



## EXECUTIVE SUMMARY

# Nutrition and dementia

A review of available research



**Alzheimer's Disease  
International**

*The global voice on dementia*

Supported by



## **Nutrition and dementia - executive summary**

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### **Authors**

Chapter 1: Dr Maëlienn Guerchet\*, Dr Matthew Prina\*, Professor Martin Prince\*

Chapter 2: Professor Emiliano Albanese\*†

Chapter 3: Dr Matthew Prina, Professor Emiliano Albanese

Chapter 4: Professor Emiliano Albanese, Dr Matthew Prina

Chapter 5: Professor Martin Prince, Dr Mario Siervo‡, Dr Daisy Acosta§, Dr Maëlienn Guerchet, Dr Matthew Prina

\* The Global Observatory for Ageing and Dementia Care, King's College London

† University of Geneva, Switzerland

‡ University of Newcastle

§ Universidad Nacional Pedro Henríquez Ureña, Dominican Republic

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ADI is fully responsible for the content

Design by Julian Howell

### **The Global Observatory for Ageing and Dementia Care**

The Global Observatory for Ageing and Dementia Care, hosted at the Health Service and Population Research Department, King's College London, was founded in 2013. Supported by Alzheimer's Disease International, and King's College London, the Observatory has a tripartite mission:

- 1 To build upon ADI's 10/66 Dementia Research Group programme of population-based and intervention research in low and middle income countries, maximising the impact that research findings from our data can have upon policy and practice.
- 2 To develop, evaluate, and promote primary care and community interventions for people with dementia.
- 3 To synthesise global evidence for policymakers and public, in particular, continuing and developing our role in the preparation of high impact evidence-based reports for Alzheimer's Disease International (World Alzheimer Reports 2009, 2010, 2011 and 2013), the World Health Organization (Dementia: a public health priority, 2012) and other relevant intergovernmental organisations.

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Professor Martin Prince

Professor Emiliano Albanese

Dr Maëlénn Guerchet

Dr Matthew Prina

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# Introduction

Eating and having a good meal is part of our everyday life and important to everybody, not least to people living with dementia. But it is still an almost totally neglected area of focus in relation to these diseases.

Compass Group and Alzheimer's Disease International (ADI) have come together in commissioning this report to investigate how the right nutrition can help to make life better for people who live with dementia. This is clearly reflected in ADI's mission and vision: 'an improved quality of life for people with dementia and their carers'. Compass Group, as world-leading food and support services organisation, shares this vision in their work to support people who are affected by dementia.

This report was prepared by Professor Martin Prince, Professor Emiliano Albanese, Dr Maëlénn Guerchet and Dr Matthew Prina for the Global Observatory for Ageing and Dementia Care, King's College London. They have reviewed a number of areas in existing research regarding the relevance of nutritional factors to primary and secondary prevention of dementia, undernutrition in dementia and interventions to improve the nutrition of people living with dementia.

The report shows the importance of each of these factors in the everyday nutrition and care of people with dementia. In addition, it identifies how we can start building methods and guidelines that will complement clinical treatment of the diseases. It highlights:

- the link between nutrition and quality of life
- the previous neglect of this important issue, as evidenced by the high prevalence of undernutrition and inadequate food intake among people with dementia
- the untapped potential to improve outcomes for people with dementia, given the evidence for effective interventions
- the need for more research in this area.

A healthy diet and nutrition is fundamental to wellbeing at any stage of life and to helping to combat other life-threatening diseases. We believe it can play as important a role in relation to dementia.

ADI believes that the key to winning the fight against dementia lies in a unique combination of global solutions and local knowledge. As such, it works globally to focus attention on the epidemic of dementia, while also empowering local Alzheimer associations to promote and offer support for people with dementia and their carers.

Compass Group is a company that operates in more than 50,000 client locations in around 50 countries and serves over 4 billion meals per year. By working closely with our care home clients, we can improve the quality of their food and support services allowing them to focus on caring for their residents. People living with dementia are a small but growing constituency of Compass' business.

ADI and Compass Group believe that a focus on diet, nutrition and wellbeing is a positive approach to supporting people with dementia and their carers in dealing with this terrible disease. It is not only a good collaboration but the right thing to do.



Marc Wortmann  
Executive Director  
Alzheimer's Disease International



Mike Iddon  
Group Healthcare Director  
Compass Group

## Key messages

- 1** Undernutrition is common among older people generally, particularly in low and middle income countries. For this age group it is, arguably, a larger public health problem than obesity. The consequences include increased frailty, skin fragility, falls, hospitalisation and mortality.
- 2** Undernutrition is particularly common among people with dementia in all world regions. It tends to be progressive, with weight loss often preceding the onset of dementia and then increasing in pace across the disease course.
- 3** Obesity in mid-life may be a risk factor for developing dementia in late-life. If so, this is an important modifiable risk factor, and a matter of concern given rising levels of obesity worldwide. However, careful examination of the existing evidence casts some doubt upon the validity and robustness of this finding, which requires more research.
- 4** There are many dietary factors that might plausibly increase or decrease risk for the onset of dementia. However, we could find no clear or consistent evidence to support a causal protective role for vitamins B<sub>6</sub>, B<sub>12</sub>, C or E, folate or omega-3 PUFA (polyunsaturated fatty acids). There is quite consistent evidence from epidemiological cohort studies that adherence to a Mediterranean diet (with a high proportionate intake of cereals, fruits, fish and vegetables) may lower the risk of cognitive decline and dementia. However, to date, only one trial has been carried out, with encouraging findings.
- 5** The mechanisms underlying weight loss and undernutrition in dementia are complex, multifactorial, and only partly understood. Reduced appetite, increased activity, and, in the more advanced stages of the illness, the disruption of eating and feeding behaviours by cognitive and behavioural problems all play a part. For some forms of dementia, it may be that central regulation of appetite and metabolism is disturbed as an inherent feature of the disease.



- 6** A key finding in this report is that while weight loss is a common problem for people with dementia, undernutrition can and should be avoided. Proof of concept comes from a new review of the use of oral nutritional supplements, indicating that it is possible to stabilise or even increase the weight of people with dementia over relatively long periods. The nutritional benefits of education and training for caregivers was less apparent, although such interventions were popular and there are likely to be other benefits.
- 7** In care homes, attention to staff training and mealtime environment can lead to significant enhancement in calorie intake among residents. Eating is a social activity, and more thought should be given to how this can be optimised, normalised and made a core aspect of person-centred care. Sensitive and inclusive design of dining rooms, kitchens, furniture and tableware can all make important contributions.
- 8** There is no current evidence that nutritional supplementation whether with micronutrients or macronutrients can modify the course of dementia (cognitive and functional decline). There is currently insufficient evidence to recommend the use of any medical food. However, data are emerging indicating some potential for therapeutic benefit (e.g. Souvenaid), and trials are ongoing. Vitamin E shows some promise, but at doses that may lead to harmful side effects.
- 9** Much more attention needs to be focused upon the problem of undernutrition in dementia. This has been grossly neglected in research and practice. Studies reviewed in this report indicate that 20-45% of those with dementia in the community experience clinically significant weight loss over one year, and that up to half of people with dementia in care homes have an inadequate food intake.

# Recommendations

- 1** More research needs to be conducted into
  - The possibility that nutritional supplementation of dietary components with high mechanistic plausibility may be effective in reducing the incidence of dementia if targeted upon those with evidence of deficiency (for example vitamin B<sub>12</sub> and folate).
  - The effective components of a Mediterranean diet with respect to the prevention of dementia and progression of Mild Cognitive Impairment, and the feasibility of sustained implementation of such dietary modification.
  - The possibility that some forms of micronutrient supplementation may yet be effective in altering the course of dementia, if targeted upon those who are deficient.
  - The minimum effective dose of vitamin E as a treatment for clinical progression in dementia, and the balance of associated risks and benefits.
  - The relative efficacy of food fortification and oral nutritional supplementation in maintaining weight among people with dementia at risk for undernutrition.
  - The feasibility and effectiveness of long-term fortification or oral nutritional supplementation strategies, including the wider health and quality of life benefits.
- 2** It is important that clear, consistent and independent evidence-based advice is provided to support decision-making on nutritional supplements by those at risk of, or already living with, dementia.
- 3** Nutritional standards of care for people with dementia should be introduced throughout the health and social care sectors, and monitored for compliance.
  - All people with dementia should have their weight monitored and nutritional status assessed regularly.



- All people with dementia, and their family carers, should receive dietary advice from a dietician as a part of post-diagnostic care, updated, as appropriate, as their condition evolves, particularly with the onset of weight loss, aversive feeding behaviours, and need for feeding assistance.
- Undernutrition, once established, is a serious health concern requiring medical attention and input from a dietician and occupational therapy as appropriate. Those at risk of undernutrition require a detailed assessment of diet, feeding behaviours and need for feeding assistance. This should inform an immediate and intensive nutritional intervention to restore and maintain normal nutrition.
- Nutritional advice and natural food fortification should be tried first, but the use of oral nutritional supplements should not be delayed for those with undernutrition and those at risk who fail to respond.
- All care homes and hospitals that care for people with dementia need to develop and implement plans to optimise and monitor their nutritional status. This should include staff training; attention to the nutritional content and variety of the food provided, and its suitability for people with different eating and feeding difficulties; the way in which food is prepared and delivered; and dining room design and mealtime environment.
- Staff training in care homes and hospitals should be part of a comprehensive programme of workforce development linking managers, nursing staff, care assistants and caterers all of whom need to understand the challenges involved in maintaining adequate nutrition for people with dementia, and the part that they have to play. This should address gaps in knowledge (the nutritional content of food, the impact of dementia on diet and nutrition) and skills (in monitoring nutritional status, providing feeding assistance, managing aversive feeding behaviours).

# Executive summary

## 1 Background

### Dementia: numbers and burden

- The world's population is ageing, as improvements in public health and health care contribute to people living longer and healthier lives. However, this has resulted in a worldwide increase in the number of people living with chronic diseases, including dementia.
- The global epidemic of dementia can no longer be neglected and should be considered a public health priority in all countries.
- Dementia is a syndrome affecting memory, thinking, behaviour and the ability to perform everyday activities, usually chronic or progressive by nature, which is caused by a variety of brain illnesses, of which Alzheimer's disease, vascular dementia, dementia with Lewy bodies, and frontotemporal dementia are the most common. Dementia is not a normal part of ageing.
- It is estimated that 44 million people worldwide live with dementia in 2013, with numbers doubling every 20 years, to reach 135 million by 2050. Most of this increase will occur in low and middle income countries (LMIC); currently 62% of all people with dementia live in such regions, this proportion rising to 66% in 2030 and 71% in 2050.
- It is estimated that there are 7.7 million new cases of dementia each year worldwide, with one new case every four seconds.
- Dementia and cognitive impairment are by far the most important contributors, among chronic diseases, to disability, dependence, and transition into residential and nursing home care. Behavioural and psychological symptoms (BPSD) typically occur later in the course of the disease, have an impact on the quality of life of the old person and increase caregiver strain.
- The total estimated worldwide cost of dementia in 2010 was US\$ 604 billion, equivalent to around 1% of global gross domestic product, of which about 70% was incurred in western Europe and North America. Costs of informal care and the direct costs of social care contribute similar proportions of total costs worldwide; while the direct costs of medical care are much lower. However, in low and middle income countries informal care costs predominate, accounting for up to two-thirds of all costs.

### Malnutrition, undernutrition, and obesity: worldwide patterns of the 'double burden'

- Diet and nutrition play an important role in maintaining health and wellbeing. Diet can be defined as what we habitually eat and drink and is best conceived as a lifestyle. Nutrition encompasses the processes of ingesting and digesting foods, and absorbing and metabolising their nutrients. Adequate nutrition is essential for healthy living.
- Malnutrition comprises both overnutrition (excess food/calorie intake) and undernutrition, which is the depletion of body energy stores and loss of body mass (mainly lean mass). Malnutrition results mainly from eating an inadequate diet in which either the quantity and/or quality of nutrients does not meet the needs of our body.
- Undernutrition (insufficient calories, protein or other nutrients needed for tissue maintenance and repair) is the most common nutritional problem, affecting up to 10% of older people living at home, 30% of those living in care homes, and 70% of hospitalised older people. The prevalence of undernutrition among older people in LMIC is likely to be even higher, particularly in rural and less developed settings, and increases with age.
- Consequences of undernutrition include frailty, reduced mobility, skin fragility, an increased risk of falls and fractures, exacerbation of health conditions, and increased mortality. Risk factors include the older person's social, economic and environmental situation; problems with mouth, teeth and swallowing; mental, neurological and other chronic physical diseases; and side effects of long-term treatment with certain drugs.
- With progressive globalisation of western dietary habits and lifestyles (e.g., underactivity and increased consumption of saturated fat, animal proteins and refined carbohydrates) obesity is now rising dramatically in low and middle income countries, especially in urban settings. Obesity also has important adverse consequences for health – it is a major risk factor for diabetes, cardiovascular diseases and cancer, and is the fifth leading modifiable risk determinant for global deaths.

## 2 Nutrition and dementia across the life course

### Key life course concepts: sensitive periods and accumulation

- Evidence suggests that the determinants of dementia risk impact across the life course in a manner comparable to several other chronic diseases of late life, sometimes with relatively long latent periods before the onset of clinical dementia syndromes.
- A life course approach to late-onset dementia may improve our understanding of the disease, and provide evidence on potential additive effects of exposures over time ('accumulation'), and on 'sensitive periods' of life during which exposure to a risk factor may be more detrimental for dementia risk.
- It is therefore possible that prevention should begin early in life and be concerned not only with the onset of dementia and its progression, but also with trajectories of cognitive ageing from mid-life, when impairment likely begins.

### Nutrition for optimal brain/cognitive development

- Micronutrients and fat stores accumulated during intra-uterine life are important for brain and nervous system maturation and development, which may in turn influence risk of cognitive impairment and dementia in older age.
- Brain reserve (enhanced structural or functional brain capacity) may buffer the effects of dementia-related neuropathology and explain the observed variability in the expression and severity of the dementia syndrome in people with comparable levels of neuropathology. The extent of brain reserve is likely to be influenced by a variety of genetic and environmental factors, including early life nutrition.
- Low birth weight and stunting in early life, indicating inadequate nutrition in utero or early life, are independently associated with lower cognitive abilities in adulthood. These associations may then track across the life course; among older people studied in diverse geographic regions and cultures, longer leg length and larger skull circumference (indicating favourable early development), were associated with lower dementia prevalence.

### Role of high adiposity (overweight/obesity)

- While larger birth weight and high (optimal) body size in childhood may be associated with better cognition, overweight and obesity are generally harmful for health, and may contribute to the neurodegenerative and cerebrovascular changes underlying late-life dementia. However, while the relationship between obesity and dementia-related brain damage is biologically plausible, its complexity makes mechanistic evidence hard to reconcile.
- Obesity might, hypothetically, impact upon cognitive development, cognitive ageing, and dementia risk – all of these pathways have been assessed in cohort studies reviewed in detail in Chapter 2.
- Any associations between early life adiposity (childhood overweight and obesity) and cognitive function or impairment in mid-life seem to be accounted for by a strong confounding effect exerted by childhood intelligence and educational achievement.
- Cognitive decline that leads to dementia may begin in mid-life. Furthermore, higher levels of cognitive function in mid-life have been suggested to potentially act as a reserve to ward off the consequences of accumulated brain damage and reduce functional impairment.
- Studies on the relationship between adiposity measured in young adulthood and cognitive function or cognitive decline in mid-life show heterogeneous results but seem to indicate that any potential detrimental effect of adiposity on mid-life cognitive function may be largely confounded. Increasing adiposity (BMI gain) in younger adults is also not related to worse cognitive ageing before older age.
- The existence of a causal association between mid-life adiposity and dementia is quite widely accepted. A recent systematic review of evidence from epidemiological cohort studies estimated a relative risk for Alzheimer's disease (AD) associated with mid-life obesity of 1.60 (95% CI 1.34–1.92).
- There are several plausible underlying mechanisms, including; insulin resistance and hyperinsulinaemia caused by high adiposity; metabolic and inflammatory cytokines released by adipose tissue; cardiovascular risk factors e.g. hypertension, linked to obesity; and cerebrovascular disease for which obesity is a prominent risk factor. All of these products or processes have direct effects on brain regions linked to dementia, and may be implicated in AD neuropathologies.

- Metabolic, cognitive and behavioural changes associated with dementia and its long mid- to late-life clinical prodrome can have an impact on risk factor profiles, complicating elucidation of the direction of any causal relationships.
- The evidence, from three systematic reviews, suggests that the picture is complex. Findings for an association with mid-life body mass index (BMI) vary greatly across studies, and pooled estimates are strongly influenced by the positive findings from two large studies that relied largely upon ascertainment of dementia diagnosis by health services. Bias may have occurred since those who are obese are likely to be heavier users of health care, and are hence more likely to have their dementia detected. In one of the two studies, no attempt was made to control for education, a likely confounder associated both with obesity and dementia risk.
- Two more recent cohort studies, not included in these reviews, find no independent association of mid-life obesity with late-life dementia, any observed associations being confounded by sociodemographic factors.
- Given these methodological limitations, overall, the evidence on the association between high adiposity in mid-life and higher dementia risk is weak and remains highly conflicting.
- The association between central obesity, measured by waist circumference, and dementia risk is less studied, but much more consistent. This finding supports the hypothesis of an underlying metabolic mechanism, because central adiposity, measured by waist circumference, is a better indicator than global adiposity, measured by BMI, of obesity associated-metabolic changes (insulin resistance and hyperinsulinaemia).
- Our understanding of the complex relationship between adiposity and dementia could be improved by studies that investigate associations with dementia-related brain damage. However, evidence from longitudinal, prospective, population-based studies on this topic is scanty, and no studies have explored the association of mid-life BMI with brain atrophy and vascular lesions, the structural changes underlying dementia.
- Further research is warranted, because an improved understanding of the critical pathways that may lead from high adiposity to greater dementia risk could have a significant impact on targeting of primary prevention strategies.
- The association between adiposity and dementia may be explained by underlying

genetic and environmental factors that may influence lifelong adiposity trajectories, vascular risk profile, and late-life cognitive decline.

- Childhood intelligence may play an important underlying role. Intelligence strongly influences the maintenance of a healthy lifestyle throughout life, and may also confer advantages in brain structure (brain reserve) and function (cognitive reserve), that can buffer the impact of brain damage in late-life and delay the symptomatic onset of dementia.

## Conclusion

- The relationship between fats and the brain is extremely complex. Fats may be harmful in mid-life if in excess, but could also be an important energy reserve that could improve resilience to the effects of dementia-related neuropathology and comorbidities in later life. The same factors that influence the accumulation of adiposity across the life course be implicated in the development and decline of cognitive function.
- More research is needed to elucidate the complex relationship between adiposity and cognitive function, cognitive impairment and dementia. The use of a life course approach in future studies is imperative.

## 3 Nutritional factors and dementia prevention

- Dementia prevention is an urgent priority, both to reduce incidence and slow the progression of the condition. We need to identify important modifiable risk factors, particularly in the absence of any treatments that modify the course of dementia after its onset.
- Epidemiologic evidence can inform dietary recommendations to reduce dementia risk, when associations are consistent and biologically plausible. However, the design and interpretation of such studies is complicated by the impact of dementia on dietary habits (reverse causality) and the link between general good health and healthier diets (confounding). Long-term longitudinal (cohort) studies are required to clarify possible causal links.
- Experimental evidence from randomised controlled trials provides the best basis for guiding treatment and prevention strategies. However, given the long latent period between the beginning of complex pathophysiological mechanisms and the clinical, detectable onset

of symptoms, definitive trials may be difficult to conduct particularly when treatment or prevention may need to be implemented in mid-life to delay or prevent dementia onset in late-life.

## B vitamins

- B vitamins, which play key roles in cell metabolism, cannot be synthesised in sufficient quantities and have to be acquired through diet. Vitamins B<sub>6</sub> (pyridoxine), B<sub>9</sub> (folate) and B<sub>12</sub> (cobalamin) have all been proposed to have protective effects on cognitive ageing.
- When folate or vitamin B<sub>12</sub> are deficient, homocysteine levels rise, which predisposes to cardiovascular disease, and may contribute to amyloid and tau protein accumulation and neuronal death. Deficiencies in B<sub>12</sub> and in folate increase with age.
- The association between B vitamins and cognition has been the subject of several recent systematic reviews with further new studies published since then.
- There is insufficient evidence, despite a large number of cohort studies, for an association between vitamin B<sub>6</sub>, folate or vitamin B<sub>12</sub> and cognitive decline or dementia. There is, however, consistent evidence that high levels of homocysteine are associated with cognitive decline.
- Randomised controlled trials targeting elevated homocysteine levels have shown that supplementation with B vitamins (B<sub>6</sub>, B<sub>12</sub> and folate alone or in combination) consistently reduces homocysteine levels, but without any significant effect on cognitive function. There is a suggestion from some studies that those with higher homocysteine levels at baseline, or clear and defined vitamin deficiencies may benefit from supplementation. However, this has not been clearly demonstrated, and more research is required.

## Antioxidants

- Neural inflammation and oxidative damage are thought to be key mechanisms in the development of dementia. Oxidative stress directly damages cell components, resulting in damage to synapses and nerve cell death. Antioxidants are thought to act against neurodegeneration by limiting the production of toxic substances and reducing damage by free radicals.
- Nutrients with antioxidant properties include vitamins C and E and flavonoids.

Most research has focused on the potential protective effect of vitamin E.

- There is currently insufficient evidence from either longitudinal epidemiological studies or randomised controlled trials to support a role for antioxidants in cognition.
- The only consistent associations were reported in epidemiological cohort studies that have assessed vitamin E status using food frequency questionnaires, rather than biochemical measures. Three randomised controlled trials failed to show any clear or consistent benefit of vitamin E supplementation on cognitive decline or dementia incidence among those with mild cognitive impairment.
- One recent cohort study indicated a possible relationship between flavonoid consumption and cognitive decline, and one randomised controlled trial indicated possible benefits of flavonoid supplementation.
- No clinical trials were specifically limited to people with low levels of vitamin E/C or flavonoids.

## Omega-3 polyunsaturated fatty acids (PUFA)

- Omega-3 PUFA (polyunsaturated fatty acids) cannot be synthesised in the human body but are an essential dietary constituent, particularly for the brain. Over 22% of both the cerebral cortex and the white matter are made of phospholipids, and the function of neuronal cell membranes is modulated by their fatty acid composition. Dietary omega-3 PUFA are also implicated in neuronal growth and influence synapse formations. Omega-3 PUFA may be implicated in the vascular, inflammatory and also the amyloid pathways of dementia, and are therefore potentially important in vascular dementia, Alzheimer's disease and mixed forms.
- The main food sources of omega-3 PUFA are 'oily fish' such as salmon, mackerel, herring, sardines, fresh tuna, and swordfish.
- The evidence from epidemiological studies on the beneficial effects of fish consumption to prevent dementia incidence is conflicting, with no clear evidence for a protective effect. Confounding by healthy lifestyles and life circumstances (including socio-economic and educational level) that are associated both with higher fish consumption and lower dementia risk may explain positive results found in some studies.



- Evidence from experimental studies on the beneficial effects of omega-3 PUFA supplementation is insufficient to recommend their use in populations either for the prevention, or treatment of dementia. However, dietary recommendations to increase the amount intake of omega-3 PUFA from foods and the use of supplements in those who are deficient in these fatty acids is indicated for other reasons.
- There are some limitations in experimental studies conducted to date. Longer follow-ups may be needed to observe significant changes in cognitive function in primary prevention trials because changes in cognitive function were small in both the treated and placebo arms of existing trials. Inability to control fish consumption as part of the experimental design may have diminished the difference in total dietary omega-3 PUFA intake between those who were given the supplement and those who receive placebo.

### Mediterranean diet

- A Mediterranean diet (with high intake of cereals, fruits, fish, legumes, and vegetables) has been associated in some studies with reduced risk for cardiovascular disease, type 2 diabetes, some forms of cancer and overall mortality.
- Mediterranean diet could reduce the risk of dementia through its effects on the vascular system, reducing cardiovascular disease, by increasing the concentration of plasma neutrophins, which protect neurons against oxidative stress, or by limiting pro-inflammatory cascades.
- Moderate evidence from epidemiological studies suggests an association between adherence to the Mediterranean diet and reduced dementia risk. Not all the studies did, however, report positive findings, in particular regarding cognitive decline.
- Only one study, the PREDIMED-NAVARRA randomised trial has attempted to test this association in an experimental design, by comparing a nutritional Mediterranean diet intervention supplemented with either extra-virgin olive oil (EVOO) or mixed nuts, with a low-fat control diet. The intervention, lasting 6.5 years showed encouraging results; participants that supplemented Mediterranean diet with EVOO but not with mixed nuts, had better cognitive function, and less incident mild cognitive impairment (MCI) than the control group (OR for MCI = 0.34, 95% CI 0.12–0.97).

### Conclusion

- Overall, there is currently insufficient evidence to confirm a relationship between the micro- and macronutrients described above (vitamin B<sub>6</sub>, vitamin B<sub>12</sub>, folate, vitamin C, vitamin E, flavonoids, omega-3, Mediterranean diet) and cognitive function. Although some studies have shown positive results, particularly those using cross-sectional designs, the findings have not been consistently supported in prospective cohort studies, and preventive interventions have generally failed the critical test of randomised controlled trials.
- The strongest and most consistent evidence to date is for the potential benefits of adherence to a Mediterranean diet. Implementing such an intervention on a large scale, and in a sustainable way, would be difficult. More intervention studies are needed to further understand the preventive role of the Mediterranean diet, and the active ingredients for improving cognitive function and reducing dementia risk.
- A general limitation is that very few randomised controlled trials to date have targeted supplementation upon those who are deficient in the relevant micronutrient.

## 4 Undernutrition in dementia

- Undernutrition and underweight are common problems in older people. Weight loss is associated with increased morbidity and mortality, and it also worsens the prognosis for several chronic diseases.

### Mechanisms

- Progressive malnutrition and weight loss are observed almost inexorably in dementia patients, resulting from an imbalance between nutrient/energy intake and needs. There are numerous potential mechanisms, divided into those that may cause a reduction in energy intake and those that may cause an increase in energy expenditure, which may act from as early as the pre-clinical and asymptomatic phase of the disease to the most advanced stages.
- Evidence suggests that dementia-related brain atrophy may impact on brain regions implicated in appetite control and energy balance, with metabolism in these regions significantly reduced in dementia.
- Dietary habits are influenced by diverse factors, from food availability and preparation, to appetite, taste and feeding problems.



Brain damage in general, and the cognitive and behavioural symptoms of dementia in particular, influence these factors and hence may impact on dietary habits in different ways at different stages of dementia.

- Aversive feeding behaviours are common, severely disrupting dietary intake, and making assistance at mealtimes indispensable and progressively more problematic. They also are, understandably, a source of considerable anxiety and strain for family caregivers.

### Occurrence and dynamic of dementia-related undernutrition

- Numerous studies have investigated the association of dementia, or dementia severity with weight loss.
- Evidence on the association between dementia and weight loss is compelling. Several epidemiological studies have confirmed that people with dementia experience a significantly more marked decline in body weight in older age, across high income countries and LMIC. This weight loss likely starts sometimes in late mid-life, and may even represent an early marker of disease.
- Several mechanisms may be implicated and are not fully understood. It is likely that causal pathways vary from the pre-clinical phase, to the clinical onset and through the severity of dementia.
- Future studies should also investigate whether faster cognitive ageing in mid-life is associated with any weight loss before older age. Monitoring of weight change is highly recommended in people with dementia, and in older people. Further research is needed to determine whether monitoring in mid-life may also be beneficial for prevention.

### Consequences of dementia-related undernutrition and weight loss

- The consequences of weight loss and undernutrition in people with dementia are well characterised. Overall weight loss and undernutrition have a significant impact on the course of the disease, on both cognitive and functional symptoms, and on the overall clinical prognosis.
- Weight loss may be part of the clinical expression of dementia, worsens the clinical course of dementia, leads to greater functional impairment and dependence, and increases the risk of morbidity, hospitalisation, institutionalisation, and ultimately mortality.

- Close monitoring of body weight is very important in people with dementia, and should guide strategies to prevent and treat weight loss.

## 5 Improving nutrition for people with dementia

- In considering strategies to improve the nutrition of people living with dementia it is important to consider care homes and hospitals, as well as the home setting.
- There may be benefits from systems level interventions; for example a hospital or care home introducing staff training or changes to the environment, ambience and context in which food is provided; as well as individual approaches.
- Studies have been conducted to assess the effect of four main types of intervention; training and education programmes for caregivers; mealtime environment or routine modification; nutritional supplements; and provision of feeding assistance.
- A structured assessment of the problem is the first step. Nutritional support (simple dietary advice, with assessment and management of risk factors, and attention to needs for feeding assistance) may suffice. If this fails, or in the case of more severe undernutrition, high-energy and/or high-protein oral nutritional supplements (ONS) may be a quick, reliable and generally well-tolerated way of improving nutritional status.

### Nutritional assessment for people with dementia

- The continuous monitoring and surveillance of nutritional status is critical to plan, and evaluate the efficacy of nutritional interventions for people with dementia. The main types of nutritional assessment are: 1) dietary assessment, 2) weight history, 3) physical anthropometry, 4) screening questionnaires for nutritional status, 5) nutritional biomarkers and 6) eating and feeding behaviour. Anthropometric measures and screening questionnaires are most widely used.
- Dietary assessment of food intake can be prospective or retrospective. Commonly used methods include 24-hour dietary recall, food frequency questionnaires and food records. Prospective methods require the diarised recording of foods and fluids consumed over a specified period of time, and can be carried out by a family member or care assistant.

- A detailed weight history should be obtained along with current weight (a history of weight loss, whether intentional or unintentional, and over what period). Weight loss exceeding 5 kg (10lb) over six months is a red flag for further assessment.
- Body weight and height are the essential physical parameters. Body Mass Index (BMI) is the ratio of weight to height-squared ( $\text{kg}/\text{m}^2$ ) and is widely used to assess nutritional status. A BMI cut off of  $<18.5 \text{ kg}/\text{m}^2$  defines adult chronic dietary energy deficiency. Overweight is defined as a BMI between 25 and  $29.9 \text{ kg}/\text{m}^2$  and obesity as  $\text{BMI} \geq 30 \text{ kg}/\text{m}^2$ .
- Other simple physical assessments used to monitor nutritional status include triceps and truncal skinfold thickness, and mid-upper arm or calf muscle circumference.
- Nutritional screening aims to identify those who are malnourished or 'at risk' of malnutrition, and composite screening tools have been developed, e.g. the widely used Malnutrition Universal Screening Tool (MUST) (<http://www.health.gov.au/download/ng/N500-19.pdf>) and the six item mini nutritional assessment (MNA-SF<sup>®</sup>) <http://www.mna-elderly.com/>
- Nutritional biomarkers are part of a comprehensive assessment of nutritional status of frail older persons. An initial screen might comprise haematology (full blood count with differential) and biochemistry (electrolytes, urea and creatinine, fasting glucose, albumin, and ferritin).
- Eating and feeding behaviour assessments are usually observer rated, and assess aversive feeding behaviours and feeding dependency (need for assistance). The most widely used and best validated measure is the 10 item Edinburgh Feeding Evaluation in Dementia Scale (EdFED), developed for those with moderate to late-stage dementia, and brief and simple enough to be used in routine care. It establishes the level and type of feeding disability and can be used to plan effective interventions.
- Measurements of energy expenditure (resting, physical activity and dietary) and body composition (fat and lean body mass) do not form a part of current routine clinical assessment. However, assessments are becoming cheaper and easier to perform, and such evaluations, in research, may help to identify mechanisms explaining weight loss in dementia.

## Education and training interventions

- Most caregivers understand that nutrition is an important component of the care that they provide. New skills must be learnt, and roles assumed, particularly for male caregivers who plan meals, shop for food and cook.
- Spouse caregivers gradually assume decision-making responsibility for what to eat, and when to eat it, where this may have previously been a shared activity. This can weigh heavily. Weight loss, and how to prevent or treat it is a preoccupation for many caregivers. As dementia evolves it is increasingly likely that aversive feeding behaviours develop, and that the person with dementia may need feeding assistance. Managing such problems is demanding of caregiver time, and requires patience, empathy and skill.
- People living in care homes are more likely to have advanced dementia, and feeding dependence and aversive feeding behaviours are therefore more prevalent. Residents with dementia take longer to eat, require prompting and encouragement, and may have problems with coordination and swallowing. Mealtimes are a busy time for care assistants. Feeding a person with dementia can take up to 40 minutes per resident.
- In a large US study of care home residents with dementia, 54% had low food intake, and 51% had low fluid intake. In another study in up to a quarter of cases of advanced dementia with feeding difficulties the family was not satisfied with the assistance provided.
- There is no reason to assume that family caregivers, or indeed care assistants in care homes are naturally equipped with the knowledge and skills to assess and manage the often complex nutritional needs of a person with dementia. Education and training interventions targeting caregivers may therefore have an important part to play in decreasing negative outcomes and increasing quality of life.
- There are many excellent practical guides and sources of information for caregivers of people with dementia, one of which is the factsheet prepared by the UK Alzheimer's Society 'Eating and Drinking' ([http://www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=1799](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1799)). This explains the importance of a healthy balanced diet, and the risks of weight loss in people with dementia. The contributions of cognitive problems, sensory deficits and aversive feeding behaviours are described, and strategies proposed to address them.

- We identified seven studies of education and training interventions.
  - In two Taiwanese studies, training was provided to people with dementia who were resident in care homes in an attempt to modify their feeding behaviours. Montessori-based activities (practicing hand-eye coordination, scooping, pouring, and squeezing, and distinguishing food from non-food items) were associated with a significant reduction in feeding difficulties with some evidence for reduced need for feeding assistance. In neither study was the intervention associated with improvements in weight, BMI or overall nutritional status.
  - In two other studies, the intervention comprised education and training of professional caregivers in nursing homes or other long-term care facilities for people with dementia. While improvements were noted in staff knowledge, attitudes and behaviour, there was no increase in food intake in one study, while in the other study an improvement in intake was not associated with improvement in nutritional status of the residents with dementia.
  - Education programmes for informal caregivers were evaluated in three studies, two randomised controlled trials, and a controlled non-randomised study. The format of the training programmes was similar, comprising group sessions conducted by a dietician or other health professional. Topics covered included; the importance of a healthy balanced diet; dietary challenges in dementia; monitoring food intake, weight and nutritional status; advice on enriching dietary protein and energy content; and strategies to manage aversive eating behaviours. The largest trial indicated a moderate positive benefit for overall nutritional status, but no change in weight. The other trial did indicate statistically significant weight gain, but with a smaller effect size than for another arm of the same trial that was randomised to oral nutritional supplement.
  - There is currently little or no evidence to suggest that training and education interventions, whether for paid care assistants in care homes, or for family caregivers of people with dementia, result in clinically meaningful improvements in the nutritional status of people with dementia. That is not to say that there may not be benefits. Surprisingly little research has been conducted in care homes, and evidence regarding training and education for family caregivers is dominated by one large well-conducted cluster-randomised controlled trial.
  - Training and education on diet and nutrition is generally appreciated by caregivers, and there is a clear need for support particularly when aversive feeding behaviours and feeding difficulties occur. It may be that basic information should be provided to all families, while more concentrated training and dietician services should be focused upon those developing feeding difficulties or undernutrition.
- ### Modifications to mealtime environment and routine
- In terms of experimental evidence, according to a recent systematic review applying standard criteria, ‘insufficient evidence’ exists to make clear recommendations regarding mealtime environment and routine modifications given the poor quality and limited quantity of trials (mostly small time-series comparisons).
  - While poorly researched, this is currently a fertile area for innovation with successful advocacy driving forward change based to a large extent upon core principles, supported by some evidence and expert opinion.
  - The last 30 years have seen a gradual transition to flexible, individualised and person-centred care in care settings that more resemble households or homes. The four core design principles relate to their scale, the nature and use of space, the relationships between living areas, and creation of spaces that support the autonomy and independence of residents. Kitchen and dining areas are an important part of this broader design framework.
  - ‘Households’ typically comprise 8–12 residents, and the Life Safety Code Task Force has recommended 24 as the maximum feasible number. Household designs seek to replicate the living areas of houses, comprising resident rooms with bathrooms, a kitchen and dining area, and a living room or activity space.
  - Large communal dining areas should be avoided, in particular for residents with dementia. It takes time to assemble residents, meaning that some will be left waiting for long periods for the meal to begin. Large dining spaces can be noisy and confusing, with too much sensory distraction, and do not provide the sensory cues that orientate a person with dementia to mealtime.

- Smaller dining rooms can have a more intimate and familiar ambience, and reduce confusion as to the function of the room. Smaller dining rooms, 'bright and welcoming' colours, and other residential features (sideboards, paintings, objets d'art, use of a bulk re-thermalization system in place of tray service) seem to be associated with increased food intake. Low food intake is less common in smaller assisted living and residential care facilities, in facilities with 'non-institutional' dining rooms, and where residents take their meals in public dining rooms.
- As a design principle for care homes, ideally, each room should have just one activity associated with it. For people with dementia it may be particularly important to have a dedicated dining room, the use of which is limited to meals and food. This should look like a dining room in a home, with recognisable furniture such as dining tables and sideboards.
- The room can be a social hub throughout the day; for having coffee with friends after breakfast, inviting visitors to share food snacks from the kitchen between meals, and having afternoon tea with staff and residents.
- 'Eat-in-kitchens' linked to dining areas help to involve residents in meal preparation. Kitchens evoke feelings of warmth, comfort and security. Linking the eating area with a kitchen stimulates all of the senses with the smell and sound of cooking, cueing that a meal is about to take place. Diffusion of food-preparation smells has been suggested to stimulate the appetite of people with dementia and to remind them of meal times.
- Meals should be relaxed, unhurried and free from distraction. People with dementia find it difficult to concentrate on meals, and are sensitive to excessive noise and stimulation. Staff activities and other intrusions should be kept to a minimum and services areas (for food preparation and plating) should be outside the dining area. On the other hand, staff dining with residents may normalise the activity and foster person-centred care. For those with eating difficulties, quiet spaces free from distracting views can be helpful.
- While distracting noise should be reduced, familiar background music may increase calorie consumption.
- Good quality lighting is essential in dining areas so that older people with visual impairment can identify food and cutlery. In a study conducted in US care homes, increasing the light levels at table level led to an increase in food intake and feeding independence. A lighting intensity of 50 foot candles (540 lux)

has been recommended for dining areas. Food consumption also increases when there is high contrast between the plate and table.

- Residents should sit in chairs with arms that slide under the table, so that they can be close enough to focus their attention on eating. Tables should be high and broad enough to allow wheel chairs to be accommodated, and with no central columns or support structures to restrict access.
- The creation of a 'family-style' eating environment with food served at table, more staff involvement and less distraction was associated with impressive improvements in energy intake, body weight, quality of life and physical performance in a large cluster-randomised controlled trial in Dutch nursing home residents without dementia. A much smaller study of a similar intervention in cognitive impairment nursing home units in Canada showed similar results, and the greatest nutritional benefit was gained by the most cognitively impaired residents.

### Macronutrient oral nutritional supplementation (ONS)

- Oral protein and energy supplements are widely used in older people with undernutrition, or at risk of undernutrition, among whom their use is associated with significant weight gain, and a reduction in mortality for those who are undernourished.
- The main concerns associated with their use are problems with the willingness and ability of older people to consume them, the potential for gastrointestinal adverse effects, and the risk that the additional calories from the supplement may be more than offset by a compensatory reduction in customary diet.
- We conducted a review of studies identified in three previous systematic reviews, supplemented by a recently completed and unpublished systematic review of nutritional interventions for frail dependent older people (personal communication AT Jotheeswaran). Our objective was to identify all randomised controlled trials and controlled studies of oral nutritional supplements for people with dementia.
- We identified six randomised controlled trials (RCTs) of ONS, one crossover trial, a controlled trial, and an RCT of micronutrient supplementation in which both arms received macronutrient ONS. All of the studies were small ranging from 33 to 99 participants. In all 440 participants with dementia were included in placebo or other controlled comparisons



of ONS, and pre-post within group data was available for 246 individuals receiving ONS.

- Six of the studies were conducted in care homes or other long-stay accommodation, and three in the community.
- Oral nutritional supplements provided were between 125 and 680 kcal per day, and were generally offered between meals and mainly in the morning to maximize adherence and reduce substitution. Duration of the intervention varied between three weeks and one year. Total calorie supplementation varied between 5,418 and 91,350 kcal.
- There was strong evidence that ONS was effective in increasing weight (pooled mean difference in % weight gain across five studies = 3.43%, 95% CI 2.08–4.78) and body mass index (pooled mean difference across four studies 1.15 kg/m<sup>2</sup>, 95% CI 0.48–1.82).
- The % gain in body weight was proportional both to the daily calorie supplementation, and to the duration of ONS.
- ONS was generally well tolerated, and the calorie value of supplements was not offset by a reduction in the usual diet from regular meals.
- There was insufficient evidence to judge the impact of ONS on mortality among people with dementia (RR 0.69, 95% CI 0.00–1.46). No effect of ONS on cognitive function was observed in three RCTs, while in one non-randomised controlled study cognitive deterioration was more marked in the ONS intervention group. No benefit of ONS on activities of daily living was observed in five studies.

### Micronutrient supplementation

- Micronutrient deficiencies are relatively common among older people, due to insufficient dietary intake, inefficient absorption, or both. Low levels of vitamin B<sub>12</sub> and folate (folic acid) are associated with high blood levels of homocysteine which has been linked with the risk of arterial disease, dementia and Alzheimer's disease (AD). Evidence that free radicals may contribute to the pathological processes of Alzheimer's disease has led to interest in the use of vitamin E, which has antioxidant properties, in its treatment.
- There was no evidence, from several RCTs that supplementation with either folate or vitamin B<sub>12</sub>, alone or in combination has any beneficial effects on cognitive function in people with dementia. In one trial, those randomised to

folate were much more likely to be considered as 'treatment responders' to cholinesterase inhibitors (OR 4.06, 95% CI 1.22–13.53), but this finding requires replication. While the standard recommendation from systematic reviews is that there is insufficient evidence to conclude either way on the possible benefits or harms of supplementation the evidence on cognitive impairment does seem conclusively null.

- Two multi-centre RCTs conducted in the USA indicate some possible benefits of vitamin E supplementation in slowing clinical progression and/or functional decline in Alzheimer's disease of mild to moderate severity. In the most recent trial all-cause mortality and safety analyses did not suggest increased rates of adverse outcomes in the vitamin E group.

### Medical foods

- Medical foods are defined as a special category of products that are intended for the dietary management of a disease or condition with distinctive nutritional requirements. Three medical foods have claimed to have benefits for people with dementia and are available in the USA and/or Europe: Axona<sup>®</sup> (AC-1202, Accera, Inc., CO, USA), Souvenaid<sup>®</sup> (Danone Research, France) and CerefolinNAC<sup>®</sup> (LA, USA).
- Randomised controlled trials of Axona do not support any consistent or clinically significant cognitive benefit, and no studies have been reported regarding the efficacy of CerefolinNAC.
- More research has been conducted into Souvenaid, both pre-clinically and clinically, with some evidence of 'proof of concept' and good safety data from well conducted trials, although clinically significant benefit has not yet been convincingly demonstrated.

### Conclusion

- There is consistent evidence that macronutrient oral nutritional supplementation (ONS) is effective in maintaining or improving weight among people with dementia. Supplements are well tolerated, with high levels of adherence under controlled clinical trial conditions.
- Nutritional benefit from ONS is proportionate to its intensity and duration, but benefits gained from short term supplementation, over weeks or months, is retained in the short to medium term. Hence brief cycles of ONS may be as effective as long-term supplementation.

- Most trials focused mainly on those who were at risk of undernutrition, or normally nourished. There is therefore an important outstanding question as to the effectiveness of ONS among people with dementia who are already undernourished.
- Given the health hazards of undernutrition, particularly when this involves protein catabolism and loss of lean body mass, one might expect maintenance of nutritional status with ONS to be associated with wider health benefits than those identified in the studies reviewed. This may be due to the short period of nutritional support and follow-up (disability, mortality), and the failure to assess relevant outcomes (quality of life, depression, physical functioning).
- There is, as yet, no evidence to recommend the use of micronutrient supplementation at any stage of dementia. The possible exception to this advice is that of vitamin E supplementation given two positive trials with respect to cognitive and functional decline outcomes, although the balance of risks and benefits need to be more clearly established.
- There is currently no evidence to support the widespread screening for folate and B<sub>12</sub> deficiency enshrined in many good-practice post-diagnostic recommendations. Supplementation does not seem to affect cognitive function, and the cost-effectiveness of these non-evidence based recommendations needs to be established in RCTs.
- There is currently insufficient evidence to recommend the use of any medical foods currently marketed for the treatment of Alzheimer's disease. However, data are emerging indicating some potential for therapeutic benefit, and trials are ongoing.
- Given the strong theoretical basis for micronutrient supplementation, it is under researched, with relatively few trials, most of which are small and underpowered, do not focus upon those with proven micronutrient deficiency, and have relatively short follow-up periods.

### Feeding Assistance – managing aversive feeding behaviours in advanced dementia

- A case study from the Dominican Republic demonstrates the importance, and the feasibility of managing aversive feeding behaviours, through training paid caregivers of people with dementia, whether domestic

workers (hired originally to clean the house and prepare food), or care assistants in nursing homes. Neither the behaviours, nor the consequent weight loss were recognised as part of the illness.

- Dr Daisy Acosta obtained consent to videotape several settings; private homes, nursing homes and state nursing homes; identifying the different types of eating behaviours and how the staff reacted and handled them. She then watched the videos with the staff and explained what was happening.
- Dr Acosta provided caregivers with tools to assess cognitive and functional impairment, and identify and classify feeding behaviours and needs for feeding assistance. 'In other words, I went with them, the staff, through a process of informal education about dementia, the course of dementia, and feeding and eating problems through the illness'. In private homes, both the paid caregiver and the main family caregiver were involved in the same education process.
- Dr Acosta then worked with nursing home staff and home caregivers to find approaches to help improve 'eating time' without incurring additional expense. The lessons learnt from this programme were that:
  - The enthusiasm and active involvement of the staff in the process was crucial. They began to give ideas as to how to improve each patient's behaviour and were very creative in their suggestions.
  - Categorising the behaviour was an essential first step in order to plan and implement measures to help it.
  - The measures can be very simple, not costly, and some of them were quite effective (see Chapter 5 for details).
  - The education and the positive attitude of the feeder were crucial in determining the success of the intervention. The education of those involved, about eating and feeding in patients with AD, helped to reduce the neglect of this essential aspect of care.
  - Not all people with dementia would have equal needs for calorie intake - think of hunger as a possible explanation for those residents who screamed or otherwise vocalised distress.
  - As well as calorie intake, staff needed to be taught about the importance of offering liquids often, and to avoid fluid restriction with the intention of avoiding incontinence or frequent diaper changes.



## Assistive tableware

- Research by a Royal College of Art design team revealed that assistive tableware was not used as much as it might have been in UK care homes. Some care home managers opted not to use it because of a lack of aesthetic appeal. Since residents had different needs and abilities, and assistive tableware stood out from standard items, users of assistive table settings felt different, and stigmatised.
- The aim of the design team was to create a range of matching tableware that formed a complete set, could be used by people of all abilities, and resembled standard domestic tableware.
- Colour contrasts help to distinguish food from the plate upon which it is placed, and from the table covering. The same approach can be used to highlight the handle of a cup and its rim.
- Special plates with high lips were designed to assist those eating pureed or diced food with just a plate and spoon.
- The ‘care cup’ is one of the most disliked assistive tableware items, because of its similarity in appearance to a baby product (made from plastic with two handles and a nipples lid). The design team normalised this product by crafting it in ceramic but with a double skin to insulate the heat and prevent burning. The lid minimises the association to the nipple of a baby cup by elongating the form around the rim.
- The tableware includes items designed specifically for use with assisted feeding, including a plate, a bowl and lids for cups. The items are reduced in weight, and designed so that they can be easily and securely grasped by the carer, with one hand. The plate allows the carer to orientate it in an ‘offering position’ (in the sensory range of the person being fed so that they can see and smell what they are eating).

## Managing oropharyngeal dysphagia in advanced dementia through enteral tube feeding

- Problems with swallowing are common in advanced dementia. However, the use of nasogastric or percutaneous endoscopic gastrostomy (PEG) feeding tubes, while widespread, is controversial, and needs to be evaluated carefully with respect to patient and caregiver preferences, and the balance of risks and benefits for individual patients.

- A Cochrane systematic review suggests that tube feeding for people with dementia does not confer any benefit regarding nutritional status, reduction of pressure sores, mortality risk or survival time.
- Families and health professionals often have unrealistic expectations of the outcomes of tube feeding. Potential for harm exists from an increase in urinary and faecal incontinence, leading to pressure sores; from discomfort, and attempts to remove the tubes, which may lead to sedation being given.
- Advanced eating and swallowing problems need to be seen more in the context of holistic palliative end-of-life care. Communication and shared decision-making are key factors, and having trust in doctors and surrounding staff is essential for patients and caregivers. However, many nurses and care home staff do not feel confident with issues related to end-of-life and dying with dementia, and there is a need to improve training.

## Summary and conclusion

- Micronutrient and macronutrient (protein and energy) deficiency are common in dementia and Alzheimer’s disease, and it is clear that undernutrition has important consequences for health, quality of life and survival. Loss of body weight seems on the one hand to be a natural part of the condition, with complex multifactorial determinants, and yet to be amenable to intervention.
- Standard recommendations for dietary management in dementia emphasise the role of dietary advice including fortification of existing diet to boost the protein and energy content, before resorting to oral nutritional supplements (ONS). Boosting calorie intake should improve nutritional status, and doing this through natural foods is likely to be more appealing than supplements, which can be costly. However, the evidence to support the efficacy, safety and tolerability of ONS is particularly strong, and this may be the most reliable means of restoring nutritional balance.
- Therefore, while dietary advice and food fortification can be tried first, ONS should be implemented without delay if this approach fails to improve nutritional status. This is particularly the case for those with established undernutrition.
- Given the relative lack of large definitive long-term trials in this area, there are still some important questions to be resolved:
  - Should those with undernutrition receive continuous ONS (and is this feasible and

acceptable), or is short interval ONS equally effective and more acceptable?

- Is ONS as effective for those with undernutrition as for those at risk of undernutrition?
- Is long-term ONS associated with net benefits for cognition, functional status, depression, quality of life, and survival?
- Dietary advice should remain a standard recommendation. There is a clear demand from caregivers for advice and support, particularly with aversive feeding behaviours. There has been remarkably little research into nutritional training and education of care assistants in long-term care facilities, with many anecdotal examples of potential benefit.
- While many people with dementia use micronutrient supplements, there is little or no evidence of any benefit as regards progression of the condition. On the current evidence, the recommendation would be that these supplements should not be used for the treatment of Alzheimer's disease or other forms of dementia. B<sub>12</sub> or folate deficiency, if identified, should be corrected. However, the overall cost-benefits of screening for these deficiencies in all patients with newly diagnosed dementia are not established, and current recommendations are not based on evidence.
- Very few older people are deficient in vitamin E. However, hypersupplementation of this vitamin (2000 IU total daily) does seem to be associated, in two randomised controlled trials, with slower progression of the cognitive and functional impairment of Alzheimer's disease. However, these doses are 100 times higher than the recommended daily allowance to maintain vitamin E levels and exceed the tolerable upper intake level. Excess intake of vitamin E, particularly over the longer term may be associated with bleeding and haemorrhagic stroke. Therefore the use of this agent cannot be recommended until more data is available on the balance of risks and benefits.
- There is strong evidence, although not from randomised controlled trials, that systems level interventions, for example small scale household level dining, 'family style' eating arrangements, and use of appropriate tableware and lighting levels may be associated with increased calorie consumption and increases in weight. Much more work needs to be carried out into the effectiveness of assistive feeding interventions to address aversive feeding behaviours.
- Although much of the work on nutritional interventions has been carried out in long-term care facilities, many of the findings are generalisable to home care by informal carers. This would include the benefits of ONS (and the relative inefficacy of dietary advice alone), the importance of a home dining environment, and including the person with dementia as part of the family social dining activity. Many informal caregivers struggle with aversive feeding behaviours, and the benefits of focused support and training interventions needs to be evaluated in this group.

### **Compass Group PLC**

Compass House, Guildford Street, Chertsey, Surrey KT16 9BQ, UK · Tel: +44 1932 573000 · [www.compass-group.com](http://www.compass-group.com)

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### **Alzheimer's Disease International**

64 Great Suffolk Street, London, SE1 0BL, UK · Tel: +44 20 7981 0880 · Fax: +44 20 79282357 · [www.alz.co.uk](http://www.alz.co.uk)

ADI is the international federation of 79 Alzheimer associations around the world, in official relations with the World Health Organization since 1996 and with the United Nations since 2012. Each member is the Alzheimer association in their country who support people with dementia and their families. ADI's vision is an improved quality of life for people with dementia and their families throughout the world. Its main objectives are to raise awareness, to support and strengthen its member associations and to make dementia a global health priority.



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**Alzheimer's Disease International**  
64 Great Suffolk Street  
London SE1 0BL  
UK  
Tel: +44 20 79810880  
Fax: +44 20 79282357  
[www.alz.co.uk](http://www.alz.co.uk)



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