition for patients with dysphagia we refer to the ESPEN Guideline Clinical Nutrition in Neurology [99].

3.2.3.2. Oral nutritional supplements. ONS are pre-packaged liquids, powders, desserts or bars containing macro- and micronutrients. ONS may contribute to the nutritional management of patients who may not otherwise meet their requirements through usual diet. Some ONS may be nutritionally complete and therefore may be suitable as a sole nutritional source, but usually ONS are used as a supplement to dietary intake. ONS are of particular interest in the nutritional management of persons with dementia who may be at increased risk of weight loss and malnutrition.

Should persons with dementia be offered oral nutritional supplements?

Recommendation 27

Persons with dementia and (risk of) malnutrition shall be offered oral nutritional supplements to improve energy and protein intake and improve or maintain nutritional status.

Grade of Recommendation A – strong consensus (100% agreement)

Commentary

ONS provide all patients, including those with dementia, the opportunity to receive additional energy and nutrients in a concentrated form. Two SRs have explored the effects of ONS specifically in persons with dementia [62,193]. While Borders et al. [62], also took other interventions and uncontrolled trials into account (7/15 trials), Tangvik et al. [193] had a specific focus on the effects of ONS on the nutritional intake and clinical outcomes in RCTs. This review of critically low quality (because of lacking list of excluded studies and lacking risk of bias assessment of included studies) identified nine trials (including seven RCTs). Eight trials were in accordance with the previous ESPEN guideline 43, and one new original study was identified [194]. Meta-analysis was not possible due to heterogenous reporting of outcomes.

Included studies from the previous ESPEN guideline [43], along with the new study [194] are summarized in the evidence tables (Appendix A) in the respective section. Most of the studies were small in size, most were conducted in nursing homes or in psychiatric/geriatric hospital units, and nutritional status of the participants at baseline was diverse. ONS provided 125–680 kcal per day in addition to oral intake, intervention time varied between three weeks and one year. ONS were generally offered between meals.

Improvements in protein and energy intake, and body weight/BMI associated with ONS use were reported consistently across the included studies addressing the respective outcomes. Other changes in nutritional status reported in some, but not all studies, were improved fat free mass and serum protein. Other measures of body composition including triceps skinfold thickness and mid-upper arm circumference also improved in some intervention groups. No studies compared the increased energy intake obtained from ONS to food-first approaches such as fortified meals and snacks.

In summary, positive effects on energy and protein intake and body weight are consistently reported across the relevant literature. Thus, ONS are recommended for persons with dementia who are unable to meet their nutritional requirements by usual and enriched foods despite adequate supervision and assistance to support their intake. In addition, persons with dementia may benefit from supervision and support when consuming ONS; it is only one of the various approaches to support nutritional intake in persons with dementia; their use should always be tailored to the patient.

Recommendation 28

Oral nutritional supplements should NOT be used in persons with dementia to correct cognitive impairment or prevent further cognitive and functional decline.

Grade of recommendation B – strong consensus (100% agreement)

Commentary

The effects of standard ONS on cognitive outcomes are reported in two SRs, one considering two RCTs [195], the other three RCTs [193], all also identified for the present guideline (evidence tables, Appendix A, see also rec #27). From all available eleven RCTs [75,85,194,196–204] (evidence tables, Appendix A), five reported cognitive outcomes [194,197–200]. The tool used to assess cognition in all studies was the MMSE. No beneficial effects were consistently reported.

Accordingly, in all six trials examining physical functional outcome (mainly by basic activities of daily living), no statistically significant differences were observed between intervention and control groups [85,194,196–198,203].

It can be assumed that by improving nutritional status, general condition and functions will also improve, this is however not confirmed by the existing studies. A number of factors – including e. g. duration of the intervention, type and stage of dementia, nutritional status and amount and combination of nutrients provided – may explain the lack of beneficial findings. Future studies have to further clarify the effects of ONS on cognitive and physical function.

In summary, available trials do not suggest beneficial effects on these outcomes. Because of the very limited evidence base, the level of recommendation was downgraded from A to B.

3.2.3.3. Dementia-specific oral nutritional supplement. Should persons with dementia be offered dementia-specific oral nutritional supplements to correct cognitive impairment or prevent further cognitive decline?

Recommendation 29

Dementia-specific oral nutritional supplements should NOT routinely be offered to persons with dementia to improve cognition or prevent further cognitive decline.

Grade of recommendation B – strong consensus (96% agreement)

Commentary

Based on the assumption that certain nutrients and nutritional compounds have specific functions for brain integrity and metabolism, specific ONS containing combinations of these substances have been developed with the aim to prevent, delay, or even correct cognitive decline in persons with cognitive impairment or dementia. Moreover, lower plasma levels of several nutrients have been found in individuals with AD compared with cognitively healthy older individuals indicating that a combination of nutrients may be more effective than single nutrients [205].

The most studied product in this context is an oral liquid nutritional supplement enriched with a specific combination of omega-3 polyunsaturated fatty acids (n3-PUFAs), uridine monophosphate, choline, phospholipids, vitamins E, C, B_6, B_{12}, folic acid, and selenium. The composition of this product is based on a well-founded pathophysiologic concept and thorough exploration of related preclinical evidence [206]. Several well-designed, double-blind RCTs have examined this product in persons with prodromal, mild or mild-to moderate AD which were evaluated in three SRs [207–209], two with meta-analysis [207,209]. Based on three [207,208] or four [209] of these studies with intervention periods of twelve weeks to 24 months and control groups consuming standard ONS, it is unanimously concluded that these trials do not suggest beneficial effects on cognition, functional ability or general clinical course. More recent work about the effects of this product in patients with prodromal AD after 36 months, in contrast, reports reduced decline in cognitive and clinical outcomes suggesting beneficial effects in the longer term [210,211].

Subsequently, the effects of multi-nutrient formulas containing a combination of n3-PUFA and B vitamins on cognition were examined in a high-quality SR with meta-analyses [212]. Based on eleven RCTs, including five RCTs with the enriched ONS described before, four with other multi-nutrient combinations and two with only n3-PUFA and B vitamins (three in healthy older adults, four in subjects with prodromal/MCI, four in diagnosed AD), benefits regarding global cognition and episodic memory were reported but no effect was seen on domain-specific measures of executive function. Significant heterogeneity between the studies is acknowledged as a potential reason for minimal effect.

Another ONS product enriched with micronutrients (vitamins E, C, B_{12}, folate, zinc, copper, manganese and arginine) was tested in an earlier small RCT ($n = 44$) compared to standard ONS for six months with the aim to slow the progression of mild AD [213]. No significant differences in cognitive function were observed between the groups.

A combination product consisting of folic acid, vitamin B_{12}, vitamin E, S-adenosyl-methionine, N-acetyl cysteine, and acetyl-l-carnitine was developed with the aim of achieving neuroprotective effects by correcting folate deficiency, lowering homocysteine and reducing oxidative stress [214]. The product was tested in two small RCTs in participants with AD [215,216]. Small positive effects on cognition (Dementia Rating Scale, clock-drawing test) are reported after three months but no effects on activities of daily living (ADL).

In summary, there is some evidence that multi-component products providing n-3 PUFA and B vitamins could be beneficial in the long run. Regarding the minimal risk of adverse effects, they can be considered as an option for some patients who are willing and likely to be able to consume the product for several years, in very early rather than advanced stages of the disease and after careful discussion of burden and benefits with a specialized physician.

A general recommendation for any of the products does not seem justified with the evidence currently available. Due to the limited existing data to date, the level of evidence was downgraded from A to B.

3.2.3.4. Ketogenic interventions. Should persons with dementia be offered ketogenic interventions to correct cognitive impairment or prevent further cognitive decline?

Recommendation 30

Ketogenic interventions should NOT routinely be offered to persons with dementia to correct cognitive impairment or prevent further cognitive decline.

Grade of recommendation B – strong consensus (100% agreement)

Commentary

Ketogenic interventions aim to increase ketone bodies in the blood which serve as alternative energy source for brain neurons instead of glucose. This can be achieved by a very low carbohydrate (and very high fat) diet (ketogenic diet, KD) or also by supplementing a normal diet with ketogenic agents, such as medium chain triglycerides (MCT). Historically, the KD has been used in the treatment of epilepsy, but observations of deteriorated brain glucose metabolism in the early stages of dementia suggest that alternate energy sources aimed at increasing neuronal metabolism may protect neurons and thus play a role in the prevention and treatment of AD as well [217].

Four relevant SRs [218–221] were identified considering up to eleven RCTs with ketogenic interventions in persons with MCI or mild-to moderate AD. In addition, one newer RCT with a crossover-design not considered in these reviews was identified, testing a modified KD for twelve weeks in 26 persons with AD [222].

Meta-analysis of 3 RCTs with MCT in one SR found no significant effect on the severity of cognitive symptoms of dementia measured by ADAS-Cog (Alzheimer's Disease Assessment Scale-Cognitive Subscale). By adding a trial with MMSE as outcome variable and thus combined ADAS-Cog/MMSE scale to this meta-analysis, the effect became just significant [218]. Overall, the studies that are currently available suffer from mostly small sample size, short duration, different types and dosages of intervention and varying outcome measures and reporting of mixed results.

The largest single trial [223]; considered in the most recent SR [220], with more than 400 participants and placebo-controlled, double-blind design found no effect of MCT supplementation in mild-to moderate AD after 26 weeks, neither on cognitive nor on other outcomes.

In summary, there is currently no convincing evidence for a relevant cognitive or clinical benefit of ketogenic interventions in persons with dementia. Larger high-quality long-term studies are recommended in all reviews [218–221,224]. Due to the limited quality of available studies, the level of evidence was downgraded from A to B.

Importantly, potential undesirable effects of ketogenic interventions should not be ignored, e.g. gastrointestinal problems, but most relevant insufficient dietary intake when following a KD. Ketogenic diets are very difficult to implement and drastically limit food choices. They clearly increase the already high risk of malnutrition in persons with dementia and can therefore not be recommended also for this reason (compare #13).

3.2.3.5. Omega-3 fatty acid supplementation. Should persons with dementia be offered omega-3 fatty acid supplements to correct cognitive impairment or prevent further cognitive decline?

Recommendation 31

Omega-3-fatty acid supplements shall NOT routinely be offered to persons with dementia to correct cognitive impairment or prevent further cognitive decline.

Grade of recommendation A — strong consensus (100% agreement)

Commentary

n3-PUFA from fish and plant sources are considered as a promising non-medical alternative to improve brain functions and slow down the progression of dementia. They are important brain constituents with anti-inflammatory properties. Epidemiologic evidence suggests a relation between dietary intake of n3-PUFA as well as fish and cognitive function [225].

Several SRs from high [226] to critically low quality [227] examined the effects of n3-PUFA supplementation on cognition in persons with mild to moderate dementia and/or cognitive impairment [226–233].

A Cochrane review [226] included three RCTs with 632 participants with mild to moderate AD, testing combined eicosapentaenoic acid (600–975 mg/d) and docosahexaenoic acid (675–1720 mg/d) supplementation over six, twelve and 18 months. No benefit was found in any study. Meta-analyses also did not result in positive effects after six months, neither on cognitive or functional outcomes nor on dementia severity. The trials were of high methodological quality and the overall quality of evidence was also rated as high for most of the outcomes.

In subsequent reviews, which included further (newer as well as older) studies, partly also in persons with MCI do not come to a different conclusion. No further meta-analyses were performed.

In summary, available intervention studies do not support the use of n3-PUFA to improve cognition or prevent further cognitive decline in persons with mild to moderate dementia.

It has been suggested that plasma homocysteine levels and thus adequate B vitamin status [228,234], APOE-4 genotype [225,230] and degree of cognitive impairment [233,235] play a role, but this would need to be confirmed in further studies with longer follow-up periods and also with a combination of nutrients such as n3-PUFA and B vitamins (see #29).

3.2.3.6. Probiotics. Should persons with dementia be offered probiotics to correct cognitive impairment or prevent further cognitive decline?

Recommendation 32

Probiotics should NOT routinely be offered to persons with dementia to correct cognitive impairment or prevent further cognitive decline.

Grade of recommendation B — strong consensus (100% agreement)

Commentary

Probiotics are live microorganisms that are intended to have health benefits when consumed and are available in the form of powders, capsules and pre-packaged liquids/yoghurts. Based on the bidirectional communication between gut and brain through the vagus nerve (gut–brain axis), gastrointestinal dysbiosis as a possible cause of neuroinflammatory conditions that promote cognitive decline, and on preclinical observations of reduced cognitive decline after probiotic supplementation in animal studies, probiotics are of interest in the nutritional management of persons with dementia.

The impact of probiotics on cognitive outcomes in persons living with AD has been investigated in eight SRs: one of high [236] and seven of critically low quality [237–243]. These reviews had a focus on studies undertaken in humans, some also considered animal studies and humans with cognitive impairment. Meta-analyses, conducted within five of the SRs [236,239,240,242,243], show great heterogeneity and report inconsistent results.

The high-quality review of Krüger et al. [236] focused specifically on persons with AD and included three eligible RCTs with 161 institutionalized participants [244–246]. The meta-analysis found no beneficial effect of probiotic supplementation on cognitive function, with very low certainty of evidence. The studies are heterogeneous in populations, sample size, probiotic dose and type, and cognitive outcome measure and had additional confounding aspects, including the usual diet.

As such, current evidence is insufficient and the overall confidence in the results of the reviews is limited, leading to downgrading of the recommendation from grade A to B.

3.2.3.7. Micronutrient supplementation. Should persons with dementia be offered micronutrient supplements to correct cognitive impairment or prevent further cognitive decline?

Recommendation 33

Persons with dementia should NOT be offered micronutrient supplements unless there is an indication of deficiency.

Grade of recommendation GPP — strong consensus (100% agreement)

Commentary

Several micronutrients (i.e. vitamins, minerals and trace elements) play an important role in brain functionality, e.g. as cofactors for metabolic processes or protection against oxidative damage. Thus, an inadequate supply of these nutrients can contribute to cognitive decline, and micronutrient supplementation could potentially maintain or improve the cognitive abilities of persons with dementia.

Due to the large number of possibly relevant nutrients and the vast amount of literature, it was unfortunately not possible to analyze the available evidence in this regard systematically, and we refer to the original version of this guideline [43]. As far as we know, no controlled intervention study has been able to demonstrate a cognitive benefit for persons with dementia from supplementing a single nutrient, neither folic acid, vitamin B_1, B_{12}, D, E or selenium neither any other micronutrient. Although supplements consisting of a combination of several relevant nutrients are theoretically more likely to be effective than single nutrients, the evidence is not yet convincing here either (see #29). We, thus, do not recommend the systematic use of micronutrient supplements to prevent or correct cognitive decline in persons with dementia.

Relevant factors for an effect, however, are supplement dose and duration, type and stage of dementia, and – most important – dietary intake and nutrient status of the person with dementia, and there may be circumstances, where an additional administration is indicated.

Definitely, in the case of specific nutrient deficiencies, the respective nutrient should be supplemented. Preferably normal doses (not mega-doses) should be used and potential toxic effects of high doses must be taken into account. Pronounced nutrient deficiencies mainly occur as a consequence of diseases associated with malabsorption, metabolic disorders or increased excretion, but may also develop in persons with long-term unbalanced diets. Also, general malnutrition implies a shortage of micronutrients along with energy and protein deficiency, however with a deficiency of several or all micronutrients, so that the administration of a single nutrient does not seem appropriate.

As persons with dementia are at particular risk of an inadequate and unbalanced diet, the possibility of existing nutrient deficiencies should be considered for each individual patient, and any suspicions clarified. Comprehensive practical guidance on the assessment of micronutrient status and micronutrient supplementation is available in the ESPEN Micronutrient Guideline [247]. In the case of general malnutrition, however, instead of the administration of individual nutrients, a more comprehensive treatment is indicated.

In summary, when no deficiency exists, specific supplementation does not seem reasonable, and we generally recommend providing adequate amounts of all essential nutrients primarily through a balanced dietary pattern (see #21).

3.2.4. Enteral and parenteral nutrition and hydration

EN and PN allow the provision of energy and nutrients to patients who are unable to consume adequate amounts orally. These modes of feeding, however, in particular via percutaneous endoscopic gastrostomy (PEG), are invasive interventions with potential complications that are not negligible [248] and have to be weighed against the potential benefits of improved nutrition.

RCTs studying the effects of (par)enteral nutrition compared to no intervention are not available.

Existing observational studies on the effects of EN in patients with dementia are generally of limited quality. In most studies the control group is not adequate and the population, the type and stage of dementia are not well defined. Studies on the effects of PN are completely lacking. Therefore, existing scientific evidence is inconclusive, and recommendations have to include expert consensus.

3.2.4.1. General. How should decisions about (par)enteral nutrition and/or hydration for persons with dementia be made?

Recommendation 34

Each decision for or against (par)enteral nutrition and hydration for persons with dementia shall be made on an individual basis with respect to the patient's clinical situation, general prognosis and preferences.

Grade of recommendation GPP – strong consensus (100% agreement)

Commentary

Since (par)enteral nutrition and hydration constitute medical treatment, that requires an invasive procedure, the decision to initiate and also discontinue (par)enteral nutrition and hydration must be based on a medical indication [249]. Only if there is an indication for a therapeutic procedure that can realistically achieve therapeutic goals – like prolonging life without prolonging suffering and discomfort at the end of life, or maintaining independence and physical function – weighing of probable benefits and burdens of the therapy can be considered. This is in line with the ethical concepts of beneficence and non-maleficence [250,251].

After evaluating the medical indication and weighing the clinical benefits and burdens of (par)enteral nutrition and hydration, it is of utmost importance that the individual patient's wishes, his or her values and goals of care are respected and incorporated in an open discussion with the patient, their family and next of kin and in the multidisciplinary team taking care of them [252,253]. It is then up to the individual patient to decide whether to accept the therapy, thereby upholding the ethical principle of patient autonomy.

Patients in advanced stages of dementia, however, may not be capable of making overt decisions. They are potentially unable to understand their prognosis and treatment choices, and informed consent is often not possible. In this situation, advance directives stating the patient's preferences will guide action, and/or formally appointed proxies will make the decision, provided there is a clinical indication. It is encouraged that living wills be drawn up as early as possible in the course of the disease.

(Par)enteral nutrition and hydration can have a symbolic importance apart from any measurable benefits for the patient. Such views, often expressed by family members, should be understood and respected in accordance with the patient's and family's values, religious beliefs and culture [251]. Communication is crucial in this situation, explaining the patient's condition and prognosis, that the inability to eat and drink can be a natural part of dying and is not synonymous with suffering. Optimal palliative care is indicated in this situation, including provision of careful “hand feeding”. In situations when there is uncertainty whether a patient will benefit from (par)enteral nutrition and hydration, a time-limited trial may be useful [252,253].

Competent palliative care counseling or the possibility of discussing individual problematic cases with a clinical ethics committee should be available [254].

Should (par)enteral nutrition and/or hydration be offered to persons with dementia in the terminal phase of life?

Recommendation 35

Enteral and parenteral nutrition and parenteral fluids shall NOT be initiated in persons with dementia in the terminal phase of life.

Grade of recommendation GPP – strong consensus (96% agreement)

Commentary

The terminal phase of life cannot be identified in every patient. Generally, the term describes the last few weeks of life, when severe health deterioration is not reversible and it is expected that the patient will die within the next few weeks.

In this stage of life, (par)enteral nutrition and hydration are associated with uncertain benefits and substantial risks [253,255,256]. In addition to the risks of the respective insertion-procedure, there is also a higher risk of aspiration pneumonia, diarrhea, gastrointestinal discomfort and pressure ulcers for EN [254,257,258], while PN entails an increased risk for blood stream infections [259]. In the dying process, (par)enteral nutrition and hydration can also cause discomfort due to increased oral and pulmonary secretions and dyspnea due to pulmonary edema [255]. Further, the possible need for physical restraints and their inherent risks must also be taken into account.

Generally, (par)enteral nutrition and hydration should not be started or continued for the dying patient with or without dementia as it is associated with complications and additional symptom burden.

The sensation of hunger is generally not present in dying patients; when offered they will take very little nourishment. The major discomfort is thirst, which can be satisfactorily managed by sips of fluids, ice cubes, hard candy or good oral care moistening the oral cavity [255,260,261]. There is little correlation between the sensation of thirst in patients in the terminal stages of their lives and their actual intake of fluids, even when administered intravenously [253,255,261,262].

Observational studies indicate that forgoing (par)enteral nutrition and hydration in patients with insufficient intake and severe dementia who have attained the terminal phase of their life, marked by severe disability and complications like recurrent infections, is in general not associated with high levels of discomfort if optimal palliative care is provided [263,264]. Further studies are needed on this topic, though they are difficult to design and to conduct for ethical reasons [265].

3.2.4.2. Enteral nutrition. Should enteral nutrition be offered to persons with dementia?

Recommendation 36

Enteral nutrition should be used temporarily in persons with mild or moderate dementia, if significantly low nutritional intake is predominantly caused by a potentially reversible condition.

Grade of recommendation GPP — strong consensus (100% agreement)

Commentary

If there is a valid medical indication, EN should be initiated irrespective of the presence of early, mild or moderate dementia (see also the ESPEN Guideline on Clinical Nutrition and Hydration in Geriatrics [52]). In this situation, EN should be performed to overcome a crisis situation with markedly insufficient oral intake, if no other means are able to cover the nutritional needs of the patient orally. This may be the case e.g. when anorexia is a major concomitant symptom during an infectious period, in case of dysphagia due to acute stroke or in case of delirium with markedly reduced fluid and food intake in a patient with mild or moderate dementia.

There is no data available as to what extent of oral intake deficit EN may enhance the clinical situation and prognosis and what could be a beneficial time frame for EN. From the experts' point of view, an intake below 50% of energy requirements expected for more than seven days in spite of adequate support and oral supplementation would be a reasonable indication for nasogastric feeding (see also the ESPEN Guideline on Clinical Nutrition and Hydration in Geriatrics [52]). If the period of markedly low intake is expected to last longer than two weeks or if nasogastric feeding is not tolerated or accepted, a PEG should be inserted.

If EN is performed in such a situation, the indication should be reassessed every week during the first month and monthly thereafter. If nutritional demands are again partly covered orally, an attempt without EN might be useful to make further judgments on the source of nutrition for the patient.

Recommendation 37

Enteral nutrition shall not be initiated in patients with severe dementia.

Grade of recommendation GPP — strong consensus (100% agreement)

Commentary

Although in some studies the term severe dementia is not clearly defined, it generally refers to patients with dementia and severe loss of memory and orientation. Affected persons are dependent in basic ADL and are, at most, oriented to their own person, corresponding to stage 6 and 7 of the Reisberg Global Deterioration Scale (GDS) [5] (see Table 1).

A Cochrane review from 2021 about the effectiveness and safety of EN for persons with severe dementia identified 14 controlled, non-randomized trials that included 49,714 participants, 6203 of whom were tube-fed. Participants with no feeding tube were given standard care or standard care with extra treatments to encourage eating and drinking. Four studies with 36,816 participants assessed survival time as an outcome, none found an effect. None of the studies assessed quality of life [83].

The by far largest study within this meta-analysis is a prospective database analysis from Teno and colleagues [258], confirming the evidence from many studies with smaller sample size. They evaluated minimum data set (MDS) information of 36,492 US nursing home residents with advanced dementia and newly developed eating problems. The study compared 1956 residents who underwent PEG insertion with 34,536 residents who were fed orally and found no significant difference for survival.

One study with 4421 participants, included in the Cochrane review, found an increased rate of pressure ulcers in the group with EN via PEG [266].

Another SR and meta-analysis from 2021 including 1805 patients with and 3861 without EN from twelve trials, came to the conclusion that patients with advanced dementia with PEG EN have significantly higher risk of pneumonia (OR 3.56; 95% CI 2.32–5.44; $p < 0.001$) and pressure sores (OR 2.25; 95% CI 1.92–2.63; $p < 0.001$), but no difference between groups was found for the survival period and nutritional status [267].

A high or very high risk of bias in all available studies should be noted [83]. No evidence at all is available for the effectiveness of EN for older persons with advanced dementia regarding their physical and mental function, behavioral and psychiatric symptoms of dementia.

Considering the available evidence and clinical experience of experts in the field, there may rarely be an individual situation where EN seems advantageous. The initiation of EN in the advanced stage of dementia should be a very rare exception which should always be preceded by ethical counselling. In case of a treatment trial, it should be regularly controlled, if the expected benefits of EN will occur. From the medical perspective, EN can be discontinued like any other medical procedure, if a beneficial effect is not observed or no longer expected [251].

In some cultures, the initiation or maintenance of (par)enteral feeding is regarded as a basic human right and not a medical procedure, and it may be considered unacceptable to discontinue (par) enteral feeding for fear of accelerating the dying process. In view of the available evidence that EN does not prolong survival in the final stages of dementia, this argument no longer seems to be valid.

In the vast majority of cases, careful hand-feeding according to individual needs and capacity, so-called comfort-feeding, in a relationship-centered way is the best alternative. The concept of comfort-feeding describes the approach that affected persons are adequately supported to eat and drink what they like and as much as they like, while nutritional requirements become irrelevant in the final stages of their life [264,268].

3.2.4.3. Parenteral nutrition. *Should parenteral nutrition be offered to persons with dementia?*

Recommendation 38

Parenteral nutrition can be used temporarily in patients with mild or moderate dementia, if significantly low nutritional intake is predominantly caused by a potentially reversible condition, but enteral nutrition is contraindicated or not tolerated.

Grade of recommendation GPP — strong consensus (100% agreement)

Commentary

There are no data available regarding the effects of PN in patients with dementia. We therefore also refer to the ESPEN Guideline on Clinical Nutrition and Hydration in Geriatrics [52].

As in patients without dementia, (par)enteral nutrition and hydration should be predominantly performed via the enteral route whenever possible. In case of contraindications for EN, PN may be a substitute. If additional nutritional support is necessary for a shorter period than ten days or if nasogastric feeding is not accepted, peripheral PN might help to overcome a crisis situation of low intake. The same is true if a central venous line is already in place for other reasons, i.e. in the perioperative period.

In any case a medical indication is required, the individual patient's will has to be considered, and potential risks have to be weighed against the potential benefits of improved nutrition (see also #34).

Thus, PN will be reserved to justified individual cases of mild to moderate dementia. In the vast majority of cases, careful hand-feeding according to individual needs and capacity, so called comfort-feeding [264], is the best alternative (see also #37).

3.2.4.4. Parenteral hydration. *Should parenteral hydration be offered to persons with dementia?*

Recommendation 39

Parenteral fluids can be given temporarily in periods of insufficient fluid intake to overcome a crisis situation.

Grade of recommendation GPP — strong consensus (100% agreement)

Commentary

There are clinical circumstances when patients with dementia may require parenteral administration of fluids, i.e. due to temporarily low intake or increased demands. Frequent examples are increased fluid losses due to diarrhea or vomiting and increased demands due to fever or a climatic heat period. In addition, fluid intake may be a challenge in persons with oropharyngeal dysphagia or other superimposed diseases.

In these situations, parenteral fluids are often helpful, if fluid requirements cannot be covered via the oral route.

In case of mild and moderate dehydration, particularly if the person is able to stay at home or in the nursing home, the subcutaneous route should be preferred. Infusion of fluids into the subcutaneous tissue — hypodermoclysis — is an easy, effective and safe hydration technique for mild to moderate dehydration, particularly in older cognitively impaired patients [269–272]. There is little discomfort inserting and maintaining the subcutaneous infusion, and patients are less likely to interfere with subcutaneous infusions than with intravenous lines [271].

There are no studies about hypodermoclysis including only patients with dementia, they all consider the general patient population including geriatric patients with various stages of cognitive impairment. We therefore also refer to the ESPEN Guideline on Clinical Nutrition and Hydration in Geriatrics [52].

SRs comparing subcutaneous with intravenous fluid administration [271,273–275] come to the conclusion that subcutaneous fluid administration is accompanied by less side effects compared to the intravenous route. However, the fluid volume administered subcutaneously was less. Therefore, subcutaneous administration should be restricted to mild and moderate dehydration. The infused electrolyte solutions should be isotonic, it is recommended that the infused volume should not exceed 3000 mL/d (max. 1500 mL per infusion site), however in the majority of the reported cases, the infused daily volumes do not exceed 1000 mL [270–272,276].

The subcutaneous application is not suitable for patients needing larger volumes and hypertonic or electrolyte-free solutions. Thus, in the situation of severe dehydration, fluid administration via an intravenous route should be preferred. Coagulation disorders, dermatological problems on the infusion site, and lack of subcutaneous tissue in severely malnourished patients are further limitations of the subcutaneous route [270,277].

3.2.5. Individualized, comprehensive approach

Should persons with dementia be offered an individualized, comprehensive, approach?

Recommendation 40

Persons with dementia should be offered an individualized, multi-professional and multicomponent approach to support food and fluid intake and maintain or improve nutritional status.

Grade of recommendation GPP — strong consensus (100% agreement)

Commentary

Multicomponent approaches, combining different strategies to support food and fluid intake of persons with dementia, are addressed in several SRs [62,63,66–68,91,278]. These reviews refer to one to four mostly different original studies, which all combine different intervention components, e.g. mealtime assistance, meal and/or environmental modifications, in varying forms. Improvements of nutritional intake and nutritional status are reported, but results are not consistent. Some of the studies are not limited to persons with dementia and the overall quality of both the original studies and most of the reviews is unfortunately limited.

Nevertheless, it seems appropriate to combine different measures in order to address individual problems, resources and needs adequately. Positive effects of such a comprehensive and individualized concept are reported from a national preventive care program in Sweden consisting of the following components: assessment, analysis of underlying causes, actions performed and documentation of results. The implementation of all four planned steps was associated with weight gain in registered persons with dementia and malnutrition or at risk of malnutrition [279].

Further, an integrated homecare program for persons with advanced dementia in Singapore with visits and phone calls by a multidisciplinary team – including dietary advice and teaching of safe feeding techniques – improved symptoms and quality of life of those who could be reviewed after five months (53 of 254 patients at baseline, pre-post design) [280].

As indicated in a 24-week pilot cluster RCT with 91 residents with dementia from seven French nursing homes, non-nutritional measures such as exercise and social activities can also help to improve nutritional status [120].

Thus, in line with the basic principles of geriatric care in general, nutritional care for persons with dementia should be based on a comprehensive multicomponent, multi-professional and individualized approach, characterized by close dialogue and cooperation of the various persons and professions involved. From all available options described above for optimizing nutritional intake of persons with dementia, the individually suitable combination must be determined and implemented.

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Disclaimer

This guideline has been developed with reasonable care and with the best of knowledge available to the authors at the time of preparation. It is intended to assist healthcare professionals and allied healthcare professionals as an educational tool to provide information that may support them in providing care to patients. Patients or other community members using this guideline shall do so only after consultation with a health professional and shall not mistake this guideline as professional medical advice. This guideline must not substitute seeking professional medical and health advice from a health professional.

Conflicts of interest

The expert members of the working group were accredited by the ESPEN Guidelines Group, the ESPEN Education and Clinical Practice Committee, and the ESPEN executive. All expert members have declared their individual conflicts of interest according to the rules of the International Committee of Medical Journal Editors (ICMJE). If potential conflicts were indicated, they were reviewed by the ESPEN guideline officers and, in cases of doubts, by the ESPEN executive. None of the expert panel had to be excluded from the working group or from co-authorship because of serious conflicts. The conflict of interest forms are stored at the ESPEN guideline office and can be reviewed with legitimate interest upon request to the ESPEN executive.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.clnu.2024.04.039.

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