

## Managing Eating Disorders in Elderly with Dementia and the Ethical Considerations for Tube Feeding

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### Abstract

*As dementia progresses, the elderly with dementia often have difficulties finishing their meals and weight loss is a common feature at this stage of their dementia journey. Eating disorders cause tremendous caregiver stress and burden. In considering provision of best care for this group of elderly, the hospital is probably not the best place and yet, they are frequently brought in to the hospital to seek help for fever, pneumonia, dislodged feeding tube, medical complications arising from poor feeding and dehydration. It is important to understand the aetiology of poor feeding among this group of patients and advise the patients and their family on the appropriate management strategies to improve the intake of food and to maximize their quality of life. At this stage of dementia, focusing on means to ensure nutritional needs are met may end up causing further harm and distress.*

**Keywords:** Eating disorder, dementia, environmental factors, feeding tubes, medical ethics

### Introduction

There are currently close to 50 million people living with dementia worldwide (2017). According to Alzheimer Association International, there is someone new who develop dementia every 3 seconds [1]. Dementia consists of a group of neurodegenerative diseases which result in loss of cognitive function such as amnesia, apraxia, aphasia, executive dysfunction, emergence of behavioural symptoms and progressive decline in abilities to carry out activities of daily living (ADLs).

Food is essential to life and eating together with friends and family brings people closer together. Food is also a symbol of love, nurture and security where it starts as a mother feeding her helpless newborn. In caring for people with dementia, assistance with feeding during mealtimes takes up a significant portion of time. Persistent failures to finish a meal may lead to caregiver stress. Mealtimes tend to be prolonged and anxiety levels are high with worries about choking, inadequate chewing, not swallowing and other problems. Eating disorders are present throughout the disease course of Alzheimer's Disease, although the causes may be different for the various stages. The elderly with dementia often exhibit poor appetite and poor food intake towards the end stages of dementia with weight loss almost universal among the elderly with severe dementia [2].

This review looks at eating disorders among the different types of dementia, causes of poor feeding and the ethical considerations

with pros and cons of tube feeding versus hand feeding among the people with dementia. At the end stages of dementia when cognition is severely impaired, where does one's priority lie? It is often a challenge to find a balance between meeting nutritional requirements for survival and the discomfort of tube feeding in order to sustain hydration and nutrition.

### The Neurobiology of Food Intake

There are 2 pathways which regulate our intake of food, the homeostatic pathway, and the hedonic pathway. The hypothalamus is recognized as the center for regulating food intake and this is triggered by hunger and controlled by satiety. Food intake is not solely regulated by energy requirements and availability of food. The human eating behavior is complex and is influenced by social, environmental, genetic and humoral cues. For instance, eating as a group in a nice restaurant, with an attractive menu and ambiance may increase the pleasure and amount of food consumed. On the contrary, the size of restaurant bill may influence the food choices and meal size [3].

The empty stomach secretes Ghrelin which works on the hypothalamus to trigger hunger. Adipocytes secrete Leptin which suppresses appetite. Leptin activates Oxytocin which acts on the hypothalamus to decrease appetite. Once eating commences, the amount of food consumed is controlled by the perception of fullness (satiety) and satiety refers to the lack of interest in food. The feeling of fullness is triggered by gastric distension via afferent pathways in the Vagus and spinal sensory nerves to the brain. Various parts of the gastrointestinal tract secrete various peptides in response to a presence of nutrients

in the GI tract which also give rise to satiety [4].

The hedonic pathway of food intake motivates eating despite a state of full stomach the most typical example is a helping of dessert after a full meal. Pleasure eating involves the rewarding effects from consuming foods with high fat and/or high sugar contents and is independent of energy requirements. The hedonic pathways involve the limbic, cortical regions and hypothalamus. Signaling by dopamine and opioid peptides are important in the reward and pleasure valuation of food. The desires for pleasure eating can lead to excessive eating, regardless of calorie requirements or satiety and may cause weight gain [4].

Dementia disrupts the central control of appetite and eating causing disruptions in eating pattern, habits, food preference which interfere with control of food intake and cause fluctuations in weight [4].

### Eating Abnormalities and Malnutrition in Dementia

Among the elderly with dementia, eating disorders include over and under eating. The majority of elderly with dementia develop weight loss and undernutrition towards the end of life. Chapman demonstrated that over 85% of the elderly residents in the nursing home had under nutrition due to the poor oral intake [5]. The causes of eating abnormalities are often multiple in an elderly with dementia and are listed in table 1 [6].

**Table 1: Factors which contribute to abnormal eating in dementia**

Changes to central regulation of food intake	<ul style="list-style-type: none"> <li>• Change in appetite.</li> <li>• Increased/reduced amount of food consumed.</li> <li>• Change in food preference.</li> <li>• Eating inedible objects.</li> </ul>
Physical problems	<ul style="list-style-type: none"> <li>• Loss of sense of smell/ taste.</li> <li>• Poor dental hygiene/ poorly fitting dentures.</li> <li>• Problems with chewing or swallowing.</li> <li>• Inability to sit upright for food.</li> <li>• Inability to unwrap or peel food items.</li> </ul>
Cognitive changes	<ul style="list-style-type: none"> <li>• Forget they have just eaten.</li> <li>• Inability to recognize satiety.</li> <li>• Inability to understand environmental cues.</li> <li>• Inability to recognize food placed in front of them.</li> <li>• Inability to plan quantity of food to transport to their mouths.</li> <li>• Inability to plan how fast to eat.</li> <li>• Inability to decide what to transport to their mouths.</li> <li>• Inability to use utensils/ cutlery.</li> </ul>
Social factors	<ul style="list-style-type: none"> <li>• Inability to shop for food.</li> <li>• Financial difficulties</li> <li>• Inability to prepare food.</li> <li>• Inability to eat independently and lacking a caregiver</li> <li>• Forget meal times and living alone.</li> <li>• Eating alone.</li> </ul>
Environmental factors	<ul style="list-style-type: none"> <li>• Rigid meal times in an institution like hospital or care homes.</li> <li>• Busy environment with lots of distractions.</li> <li>• Frequent turnover of staff causing unfamiliarity.</li> <li>• Staff education.</li> </ul>
Behavioural symptoms	<ul style="list-style-type: none"> <li>• Refusal to eat.</li> <li>• Refusal to open the mouth or spitting of food.</li> <li>• Hyperactive, pacing, wandering behaviour, too busy to eat with inadequate calorie intake.</li> <li>• Delusional ideation on food being poisoned.</li> <li>• Depression causing poor appetite.</li> <li>• Apathy with lack of motivation to eat.</li> <li>• Loss of interest in food/ eating.</li> <li>• Insisting on eating the same food over and over.</li> <li>• Hoarding and stealing other's food</li> </ul>
Medical problems	<ul style="list-style-type: none"> <li>• Delirium.</li> <li>• Medications cause changes in appetite.</li> <li>• Constipation.</li> <li>• Organ dysfunction causing anorexia.</li> <li>• Swallowing problems.</li> <li>• Dietary restrictions for medical conditions.</li> </ul>

Under nutrition is detrimental among the frail elderly with multiple adverse effects like poor immunity with frequent febrile episodes, pressure sores, anemia, delirium, osteoporosis, and frailty. Among the elderly surgical patients, under nutrition is known to be associated with longer length of stay, higher mortality, poorly healing surgical wounds, postoperative delirium, infections and higher healthcare costs [7, 8]. The elderly with dementia may become agitated and restless because of hunger or thirst; coupled with language deficits due to dementia, the discomfort from hunger and thirst is not communicated clearly to their caregivers. Instead, the elderly may become restless and agitated and labeled as dementia with BPSD. In an institutional setting like a hospital or nursing homes, elderly with dementia displaying challenging behaviour may end up being restrained for their safety against falls or harming themselves. Challenging behaviours should always be treated as a means of communication between the elderly with dementia and their caregivers with an active search for reversible causes or underlying unmet needs [9].

### **Eating Disorders and Types of Dementia**

In a study by Kyoko Kai eating disorders is present in 80% of patients with Alzheimer's Disease (AD) and onset can be as early as the MCI stage [10]. Among the elderly with a mild AD, about half had changes in appetite, with both increases as well as the decrease in appetite and corresponding changes in weight. The loss of appetite may be a symptom of depression which is also common among mild AD (68% in the study) and the increase in appetite may represent amnesia where they often forget they have just eaten their meals. There is also a change in food preference with reference to sweet high-calorie foods and strongly seasoned foods as the gustatory recognition of the 4 basic tastes deteriorates [11]. At the severe stage of an AD, swallowing disorders predominate resulting in poor food intake and weight loss [10].

Changes in eating behaviour, food preference and appetite have been well documented for frontotemporal dementia (FTD). For the behavioural variant FTD (BvFTD), there is documented hyperphagia, due to increased appetite resulting in hypercaloric consumption. The semantic variant FTD had a rigid eating pattern where they ask for the same food repeatedly, with no increase in total caloric consumption. The preference for sweet foods is noted for both BvFTD and semantic FTD. The increased caloric intake was not found to be associated with weight gain, which may be explained by changes in the metabolism. Similarly, patients with FTD and high BMI was not explained by increased hunger or lower satiety [12-14].

In dementia related to vascular causes like stroke disease, challenges during meal times are often due to motor deficits causing weakness of head and neck muscles resulting in chewing and swallowing problems with food hoarding in the mouth. Pyramidal, sensory, coordination problems may interfere with transporting food to the mouth [15].

### **Approach to Assessing Feeding Issues in Dementia**

Eating disorders among the elderly with dementia often have multiple contributing factors and warrant careful assessment before formulating a care plan. It is crucial to obtain collaborative history from caregivers particularly on the duration of eating problems, assistance required during meal times, food preferences, size of meals consumed, meal frequency and presence of BPSD. Swallowing disorders as evidence by frequent coughing, changes in voice quality, multiple swallow, regurgitation and choking during

meal times are prompts to refer to speech therapist for a formal assessment and intervention.

Medication review is important to exclude anorexia due to medication side effects or drug interactions. Social factors, particularly environmental and caregiver factors need to be explored.

Careful observation during mealtimes is important to recognize visual impairment, cognitive deficits interfering with food recognition, ability to use cutlery, muscle strengths of the upper limbs and head and neck regions, eating patterns and speed, chewing or swallowing disorders, hoarding food in the mouth, environmental factors causing distractions and interactions between caregivers and the patients particularly on verbal and visual cues and preference for modified diets.

### **Strategy for Managing Eating Disorders**

The aim of managing eating problems among the elderly with dementia is to ensure adequate hydration and nutritional requirements are met. Eating difficulties are indicative of profound loss in cognition and function among the elderly with dementia. Eating problems, when persistent indicates the end stage of dementia where the care burden is high. The CASCADE study showed that over 85% of the elderly with dementia who presented with eating difficulties have a mortality rate of 50% in 6 months [16].

### **Screen for Dysphagia**

Dysphagia is a common problem among the institutionalized elderly with reports of 50-70% prevalence, dysphagia resulting in aspiration and pneumonia occurs in about 30% of those with dysphagia [17]. Dysphagia among the elderly with dementia signifies a progression of dementia to severe stage. The common symptoms related to dysphagia in severe dementia include oropharyngeal dysphagia, eating problems, febrile episodes and pneumonia. The metabolic rate is down adjusted among the elderly with severe dementia due to inactivity. The occurrence of febrile episodes or pneumonia is a poor prognostic indicator, with mortality rate close to 50% in 6 months [18].

There are 2 phases of dysphagia namely oropharyngeal dysphagia which involves problems with chewing, forming a bolus and subsequently, passing the bolus from the oral cavity to the pharynx and oesophageal dysphagia which is the inability to move the food bolus from oesophagus to stomach. Oropharyngeal dysphagia is the commonest mechanism of dysphagia among the elderly with dementia, where there is a failure to recognize food in the mouth leading to the delayed trigger of chewing, bolus formation and swallow. There is also delayed closure of the larynx, increased residues in the oral cavity which may be present for several hours after the meal. All these factors increase the rate of penetration into the larynx, causing silent aspiration where the ingested materials end up in the lungs without coughing.

Screening tests for dysphagia include a bedside swallow test, such as the Toronto bedside swallowing test for stroke patients which achieves a sensitivity of 91.3% with a negative predictive value at 93%. The gold standard for diagnosing oropharyngeal dysphagia is video fluoroscopy swallowing study (VFSS) and fiberoptic endoscopic evaluation of swallowing (FEES) [19].

Once oropharyngeal dysphagia is present, interventions include

dietary modifications such as thickening fluids to various consistencies using thickeners. Thickened fluids are not as fluid and fast flowing therefore reducing risk of penetration especially since the trigger for swallow is delayed. Compensatory strategies during eating by postural changes and swallowing techniques may also reduce aspiration risks. Rehabilitative maneuvers may improve head and neck muscle strengths. However, among the elderly with severe dementia and dysphagia, some of the interventions may not be as effective since these interventions and data were collected from stroke patients. Oral stimulation using frozen lemon drops on the tongue and soft palate may improve tongue retraction and palate elevation. Thermal stimulation using hot or cold stimuli in the mouth may evoke swallowing [19].

### **Manipulating Food Texture, Taste and Presentation**

When oropharyngeal is present, thin fluids increases the risk of aspiration. Thickened fluids makes it slower to swallow and hence safer, although there are no large studies with convincing data to support its recommendations. The consistencies for thickened fluids may be nectar like chocolate milk, honey like syrup or pudding consistency like jelly [19].

Meeting the caloric and nutritional requirements is challenging among the elderly with dementia who eat very small quantities. Finding ways to optimize nutrition and maintain good hydration include providing fluids of the correct consistencies, offering choices for meals, serving smaller meals, attractive presentation of food and using oral nutritional supplements (ONS). ONS come in various forms and preparations and can be used either as top up or used to fortify food to improve the nutritional value. However, ONS has only been shown to improve weight gain with improvement in the nutritional indicators like BMI, in patients with various stages of dementia but no benefits on function or survival. It is helpful to identify risk of undernutrition early to allow for supplementation and intervention since under nutrition is shown to be linked to greater impairment of function and presentation of BPSD. Weight loss is also known to have a negative impact on progression of AD [20, 21].

The elderly are well known to have reduced sense of smell and taste which may be contributed by medical comorbidities. The poor sense of smell and taste reduces overall enjoyment of their food and causes poor appetite. Food flavoring with spices and herbs may improve the tastes, palatability and intake. Allowing the elderly with poor food intake to be off their dietary restrictions, particularly diets which restrict fat and sugar may improve their appetite. The elderly who are losing weight and eating poorly must rely on fat and sugar as their concentrated source of calories. Allowing food with higher fat and sugar content also increase palatability of most food. The choice of fats should be heart healthy but the general intention is to increase the caloric content. General strategies to boost nutrition include adding extra cheese, sauce, gravy to entrees and side dishes, adding milk powder to milkshakes, cereals, adding honey or syrup in dessert and cereals, etc. This is of course, is done under medical supervision and in consultation with the dieticians. The elderly with poor appetite tend to eat better with smaller portions of food served and a menu with fortified foods [22, 23].

### **Environmental Manipulation**

The elderly with dementia often have other neurological and cognitive deficits which make it difficult for them to feed themselves during meal times. They may have poor vision with difficulties differenti-

ating the various types of food on their plates especially if the colors are similar in shades of white. Neurological problems with upper limb involvement causing weakness, numbness, rigidity and tremor may affect their abilities to use the cutlery and transporting food to their mouths. Inability to decide how much to put in their mouths or how fast may cause choking during eating. Eating, chewing and swallowing are often much slower than elderly without dementia. Very often the process of chewing and swallowing need prompting from the caregivers making mealtimes laborious and slow.

Hence, the elderly with dementia often need assistance from trained staff to assist during meal times. Unfortunately in an institution, meal times are often rushed and the staffs are on a tight schedule to complete the task of feeding. This may cause anxiety and poor quality meal times for the elderly with dementia. The staff turnover is also high in an institution. Untrained staffs lack the patience and experience to feed an elderly with dementia at their speed. Frequent verbal cues during meal times to encourage chewing and swallowing also improve oral intake by up to 50%.

Ensuring a warm, quiet, relaxed and home like environment with minimal distractions and assistance available helps the elderly to enjoy their meals and satisfaction for both caregivers and the elderly with dementia. Eating together as a group compared to eating alone by the bedside has also been shown to improve the amount eaten [8, 22, 23].

### **Medical factors**

A review of medications causing poor appetite is often helpful since polypharmacy is common among the elderly. Other medical conditions which can be optimized include depression, poor dental hygiene, dental caries and delirium which are all potentially reversible in causing poor food intake.

### **Tube Feeding in Advanced Dementia**

Use of enteral feeding, both nasogastric tube (NG tube) and percutaneous endoscopic gastrostomy (PEG), with the aim to meet nutritional requirements, is an alternative but controversial, method of feeding in patients with advanced dementia.

In the United States, a 2-year prospective (2000 -2002) follow-up of nursing home residents without a feeding tube using Minimum Data Set (MDS) showed an incidence of feeding tube insertion of 53.6/1000 residents. More than half (68.1%) of the feeding tube insertion were performed in acute care hospital. The patients were mostly admitted for pneumonia, dehydration, and dysphagia [24].

Analysing the data from MDS for each year from 2000-2014, Mitchell found the proportion of nursing home residents receiving feeding tubes over 12 months, since the development of total dependence for eating, was 11.7% in 2000. It declined to 5.7% in 2014. This decline concurred with the discouragement of this practice from the emergence of research, expert opinion and recommendations by national organizations [25].

Researches from international populations consistently showed no benefit for tube feeding among patients with advanced dementia, compared with those without tube feeding. From the 2-year prospective follow up using MDS data (24), one year mortality after tube insertion was 64.1% with median survival of 56 days. The same group of researchers, analysed data from 1999 to 2007 showed that

there was no difference in survival between those with and without tube feeding (adjusted hazard ratio 1.03) [26]. In a prospective observational study in Brazil, comparing use of oral feeding and tube feeding in advanced dementia, the mortality were 11.1% vs 41.9% in 3 months and 27.8% and 58.1% in 6 months. There was higher incidence of aspiration of pneumonia (25.0% vs 58.1%) among the tube feeding group [27].

Tube feeding is associated with other undesirable outcomes. Nursing home residents fed with PEG tube were 2.27 times more likely to develop a new pressure ulcer. Among the study subject with a pressure ulcer, the pressure ulcers were less likely to heal among those who were fed using a PED tube (odd ratio 0.70) [28]. In Israel, a cross-sectional survey of caregivers of people with advanced dementia fed with tube living in the community, compared to nonusers of feeding tube, there were more use of restraints (35% vs 10%) and more emergency room visits (40% vs 34%). More caregivers (44% vs 19%) reported very heavy burden of care for those with feeding tubes [29].

Comparing Japanese patients with PEG and nasogastric (NG) tube, there were no difference in the mean serum albumin level before and after insertion, either PEG or NG tube, in 6 months. This study, interestingly, showed that for those with no history of aspiration pneumonia prior to insertion of feeding tubes, 3 out of 32 patients (9.4%) experienced aspiration pneumonia after insertion of PEG, and 9 out of 17 patients (52.9%) developed aspiration pneumonia after insertion of NG tube [30].

Although there is a lack of randomized trial comparing hand feeding and tube feeding in the elderly with advanced dementia, major organizations have issued recommendations against tube feeding [31-33]. A Cochrane review of observational studies in 2009 concluded that the evidence for recommendation of tube feeding in patients with advanced dementia was insufficient. There were no benefits in outcome measures such as survival, quality of life, nutrition, functional status, prevention of aspiration pneumonia and prevention and healing of pressure ulcers [34]. (Table 2)

**Table 2: Outcomes with no clear benefits on tube feeding in people with advanced dementia**

<ul style="list-style-type: none"><li>• Survival</li><li>• Quality of life</li><li>• Nutrition</li><li>• Functional status</li><li>• Prevention of aspiration</li><li>• Prevention and healing of pressure ulcers</li></ul>
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### The Legal and Ethical Perspectives in Tube Feeding in Patients with Advanced Dementia

The **Principles of Biomedical Ethics** by Tom Beauchamp and James Childress provide us four famous broad principles as a starting point for analysing biomedical ethics [35]. The 4 principles are respect for autonomy, non-maleficence, beneficence and justice.

The limited benefits and potential risks stated in the above clearly

provide the healthcare professionals with an easy and clear balance of benefit Vs risk for the patient. A doctor has no legal duty of care or moral obligation to initiate a treatment option which has very limited benefits and likely risks. The ethical dilemma, therefore, comes from the contrasting view from the patient's previous wishes and the family's expectations.

The common motivation from the family for initiation of tube feeding in patient with advanced dementia is that the patient would be "starved and died of thirst". Studies in the 1980-90s demonstrated that patients with advanced dementia without artificial nutrition did not experience a high level of distress or complaints, probably due to a reduction of thirst and hunger perception physiologically [36, 37]. Therefore the common conception of "starving and dying of thirst" is probably inaccurate.

It comes to, then, the respect of autonomy for the patient and the family in the use of artificial nutrition and hydration to sustain life. Autonomy is about people having the freedom to make decision on how they wish to live their lives [38]. The doctrine of consent enshrines this basic principle in the daily decisions made in any doctor-patient relationship. It had been argued by some judges in the Bland case that provision of artificial nutrition and hydration be considered a form of medical treatment [39]. A mentally competent patient has the right to refuse treatment offered by healthcare professionals; however, they do not have the right to demand certain treatment [40]. The law, therefore, protects the patient's right to be left alone more than the claim that one should be given the care and treatments one needs to fulfil one's goals [38].

It seems, insofar, the patient and the family have no say in the medical decision of using tube feeding in patient with advanced dementia. Almost all the patients have no mental capacity regarding this decision at the stage of advanced dementia with significant eating and swallowing difficulties. An Advanced care planning (ACP) completed before the patient loses mental capacity would be helpful in understanding the patient's wishes. This self-determination of appropriateness of medical treatment while the patient had mental capacity is based on the fundamental human right, which is reflected in medical law and ethics in the doctrine of consent. Apart from giving an agreement to perform any medical treatment by doctor, in the form of verbal and written consent, the right to refuse medical treatment is at the core of individual autonomy [41]. Since the Human Rights Act in 1998, the protection of human rights by European Convention on Human Rights (ECHR) had been recognized formally by the English law. Applying the principles of Human Rights Act in medical ethics, key Article 3 prohibits torture, inhumane, degrading treatment or punishment of the individual, and Article 8-protects the right to respect for the individual's private life. Both these principles would ensure that the treatment offered and performed by doctors is consensual or, if the patient is incapable of consent, therapeutically necessary [42].

In the absence of ACP or other directives, the family, particularly the person assigned as the donee in lasting power of attorney (LPA), would either exercise substituted judgement or make decision based on the patient's best interests [41]. In the modern practice of clinical medicine, especially in paediatric and geriatric medicine, the involvement of patient's family in decision making for clinical management cannot be underestimated. The patient's family's decisions may not concur with the medical team's recommendations.

Nevertheless, their decisions constitute an indispensable component in the formulation of the patient's best interests. This broadening approach of autonomy, known as relational autonomy, is based on the starting point that a relational life is inevitable and our autonomy can only be performed and understood by reference to our relationships with our kin. With this context of family life, a substantial amount of care work is of central value of social well-being. In contrast with the traditional individual autonomy, relational autonomy was thought to be more sensitive in the awareness of our relationships and constitute one's identity. Hence, it is both integral to autonomy and on the contrary, to impair autonomy. The supporters of this approach argue that by understanding the obligations and commitment in a relational context, one would be able to respect the deeper relational autonomy the person wishes [43]. This is particularly obvious in the use of feeding tube, in which a strong emotional component in the family prevails the discussion of benefits and risks.

Are the autonomy of the patient and family absolute? As mentioned, the right to demand certain treatment is not established [40]. Autonomy concerns free will; liberty concerns freedom from interference [44]. This invites a concept of public interest in autonomy, which was once identified as four 'state interests' and it consists of: (1) preserving life; (2) preventing suicide; (3) maintaining the integrity of the medical profession; and (4) protecting the innocent third parties [45]. Consistent evidence had clearly demonstrated that tube feeding does not prolong life in patients with advanced dementia and the withdrawal of it does not create major harm or distress to the patients. The third interests—maintaining the integrity of the medical profession—therefore, might limit a patient's and family's choice to promote the patient's best interest and/or to avoid from harm.

Different approaches on self-determination—human rights, relational perspective and public interest—reflect a wider scope of autonomy in the decision of medical treatment in both consent and refusal. In clinical practice, the best interests of the patient, the counterpart of autonomy, is the focus of healthcare professionals. It has been traditionally formulated by physicians in terms of indications and contra-indications/side effects, largely correlating beneficence and non-maleficence, based on research evidence and clinical experience. By using this formulation, it is not uncommon that disagreements may occur between physicians (best interest) and patient/family (autonomy) in clinical practice and, sometimes, even in the court of law. Numerous cases, in the English courts, is concerned with a balance of the best interest of the patient, in consenting, refusing and withdrawing/withholding treatment, by considering the aforementioned approaches on autonomy and the professional recommendation on the medical best interests of the patient. The court judgement, therefore, may provide an idea on what comprises "best interest".

The Mental Capacity Act 2005 Code of Practice indicates when a "treatment is futile, overly burdensome to the patient or where there is no prospect of recovery", it would be in the best interest of the patient to withdraw or withhold life-sustaining treatment [46]. A similar idea of intolerability, in a few cases, suggested "a judgement on whether life is intolerable is a judgement on the quality of that life [47-49]." More recently, best interest was phrased in a more positive way, such as "[t]he term "best interests" encompasses medical, emotional, and all other welfare issues" and "in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not

just medical but social and psychological..." [50, 51].

As Lord Philip MR in *Burke* put it that "it may not be possible to attempt to define what is in the best interests of a patient by a single test applicable in all circumstances.", the assessment of best interest and the balance with autonomy have to be formulated individually in each case [40]. (Table 3) Synofzik, a German neurologist, proposed that the use of tube feeding is not a dichotomic decision: to put in a PEG or not. It would instead, be better expressed in a benefit-risk profile for different levels of recommendation [52]. He illustrated there are four levels of benefit-risk assessment: the benefit significantly outweighs the risk, the benefit and risk are in balance, the risk exceeds the benefit by a small amount, and the risk significantly exceeds the benefit. He proposed that tube feeding should be recommended in the first level, tube feeding should be offered but left the application open in second level, tube feeding should be offered but advised against it use in third level, and tube feeding should not offered at all in the last level. In the first three levels, the ultimate decision after physician's recommendation—a clear explanation of goals and options—would be determined by the patient and family autonomy. The strength of this "recommend/leave open/advise/do not offer" approach, he suggested, are the strong weighting of autonomy and detailed analysis of individual prognostic factors in benefit-risk assessment.

**Table 3: proposed factors in consideration of best interest**

Proposed Factors in Consideration of Best Interest
• Medical benefit/risk assessment
• Autonomy
• Individual
• Family (Relational)
• Public interest

Decision of the method of feeding in advanced dementia, therefore, requires a contextual assessment in each individual case. One cannot administer treatment simply by the traditional approach of balancing indication and contra-indication, but a comprehensive and, sometimes, lengthy discussion with the patient (those with mental capacity) and family is essential. An emphasis of futility and do-no-harm would be crucial in establishing patient and family's trust towards the healthcare profession. A detailed and caring communication of goals, concerns, emotions and beliefs would be paramount and helpful in arriving a common understanding of the best interest of the patient with advanced dementia. False expectations and non-objective beliefs would only cause further harm to the patients and their family.

### Conclusion

As healthcare professionals, we are going to see more elderly with dementia as the world ages. Eating disorders are common at the various stages of dementia and are particularly worrying at the severe stages where most of the elderly with dementia end up eating a tiny portion of food which they are served and losing weight. Caregivers are stressed with the nutrition and hydration status and as healthcare professionals, unless they are trained by the specialists, few have the knowledge that tube feeding provide little benefits and cause more harm. It often involves several hard, long and challenging

conversations with the family members in the hospital after repeated episodes of fever and pneumonia discussing the options of tube feeding and hand feeding for these elderly and often decisions are hastily made and agreed for tube feeding in a hospital. The decisions for tube feeding at advanced stages of dementia are best made in a calm setting with the patient and his/her family while he/she still has the mental capacity to do so.

## References

1. Alzheimer Disease International. The Global Voice on Dementia.
2. Kyoko Kai, Hashimoto M, Amano K, Tanaka H, Fukuhara R, et al. (2015) relationship between eating disturbance and dementia severity in patients with Alzheimer's Disease. *PLoS One* 10: e0133666.
3. Woods SC, Seeley RJ, Porte D, Schwartz MW (1998) Signals that regulate food intake and energy homeostasis. *Science* 280: 1378-1383.
4. Guyenet SJ, Schwartz MW (2012) Regulation of food intake, energy balance and body fat mass: Implications for the pathogenesis and treatment of obesity. *The Journal of Clinical Endocrinology & Metabolism* 97: 745-755.
5. Chapman IM (2006) Nutritional disorders in the elderly. *Med Clin North Am.* 90: 887-907.
6. Older people with Dementia: Eating and drinking healthy. *Nursing & Residential Care* 9: 1.
7. Lim SC, Koh AJH (2017) Nutrition and the elderly surgical patients. *MOJ Surg* 4: 00088.
8. Si Ching LIM (2016) Nutrition and the role of tube feeding in the elderly. *JJ Gerontol* 2: 017.
9. Kyoko Kai, Hashimoto M, Amano K, Tanaka H, Fukuhara R, et al. (2015) relationship between eating disturbance and dementia severity in patients with Alzheimer's Disease. *PLoS One* 10: e0133666.
10. Lim SC, Poon WH (2016) Restraint use in the management of elderly with dementia in hospital. *Int Med Res Open J* 1: 1-4.
11. Steinbach S, Hundt W, Vaitl A, Heinrich P, Förster S et al. (2010) Taste in mild cognitive impairment and Alzheimer's disease. *J Neurol* 257: 238-246.
12. Ahmed RM, Irish M, Kam J, van Keizerswaard J, Bartley L et al. (2014) Quantifying the eating abnormalities in frontotemporal dementia. *JAMA Neurol* 71: 1540-1546.
13. M Ikeda, J Brown, A Holland, R Fukuhara, J Hodges (2002) Changes in appetite, food preference and eating habits in frontotemporal and Alzheimer's Disease *J Neurol Neurosurg Psychiatry* 73: 371-376.
14. Ahmed RM, Irish M, Henning E, Dermody N, Bartley L, et al. (2016) Assessment of eating behaviour disturbance and associated neural networks in frontotemporal dementia. *JAMA Neurol* 73: 282-290.
15. Edahiro A, Hirano H, Yamada R, Chiba Y, Watanabe Y (2013) Comparative study of eating behavior in elderly patients with Alzheimer's disease and vascular dementia: a first report. - Comparison of disturbed eating behaviour. *Nihon Ronen Igakkai Zasshi* 50: 651-660.
16. Mitchell SL1, Teno JM, Kiely DK, Shaffer ML, Jones RN, et al. (2009) The clinical course of advanced dementia. *N Engl J Med* 361: 1529-1538.
17. Marik PE1, Kaplan D (2003) Aspiration pneumonia and dysphagia in the elderly. *Chest* 124: 328-336.
18. Martino R, Silver F, Teasell R, Bayley M, Nicholson G, et al. (2009) the Toronto Bedside swallowing screening test TOR-BSST. Development and validation of a dysphagia screening tool for patients with stroke. *Stroke* 40: 555-561.
19. Wirth R, Dziejwas R, Beck AM, Clavé P, Hamdy S, et al. (2016) Oropharyngeal dysphagia in older persons-from pathophysiology to adequate intervention: a review and summary of an international expert meeting. *Clinical Intervention in Aging* 11: 189-208.
20. Pivi GA, Bertolucci PH, Schultz RR (2012) Nutrition in severe dementia. *Current Gerontology and Geriatrics Research* ID: 983056.
21. Hanson LC, Ersek M, Gilliam R, Carey TS et al. (2011) Oral feeding options for people with dementia: a systematic review. *J Am Geriatr Soc* 59: 463-472.
22. Tanvir Ahmed, Nadim Haboubi (2010) Assessment and management of nutrition in older people and its importance to health. *Clin Interv Aging* 5: 207-216.
23. Strategies to improve nutrition in elderly people. *bpac prescription foods elderly* pages 20-34.
24. Kuo S1, Rhodes RL, Mitchell SL, Mor V, Teno JM (2009) Natural History of Feeding-Tube Use in Nursing Home Residents With Advanced Dementia. *J Am Med Dir Assoc* 10: 264-270.
25. Mitchell SL, Mor V, Gozalo PL (2016) Tube-Feeding in US Nursing Home Resident with Advanced Dementia, *JAMA* 316: 769-770.
26. Teno JM, Gozalo PL, Mitchell SL, Kuo S, Rhodes RL et al. (2012) Does Feeding Tube Insertion and Its Timing Improve Survival? *J Am Geri Soc* 60: 1918-1921.
27. Cintra MT, de Rezende NA, de Moraes EN, Cunha LC, da Gama Torres HO (2014) A Comparison of Survival, Pneumonia, and Hospitalization In Patients With Advanced Dementia and Dysphagia Receiving Either Oral or Enteral Nutrition. *J Nutr Health Aging* 8: 894-899.
28. Joan M. Teno, Pedro Gozalo, Susan L. Mitchell, Sylvia Kuo, Ana T. Fulton, et al. (2012) Feeding Tubes and the Prevention or Healing of Pressure Ulcers. *Arch Intern Med* 172: 697-701.
29. Bentur N, Sternberg S, Shuldiner J, Dwolatzky T (2015) Feeding Tubes for Older People with Advanced Dementia Living in the Community in Israel. *Am J Alzheimers Dis Other Demen* 30: 165-172.
30. Kumagai R, Kubokura M, Sano A, Shinomiya M, Ohta S, et al. (2012) Clinical Evaluation of Percutaneous Endoscopic Gastrostomy Tube Feeding in Japanese Patients with Dementia. *Psychiatry Clin Neurosci* 66: 418-422.
31. American Geriatrics Society Ethics Committee and Clinical Practice and Models of Care Committee (2014) American Geriatrics Society feeding tubes in advanced dementia position statement. *J Am Geriatr Soc* 62: 1590-1593.
32. Feeding tubes for people with Alzheimers disease (2013) Philadelphia: ABIM Foundation.
33. Alzheimer's Association Statements (2011).
34. Sampson EL, Candy B, Jones L (2009) Enteral Tube feeding for older people with advanced dementia. *Cochrane Database Syst Rev* 2: CD007209.
35. Tom L. Beauchamp, James F. Childress (2012) Principles of Biomedical Ethics. Oxford University Press, 7<sup>th</sup> edition.
36. Peck A, Cohen CE, Mulvihill MN (1990) Long-term enteral feeding of aged demented nursing home patients. *J Am Geriatr Soc* 38: 1195-1198.
37. Phillips PA, Rolls BJ, Ledingham JG, Forsling ML, Morton JJ, et al. (1984) Reduced thirst after water deprivation in healthy elderly men. *N Engl J Med* 311: 753-759.

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38. Imogen Goold, Jonathan Herring (2014) Great Debates in Medical Law and Ethics. Palgrave p 3.
  39. Airedale NHS Trust v Bland (1993) 1 All ER 821, p 871.
  40. R (Burke) v GMC (2005) EWCA Civ 1003.
  41. Mitchell SL (2015) Advanced Dementia. N Engl J Med 372: 2533-2540.
  42. Elizabeth Wicks (2001) The Right to Refuse Medical Treatment under the European Convention on Human Rights. Med Law Rev 9: 17-40.
  43. Herring J (2014) Relational Autonomy and Family Law. Springer. Chapter 3.
  44. Huxtable R. Autonomy, Best Interests and the Public Interest: Treatment, Non-treatment and the Values of Medical Law. Med Law Rev 22: 459-493.
  45. Secretary of State for the Home Department v Robb (1995) Fam 127.
  46. Mental Capacity Act 2005, Code of Practice. Section 5.31. United Kingdom.
  47. Aintree v James and others (2013) EWCA Civ 65, para [49].
  48. Re B (A Minor) (Wardship: Medical Treatment) (1981) 1 WLR 1421.
  49. Re J (Wardship: Medical Treatment) (1991) Fam 33.
  50. Re Wyatt (2005) EWCA Civ 1181, para [87].
  51. Aintree v James (2013) UKSC 67, para [39].
  52. Synofzik M (2007) Tube-feeding in Advanced Dementia. An Evidence-based Ethical Analysis. Nervenarzt 78: 418-428.

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