WEIGHT LOSS DECISION-MAKING FRAMEWORK

for nurses and care staff caring for people with advanced dementia

SUPPORTING INFORMATION
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SECTION ONE: FRAMEWORK OVERVIEW

All health professionals must use their own professional judgement when using this framework and associated resources. Any decision to vary from this framework should be documented in the resident’s records to include the reason for the variance and the subsequent action taken.

1.1 Introduction to the weight loss framework

Timely assessment and management of symptoms is a major component of a palliative approach to dementia care. This framework provides a process to adopt to assess and manage weight loss in residents with advanced dementia, and is based on the best available evidence, or in the absence of evidence, expert opinion.

Use of this framework will assist nurses and care staff to improve their assessment and management of weight loss; and improve the well-being of residents, per Guidelines 36-39 of the Guidelines for a Palliative Approach in Residential Aged Care.

It is recommended that in conjunction with the use of this framework, all nurses and care staff:

- refer to the sections relating to nutrition and hydration, weight loss, cachexia, and dysphagia in the Guidelines for a Palliative Approach in Residential Aged Care;

- complete the Palliative Care Australia on-line Symptom Management Module, available to support the use of the Guidelines, from www.pallcare.org.au. Select the ‘Aged Care’ option, then select ‘Aged Care Resources’, then ‘Training Resources’ for the Guidelines;

- complete the ‘nutrition and hydration, dysphagia, and mouth care’ sections of Topic 5: Symptom control, which is one topic within the Palliative Care Australia Competency unit: CHCPA01A Deliver care services using a palliative approach, available from Palliative Care Australia.

1.2 Competencies required

This framework is for the use of both nurses and care staff within residential aged care facilities.

All nurses and care staff have a responsibility to ensure they are competent to assess and manage weight loss experienced by residents, within their scope of practice. Nurses and care staff who are concerned they do not have adequate levels of competency should discuss their concerns with their managers, so that additional training can be arranged for them.
1.3 Scope of this framework

The purpose of this framework is to provide best practice evidence, or in the absence of evidence, expert opinion, to enable nurses and care staff in residential aged care facilities to:

- monitor all residents with advanced dementia for weight loss;
- assess the causes of weight loss and manage reversible causes, per the goals of care for the resident;
- provide information and support to family members when weight loss is irreversible. Assist family members as they make the difficult ethical decisions often associated with feeding issues in advanced dementia.

1.4 Using this framework

This framework provides a comprehensive method of monitoring weight loss; managing weight loss, including treating reversible causes; and communicating with family members about weight loss in advanced dementia.

1. **Monitoring**

All residents with advanced dementia require monitoring of their weight:

- on admission, weekly for 3 weeks to gather baseline information; and
- monthly, if their weight is stable, unless the documented goals of care indicate this is no longer necessary;
- weekly, if interventions to manage weight are in progress.

2. **Manage weight loss**

- treat any reversible causes of weight loss, per the goals of care for the resident;
- use natural feeding techniques to enhance the resident’s nutritional intake.

3. **Communicate with family members about weight loss in advanced dementia**

- provide family members with a copy of the pamphlet ‘Weight loss in advanced dementia’ prior to any family conference when weight loss is discussed.
SECTION TWO: WEIGHT LOSS

KEY POINTS

- Weight loss occurs is common among people with dementia, and occurs throughout the course of the condition. It is associated with greater disease severity, a more rapid deterioration in clinical condition, and increased mortality;

- Monitoring of weight loss is important. Regularly weighing the resident and calculating the BMI will provide evidence that can assist with clinical assessment;

- Unintended weight loss may be reversible. Causes include undernutrition, fluid and electrolyte imbalance, depression, some medications, chronic infections, hyperthyroidism, pain and constipation which affects the appetite;

- In very advanced diseases such as end stage dementia, unintended weight loss may not be reversible, and is due to cachexia, a complex metabolic condition. The prognosis of any resident with cachexia is very poor;

- Feeding problems occur as dementia advances. The ability to self-feed is the first activity of daily living (ADL) to be mastered and the last ADL to be lost as dementia progresses;

- Individualise each resident’s meals as much as possible to promote eating and weight maintenance;

- Careful hand feeding can be used even if a resident has swallowing problems;

- Provide information and support to family members as dementia progresses, so they understand the irreversible nature of the weight loss that may occur.
2.1 WEIGHT LOSS AMONG OLDER PEOPLE

Introduction

Weight loss among residents with advanced dementia causes much concern for the family members and facility staff, and provides one of the greatest ethical challenges faced when caring for a person with dementia.

Providing food for another person is nurturing and symbolic of the love and affection felt between people. Mealtimes are an opportunity to interact socially with other people. Therefore, when weight is lost due to the effects of an eventually fatal condition life-limiting illness such as dementia, it may be difficult for family members and caregivers to look objectively at the causes, leading in some instances to inappropriate care decisions being made.

Whether to artificially feed or not, or supplement the diet with high-kilojoule fluids may cause concern. Residents and their family members require facility staff to have a sound understanding of the causes of weight loss; the skills to determine if weight loss is reversible; and the ability to plan appropriate care depending on the cause of the weight loss and the goals of care for the resident. This framework and the supporting documentation will assist nurses and care staff to assess and manage weight loss problems in residents with advanced dementia within their facility. In the context of this document, advanced dementia is considered to incorporate the severe and end stages of the condition, when the Mini-Mental State Examination (MMSE) score is less than 10.

Measures of weight loss

The Body Mass Index (BMI) measures the amount of body fat based on the height and weight of an individual. A BMI of less than 22 to 23kg/m² steadily increases the risk of death, particularly if the BMI falls to less than 18.5kg/m² (women) or 20.5kg/m² (men). An older person with an initial low body weight who then loses more weight will have a particularly bad outcome.

A BMI of between 24.0 and 25.9 has been recommended as the most favourable BMI in Caucasian older people, as it is associated with lowest 7-year mortality rates; however if the BMI of an older person is within the range of 22-27 that is within acceptable limits.

Physiological changes due to ageing that affect appetite and eating

The average older person is less hungry and eats less as he or she ages. Meal sizes are smaller, snacking between meals is less likely, and satiety (the feeling of fullness) is reached with a smaller amount of food. Coupled with these changes, the amount of energy expended due to physical activity may decrease. If the energy expended in undertaking physical activity remains greater than the energy obtained from food intake, then weight is lost.
From age 60 in men, and age 65 in women, there is an average annual weight loss of 0.5% \textsuperscript{6, 7}. Changes in weight, especially among older women, are associated with a decline in health-related quality of life \textsuperscript{8}. A 3kg or more change in weight after hospital discharge, whether an increase or decrease \textsuperscript{9}, and a 5% loss of weight over three years in community living older people, increases the risk of death to the individual \textsuperscript{10}. Unintentional weight loss is always cause for concern in an older person, due to the adverse consequences for the individual \textsuperscript{4}.

Body composition changes with age, with less muscle (due to less exercise and less anabolic (building up) hormones), and more body fat \textsuperscript{11, 12}. If excessive, muscle loss leads to sarcopenia, which is an age-related loss of muscle-mass and strength that affects almost half of the elderly population in the USA \textsuperscript{13}, and increases the risk to the individual of falls, dependency, admission to residential aged care facilities, and death \textsuperscript{11}.

Other changes that occur to older people that affect weight include:

- impairment of homeostatic mechanisms that restore food intake to normal levels when it has been reduced. This means that an older person who's food intake has been limited, for example by a period of ill health, will not naturally resume eating a larger amount of food once the illness has been treated. Gradually increasing the amount of food being eaten can restore the individual's ability to eat larger amounts of food \textsuperscript{4, 14};

- gastric motility is impaired, with impaired fundal compliance, resulting in a failure of adaptive gastric relaxation and early satiation due to the rapid passage of food into the atrium of the stomach \textsuperscript{15};

- the sense of taste may decline \textsuperscript{4};

- the sense of smell deteriorates, which may influence the type of food eaten, and lead to weight loss \textsuperscript{4, 14};

- hormones and neurotransmitters are altered. Opioids produced by the body can increase the pleasure associated with eating. In older people, these opioids may be reduced, leading to reduced feeding drive \textsuperscript{4}. Concentration of circulating cholecystokinin, an intestinal peptide which influences the feeling of satiety, increase in older people; and older people are more sensitive to their effects, causing anorexia \textsuperscript{4};

- satiating cytokines, which the body secretes in response to significant stress, may increase in quantity or effect in older people. Satiating cytokines are often due to malignancy or infection. They decrease food intake and reduce body weight, and are associated with cachexia \textsuperscript{4};

- significant levels of periodontal disease (affecting the tissues that support the teeth), has been shown to cause weight loss in community-dwelling older people \textsuperscript{16}. 

Decision-making frameworks in advanced dementia: Links to improved care project.  Page 7 of 62
Weight Loss Framework Supporting Information
Incidence and prevalence of weight loss among older people

In NSW in 2005, 49% of older men, and 40.3% of older women (>75 years), were overweight or obese. By comparison with these very high rates of obesity, the same survey found that 1.7% of males, and 5.6% of females, were underweight.

Alibhai et al (2005) reviewed the incidence and prevalence of unintentional weight loss in community-dwelling older people, and noted that weight loss was associated with a range of conditions:

- malignant disease (16% -36%);
- psychiatric disorder (especially depression (9% - 42%);
- gastrointestinal disease (2%-9%);
- endocrine disorder (especially hyperthyroidism) (4%-11%);
- cardiovascular disease (2% -9%);
- nutritional disorders or alcoholism (4%-8%);
- respiratory disease (approx 6%);
- neurological disorder (2%-7%);
- chronic infection (2%-5%);
- renal disease (approx 4%);
- connective tissue disease (2%-4%);
- drug-induced weight loss (medication side effects) (approx 2%);
- unknown (10%- 36%).

Other causes of anorexia and weight loss

Depression appears to be the major cause of anorexia and weight loss in older people. Other causes of anorexia and weight loss are listed below, and can be remembered by the mnemonic MEALS ON WHEELS:

- Medications (digoxin, theophylline, fluoxetine);
- Emotional causes (depression);
- Alcoholism, elderly abuse, anorexia tardive (abnormal attitudes about food intake and body image, associated with severe weight loss);
- Late-life paranoia;
- Swallowing disorders;
- Oral problems;
- Nosocomial infections (tuberculosis, Helicobacter pylori);
- Wandering and other dementia-related behaviours;
- Hyperthyroidism, hypercalcaemia, hypoadrenalism;
- Enteral problems (gluten enteropathy, pancreatic insufficiency);
- Eating problems;
- Low salt, low-fat diets (therapeutic diets);
- Shopping and food-preparation problems.

Chronic pain is also associated with self-reported appetite impairments in older adults. As yet, no causal relationship has been established. The likelihood of weight
loss increases with an increase in the number of medications an older person takes. Particular medications, especially cardiac glycoside medications (eg lancin) and angiotensin-converting enzyme (ACE) inhibitors (eg Captopril, Enalapril) are associated with increased risk of weight loss\textsuperscript{20}.
2.2 WEIGHT LOSS DUE TO UNDERNUTRITION (PROTEIN-ENERGY UNDERNUTRITION)

In undernutrition, the diet may not provide enough energy and protein, or illness prevents the body utilising the food eaten. The terms malnutrition and undernutrition tend to be used interchangeably within the available literature. However, malnutrition can also apply to over-eating associated with obesity, therefore the term undernutrition better describes abnormalities in food intake associated with weight loss.

Body composition changes with age. Older people experience greater loss of fat free mass (which includes muscle, organ tissue, skin and bone) than younger people. Despite this loss of fat free mass, in older people the percent of body cell mass, which includes muscle, viscera and the immune system, is greater. This means that the internal organs of an older person can continue to function normally when undernutrition is experienced, until undernutrition becomes severe. Once severe undernutrition is experienced, gut function breaks down causing malabsorption, diarrhoea and infections. This can be fatal.

Table 1 shows a classification scale of undernutrition, based on the Body Mass Index (BMI).

**Table 1. Classification of undernutrition in adults by BMI**

<table>
<thead>
<tr>
<th>BMI (kg/m²)</th>
<th>Classification</th>
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<tr>
<td>&gt; 20</td>
<td>Normal</td>
</tr>
<tr>
<td>18.5 – 20</td>
<td>Marginal undernutrition</td>
</tr>
<tr>
<td>17- 18.5</td>
<td>Mild undernutrition</td>
</tr>
<tr>
<td>16-17</td>
<td>Moderate undernutrition</td>
</tr>
<tr>
<td>&lt; 16</td>
<td>Severe undernutrition</td>
</tr>
</tbody>
</table>

From: Schenker, S 2003 Undernutrition in the UK p 91

Scales using the BMI to classify degrees of undernutrition are based on large population studies. Care should be taken when using a BMI measurement alone as a criterion for assessing undernutrition in an individual resident. Mistakes in measuring a resident’s height, equipment variability, and observer error may lead to inaccuracies, resulting in under or over identification of the resident’s risk of undernutrition.

**Causes of undernutrition**

Undernutrition is caused by a complex interaction between the physiological, social, psychological and other factors involved in weight loss already discussed. Table 2 lists the causes of undernutrition in older people.
### Table 2: causes of undernutrition in older people

<table>
<thead>
<tr>
<th><strong>Social factors</strong></th>
<th><strong>Psychological factors</strong></th>
<th><strong>Biological factors</strong></th>
<th><strong>Medical factors</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Poverty; Inability to shop, prepare, cook meals, and feed oneself; Living alone, social isolation, lack of social support network, loss of spouse; Failure to cater to ethnic and other food preferences in institutionalised individuals.</td>
<td>Depression; Dementia, Alzheimer’s disease; Anxiety; Alcoholism; Bereavement.</td>
<td>Decreased ability to smell and taste food; Decreased adaptive relaxation of the fundus (stomach), so the antrum fills more rapidly, sending signals that the stomach is full to the brain too early; Increased cholecystokinin (hormone that signals satiation); Increased leptin in men (leptin is a peptide hormone that decreases food intake and increases metabolism); Altered central nervous system neurotransmitters.</td>
<td>Decreased cardiac sympathetic tone; Malabsorption syndromes; Gastrointestinal symptoms eg dyspepsia, <em>Helicobacter pylori</em> infection / atrophic gastritis / Vomiting /diarrhoea / constipation / Parkinson’s disease; Hypermetabolism (eg hyperthyroidism); Cancer; Infection; Alcoholism; Poor dentition; Dysphagia; Chronic obstructive pulmonary disease; Rheumatoid arthritis; Multiple medications.</td>
</tr>
</tbody>
</table>

Adapted from Chapman (2007) page 750

### Adverse effects of undernutrition

Protein-energy undernutrition causes three conditions: marasmus, kwashiorkor (hypoalbuminaemia) or a mixture of both. In marasmus, there is a marked depletion in muscle mass and fat, caused by insufficient energy intake relative to the needs of the individual.

Marasmus develops over months. The individual will look starved, with weight <80% standard for height, below-normal size mid-arm circumference and/or skin-fold measurements. Fat (adipose tissue) is lost first.

Kwashiorkor is caused by insufficient protein intake, and is often precipitated by an acute infection or illness. The serum albumin level is less than 3.5-3.0g/dL, the individual may be oedematous.

As well as impaired muscle function and decreased bone mass, an undernourished person may also experience:
- Immune dysfunction;
- Anaemia;
- Reduced cognitive function;
- Poor wound healing;
- Delayed recovery from surgery;
- Increased mortality, with the risk of death increasing if the undernourished person also has comorbidities such as renal failure, cardiac failure, or cerebrovascular disease 4 p740.

If mobility is impaired, the decreased muscle mass may result in weight loss in a person with advanced dementia, even if undernutrition is not present 26.

**Undernutrition in institutionalised older people**

A review of the literature 27 that has been published using the Mini Nutritional Assessment tool 28 to assess risk of undernutrition has found that on average the prevalence of undernutrition in institutionalised older people is 21% (range 1-74%); with on average a further 51% (range 27-70%) being at risk of undernutrition 27. Akner et al report that in institutionalised people with dementia, between 12% and 50% have been found to be undernourished. People with Alzheimer’s disease are more likely than those with vascular dementia to have protein-energy undernutrition 29.

Careful attention to feeding can prevent weight loss due to undernutrition in institutionalised older people 24.

Kayser-Jones 30 has observed meal-times in residential aged care facilities over a number of decades and has reported the following factors that diminish food intake:

- lack of attention to individual food preferences;
- lack of ethnic (culturally appropriate) food;
- dysphagia: lack of diagnosis, lack of correct feeding technique;
- poor oral health of residents;
- pureed food, which is visually unappealing;
- inadequate staffing and lack of supervision, leading to residents being fed too quickly and too forcefully;
- incorrect positioning of bedbound residents 30.

Kayser-Jones reported the development of a pattern of weight loss due to these factors:

“Many of the residents had no or few teeth, they had swallowing disorders, and there were not enough staff to assist them at mealtime. Because they could not eat well, they began to lose weight. The underlying cause of their weight loss was never addressed. When residents lost weight they were placed on a pureed diet. This food was unappetising. The residents continued to eat poorly and to lose weight. Next, commercial supplements were ordered. The supplements destroyed their appetite for regular food. The residents continued to lose weight and became frail, and some died.” 30 pp1395-1396
Kayser-Jones & Schell \[31\] particularly highlighted the importance of having sufficient trained staff to provide feeding assistance. If there are insufficient trained staff the likelihood increases that residents will be fed too rapidly, with excessive amounts of food placed on the spoon. Pierson \[32\] also noted that spoons were loaded with too much food. In this instance, the nursing assistants explained they were trying to get as much nutrition into the resident as possible in the short time allocated. Feeding was successful while the nursing assistants were vigilant, reading and interpreting nonverbal cues from the resident, but if their attention wavered the resident could stop eating, leaving the nurse trying to interpret the behaviour, often unsuccessfully. Feeding was either continued or stopped as a result of the behaviour change, sometimes inappropriately, based on the nurse’s interpretation of the behaviour.

Staffing levels and their impact on resident outcomes have been studied on numerous occasions \[33-37\] in the USA since Kayser-Jones et al reported their findings in the 1990’s. Schnelle et al (2004) \[36\] studied care outcomes in 21 Californian nursing homes. Not surprisingly, they found that the best care was provided by the homes with the highest staffing levels. Even in the better-staffed facilities though, reporting and documentation of care processes relating to feeding was poor. Nursing assistants did not report to registered nurses when almost half (48%) of the residents did not eat at least 50% of their meal. These residents are at increased risk of weight loss. Furthermore, Schnelle et al observed that of these at-risk residents, 54% were provided with less than one minute of feeding assistance during meals.

Horn et al (2005) \[35\] reviewed data from 1376 residents in 82 long-term care facilities as part of a review of pressure ulcers. They concluded that more direct care from registered nurses per resident per day resulted in better care outcomes for the residents, including less weight loss. However, providing more care from nursing assistants did not improve weight loss outcomes. Dyck (2007) \[34\] however reported that residents receiving at least 3 hours per day of nursing assistant care had a 17% decreased likelihood of weight loss. Dyck analysed data from almost 364,000 residents from 2948 facilities across the United States of America.

Simmons & Schnelle (2006) \[37\] continued their interest in the feeding needs of residents by studying 91 residents with identified low oral intake from 6 nursing homes in southern California. The residents were observed during six meals on two consecutive days, before and after trialling a feeding intervention. Cognitively impaired residents responded better to additional assistance at meal times, while cognitively intact residents with less physical impairment improved their energy intake when snacks were provided between meals. Residents were receiving different levels of assistance with meals, from those requiring social stimulation and/or verbal prompting during meals; those requiring physical guidance during meals; to those that needed full assistance. They found that residents in all three groups needed an average of 35 to 40 minutes of staff time per meal, if food and fluid intake was to improve by 15%. This amount of assistance was a huge increase on the amount of assistance usually given, when (approximate) averages of one and a half minutes for social stimulation & prompting; three and a half minutes for physical guidance; and fourteen minutes for full physical assistance were provided. A 15% improvement in food and fluid consumption increased the energy intake by >300 calories per day.
Bachrach-Lindstrom et al. in Sweden were interested in the low rates of nutritional risk assessment and nutrition care plans written for residents in long-term care. They surveyed 252 registered nurses and nurse aides to understand their attitudes towards nutritional care. Their results indicate that just over half (53%) held positive attitudes towards nutritional care, with registered nurses holding more positive attitudes than nurse aides. Approximately one third (35%) of participants held positive attitudes towards assessment of nutritional status. Nursing staff held attitudes in favour of routinised care and organisation at mealtimes, which the researchers thought may have been due to insufficient staff numbers and time making individualised care more difficult.
### 2.3 OTHER CAUSES OF UNINTENTIONAL WEIGHT LOSS

**Unintended weight loss due to medications**

Many older people are taking numerous medications. The side effects of these medications may negatively affect food and fluid intake. Table 3 lists some of the medications with side effects that might affect oral intake and influence subsequent weight loss.

**Table 3: Medications with side effects that may affect oral intake**

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Causative Agents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anorexia</td>
<td>amantadine; amlodipine; antibiotics; anticonvulsants; benzodiazepines; cisapride; decongestants; digoxin; enalapril maleate; famotidine; fentanyl transdermal system; frusemide; gold; hydrochlorothiazide; ipratropium bromide; levodopa; levothyroxine; metformin; neuroleptics; nicotine; nifedipine; nizatidine; NSAIDs; omeprazole; opiates; paroxetine; phenytoin; potassium replacement; ranitidine; risperidone; sertraline; SSRI; theophylline; triamterene; warfarin; xanthines.</td>
</tr>
<tr>
<td>Altered taste</td>
<td>ACE-inhibitors; acetazolamide; allopurinol; alcohol; antibiotics; anticholinergics; antihistamines; calcium-channel blockers; carbamazepine; chemotherapy agents; chloral hydrate; etidronate; gold; hydralazine; iron; levodopa; lithium; metformin; methimazole; metformin; metronidazole; nasal vasoconstrictors; nitroglycerin; opiates; penicillamine; phenytoin; propanolol; selegiline; sodium cromoglycate; spironolactone; statins; sulfa-containing medications; terbinafine; tobacco products; triazolam; tricyclics.</td>
</tr>
<tr>
<td>Nausea and/or vomiting</td>
<td>amantadine; antibiotics; bisphosphonates; digoxin; dopamine agonists; hormone replacement therapy; iron; levodopa; metformin; metronidazole; nitroglycerine; NSAIDs; opioids; phenytoin; potassium; SSRIs; statins; theophylline; tricyclics.</td>
</tr>
<tr>
<td>Dry mouth</td>
<td>Antihistamines; anticholinergics; clonidine; loop diuretics.</td>
</tr>
<tr>
<td>Confusion / distraction</td>
<td>Anticholinergics; neuroleptics; NSAIDs.</td>
</tr>
<tr>
<td>Constipation</td>
<td>Anticholinergics; antispasmodics; smooth muscle relaxants;</td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>Antibiotics; medications in elixirs when sorbitol is used</td>
</tr>
<tr>
<td>Movement disorders</td>
<td>Antiemetics (metaclopramide); Parkinson’s agents (levodopa, amantadine)</td>
</tr>
<tr>
<td>Dysphagia</td>
<td>alendronate; anticholinergics; antibiotics (eg doxycycline); bisphosphonates; chemotherapeutic agents; corticosteroids; gold; iron; levodopa; NSAIDs; potassium; quinidine; theophylline.</td>
</tr>
</tbody>
</table>

SSRI = serotonin specific reuptake inhibitor; ACE= angiotensin-converting enzyme; NSAID = nonsteroidal anti-inflammatory drug.
A study reported by Martin et al found significant associations between morphine sulphate, fentanyl, antibiotics, anxiolytics and anti-psychotic medications and weight loss in nursing home residents with unintentional weight loss, although the reason for the relationship could not be explained. These authors suggest targeting residents taking these medications for anti-weight loss interventions.

**Unintended weight loss due to the use of therapeutic diets**

The American Dietetic Association (ADA) recommends liberalising diets for residents in aged care facilities to improve the residents’ quality of life and nutritional status. ‘Therapeutic diets’ are diets ordered as part of treatment of a disease or condition to decrease, eliminate or increase certain substances in the diet. In brief, the ADA recommends:

**Diabetic diets**: regular diets with consistent meal times and portion sizes may improve quality of life and nutrition in residents with diabetes. Meals and snacks should consistently contain carbohydrates. Sucrose-containing foods can be included as part of the carbohydrate content. Blood glucose should be monitored, and medications adjusted and a dietitian consulted to further individualise the nutrition plan if the blood glucose levels fluctuate.

**Diets for heart disease** such as low cholesterol, and/or low salt diets are frequently unpalatable, and have not been shown to control or affect symptoms. It is more important that the resident be offered a varied diet which is visually attractive and tasty and encourages the resident to eat.

**Diets for renal disease** frequently restrict protein. Protein need not be restricted if a resident is receiving dialysis. In other instances consult a dietitian to individualise the diet.

**Low sodium diets** for residents taking lithium may be able to be eased as well. The resident will require monitoring as the diet is changed, as increased sodium may reduce the lithium levels and exacerbate the underlying illness.

**Altering the consistency of the diet** (eg to purees) should be ordered only when a resident is at high risk of aspiration. These diets are often unpalatable and visually unappealing, and the resident may eat less as a result. Use additional seasonings and garnishes to enhance the taste and visual appeal.

**If dietary restrictions are ordered** the reasons for the restrictions should be clearly stated in the resident’s records.

**Unintended weight loss due to dehydration**

One thousand (1000) millilitres of fluid weighs one kilogram. For an older person who is losing weight, it is essential to also consider whether the cause of the weight loss is dehydration. Older people can become dehydrated quite easily, because they have
impaired thirst mechanisms, and their kidneys conserve less water. Additionally, an older person with advanced dementia will not have the capacity to ask for a drink.

Solid foods such fruits and vegetables (which contain 95% water by weight) can contribute 2 to 4 cups of water per day to the diet. The recommended intake of water (over and above the water available from foods and by-products of metabolism) for older people in residential aged care is a minimum of 1600ml every 24 hours. This is approximately 8 glasses or cups (200ml size) per day. In certain conditions such as heart failure this amount of fluid may need to be restricted.

A review by Maughan & Griffin (2003) reported that doses of caffeine found in standard servings of tea, coffee and carbonated soft drinks had no diuretic actions and thus there was no clear basis for stopping caffeinated fluids when fluid balance is important.

Nursing assessment of dehydration can include keeping an accurate fluid intake chart for 24 hours. Undertaking a urinalysis to test the specific gravity of the urine is recommended. A specific gravity value of greater than or equal to 1.020 implies an underhydrated state and requires further monitoring. Observing for signs such as longitudinal tongue furrows, sunken eyes, dry mucus membranes, upper body muscle weakness, speech difficulty and additional confusion are also important.

Using medical interventions such as subcutaneous or intravenous infusions to treat dehydration may be inappropriate for a resident in the final stages of dementia. A discussion with the family members and general practitioner about the goals of care is highly recommended. Guideline 24 from the ‘Guidelines for a Palliative Approach in Residential Aged Care’ states:

> Recommendations regarding fluid therapy that are based on an ongoing assessment of each resident’s circumstances, including the resident’s and family’s preferences, improve the resident’s and family’s satisfaction with the care that is provided.

NB: some resident’s may appear to be gaining weight when actually they have increasing fluid retention. These residents need to be carefully monitored to see whether they are consuming sufficient food.

**Weight loss due to oral health issues**

Older people with badly fitting dentures, poor dentition and those who do not receive regular oral hygiene are at increased risk of weight loss. Having a diagnosis of dementia, co-morbid conditions, and taking multiple medications increases the likelihood of oral health issues.

The ‘Guidelines for a Palliative Approach in Residential Aged Care’ recommendations for oral care state:

Guideline 31: 
> Good oral hygiene, regular assessment, cleansing of dentures and oral fluids can reduce oral complications.
Guideline 33:

*Rinsing the mouth with water and cleansing teeth with a soft toothbrush and toothpaste is an effective oral cleansing routine that is cost-efficient and reduces the resident’s risk of oral mucositis (mouth ulcers).*

**Social and psychological factors that affect weight loss in older people**

The decision to eat is driven by hunger. Hunger signals come from the gastrointestinal tract and fat stores. A hungry person may refrain from eating for cultural or religious reasons, or because they hold beliefs that prevent them from doing so, such as a paranoid idea that the food has been poisoned.

Appetite, or the enjoyment of food for itself and not just to fill a physiological need, is conditioned by social and cultural factors. Eating a meal alone can reduce the amount of food an older person consumes by as much as 50%, compared to when the food is eaten in the company of others.
2.4 IRREVERSIBLE CAUSES OF WEIGHT LOSS DUE TO ADVANCED DISEASE

Cachexia is usually associated with chronic infections and malignant conditions, although elements of cachexia have been identified in a wide variety of chronic diseases such as dementia, Parkinson’s disease, AIDS, heart failure, and among ageing people. However, weight loss due to cachexia is not reversed by increasing the amount of energy that a person consumes, unlike weight loss due to undernutrition. The prognosis of any resident with cachexia is very poor.

A resident who has advanced cachexia will have no appetite (be anorexic); feel full and stop eating after a small amount of food (be easily sated); be weak; have severe weight loss, with a disproportionate amount of muscle wasting occurring; be anaemic; and may be oedematous. Oedema is not associated with cachexia due to heart failure.

Tissue wasting associated with cachexia is out of all proportion to the anorexia experienced by the individual, so that loss of lean tissue mass occurs at the same rate as loss of adipose (fat) mass. This is in contrast to undernutrition, when adipose (fat) tissue is lost first.

At present there is no internationally agreed definition of cachexia. One definition is:

“... accelerated loss of skeletal muscle in the context of a chronic inflammatory response”

For research purposes, a reduction of 10% of body weight is often used as the criterion for cachexia. In people with chronic heart failure, non-oedematous weight loss of 6% over a period of 6 months, regardless of the body mass index, defines cachexia.

It is important to note that the physiological changes that occur due to ageing which affect appetite and eating make an older person at greater risk of developing cachexia, even after a minor illness.

Table 4 shows a comparison between three major physiological causes of weight loss in older people.

The ‘Guidelines for a palliative approach in residential aged care’ recommend:

“A review of the resident’s clinical history, the presence of substantial weight loss, laboratory tests and physical examination are required to make an accurate diagnosis of cachexia.” Guideline 27 (page 10).
Table 4: Comparison of the anorexia-cachexia syndrome due to cancer, anorexia of ageing, and sarcopenia

<table>
<thead>
<tr>
<th></th>
<th>Cancer anorexia-cachexia syndrome</th>
<th>Anorexia of ageing</th>
<th>Sarcopenia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Food intake</td>
<td>markedly decreased</td>
<td>decreased</td>
<td>unchanged</td>
</tr>
<tr>
<td>Weight loss</td>
<td>marked</td>
<td>gradual</td>
<td>gradual</td>
</tr>
<tr>
<td>Loss of adipose tissue</td>
<td>yes</td>
<td>yes</td>
<td>minimal</td>
</tr>
<tr>
<td>Loss of muscle mass</td>
<td>yes</td>
<td>minimal</td>
<td>yes</td>
</tr>
<tr>
<td>Cytokine excess</td>
<td>yes</td>
<td>possibly</td>
<td>possibly</td>
</tr>
<tr>
<td>Early satiation</td>
<td>yes</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Nausea</td>
<td>yes</td>
<td>no</td>
<td>no</td>
</tr>
<tr>
<td>Altered sense of taste or smell</td>
<td>yes</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Elevated cholecystokine levels</td>
<td>no</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Decreased testosterone (men)</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
</tr>
<tr>
<td>Increased leptin levels</td>
<td>possibly</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Decreased serum albumin levels</td>
<td>yes</td>
<td>late</td>
<td>no</td>
</tr>
</tbody>
</table>

2.5 WEIGHT LOSS ASSOCIATED WITH DEMENTIA

Weight loss preceding the diagnosis of dementia

Weight loss in people with dementia is associated with greater disease severity, a more rapid deterioration in clinical condition, and increased mortality. The weight loss begins before the onset of the condition, and accelerates by the time of diagnosis. Stewart et al \(^{56}\) compared men with and without dementia over 32 years, and found that those with dementia had experienced a statistically significant weight loss, associated with both vascular dementia and Alzheimer’s disease, during the 6 years prior to diagnosis. Buchman et al noted that the risk for developing Alzheimer’s disease increased as the BMI decreased \(^{57}\). Knopman et al reported that women with dementia had lower weight than control cases starting 11 to 20 years prior to the onset of dementia, and a trend towards increasing risk of dementia with decreasing weight. They concluded that weight loss precedes the diagnosis of dementia in women by several years. The weight loss may be due to predementia apathy, loss of initiative, and reduced smell function \(^{58}\). Nourhashemi et al have suggested that low BMI might be an early sign of disease onset rather than a risk factor for dementia \(^{59}\).

Progressive weight loss throughout the course of dementia

Weight loss occurs in approximately 40% of people with Alzheimer’s disease at all stages of the disease trajectory \(^{7}\). A study by Guérin and colleagues identified two different modes of weight loss in Alzheimer’s disease. The first, which affected one third of the 395 patients studied, was a progressive weight loss defined as being 4% or more in one year. Disease severity increased the risk of progressive weight loss, while cholinesterase inhibitors which were being given when the study commenced, decreased the risk of weight loss \(^{60}\). The finding that cholinesterase inhibitors, which are given during the mild to moderate stages of dementia \(^{61}\), decreased the risk of weight loss is in contrast to findings from other studies, where up to 17% of people receiving these medications experience a considerable weight loss that was halted when the medication was ceased \(^{62}\).

Other studies have found statistically significant weight loss as dementia progresses \(^{63},^{64}\). White et al found that a weight loss of equal to, or greater than, 5% in any year was a significant predictor of mortality, with the risk of death increasing as weight loss increased \(^{63}\). Wirth et al reported in another study that people with a Mini-Mental State Examination (MMSE) \(^{3}\) score of <11 lose substantial amounts of body weight, related to the degree of cognitive dysfunction they have. Females seem to lose more weight than men, with females more likely to lose fat mass, while men lose fat free mass (muscle, organ tissue, skin and bone) \(^{64}\).

The cause of progressive weight loss in dementia is unclear. Guérin and colleagues did not find that anorexia was a factor in progressive weight loss, while Ikeda et al \(^{65}\) found the opposite. Mazzali et al (2002) reviewed the literature on weight loss in dementia, and reported that published studies on energy intake, energy expenditure and body composition do not seem to support the hypothesis that people with Alzheimer’s
dementia have either a hypermetabolic state, where they burn more energy than normal, or a reduced energy (food) intake that could explain the progressive weight loss 66. However, White et al (2004) 67 observed a small (n=32) group of residents in two facilities in the USA, to discover whether there was a relationship between weight loss and behavioural symptoms in people with Alzheimer's disease living in institutions. These researchers found that subjects with low BMIs were likely to have more frequent and severe behavioural problems; and that an association existed between agitation/aggression and disinhibition, and weight change. Increases in the behaviours resulted in decreases in weight. The researchers attributed the weight loss to either decreased energy consumption or increased physical activity, although they acknowledged that other studies were required to verify their results. Power et al suggest that dysfunction of the hypothalamus in the brain may be implicated in this weight loss 68.

Guérin et al note that the progressive weight loss associated with Alzheimer's disease can lead to cachexia in the final stages of the condition 69, which is certainly supported by Koopmans et al who found that the immediate cause of death of over 53% of people they studied, who survived until the very end stage of dementia, was cachexia and dehydration 69. The challenge when considering weight loss associated with dementia is to ensure that optimum nutrition is given to the person with dementia, so that any weight loss that does occur is not due to reversible causes.

**Acute weight loss associated with dementia**

The second mode of weight loss identified by Guérin et al was a severe loss of >5kg weight in six months, which affected 10% of subjects during this study. These people were more severely cognitively impaired and had greater initial weight than those who did not experience severe weight loss. This weight loss was probably due to comorbid disease, which caused anorexia due to an acute inflammatory response involving cytokines. This type of anorexia can be reversed in younger people, but not older people. Guérin et al believe that acute weight loss will benefit from early nutritional care while progressive weight loss will not, and recommend older people have pathology tests to identify biological markers of acute inflammatory conditions, so that intervention can be given if appropriate 60.

**Weight loss due to eating disturbances associated with dementia**

Eating disturbances were found in 15.7% of people with dementia in one large population-based study 70, with changes in appetite, food preference and eating habits all reported. People diagnosed with fronto-temporal dementia are extremely likely to develop eating disorders 71, 65. Cravings for sweet foods, which are consumed at the expense of protein-rich foods, are common, and may result in weight gain 72. However, over time as apathy increases due to disease progression, weight may be lost 71. Watson & Green, in a recent literature review, noted that in the early and middle stages of disease progression increased and inappropriate eating is common. In the later stages of dementia, indifference, weight loss and terminal decline can be expected 73.
SECTION THREE: FEEDING ISSUES ASSOCIATED WITH DEMENTIA

Limited amounts of research and subsequent guidance are available relating to food, eating and nutrition for people with dementia, especially from the perspective of the person with dementia. An individual who requires feeding assistance has a statistically higher rate of morbidity and mortality, compared to a person who does not need feeding.

It is important for nurses and care staff to remember that a resident with advanced dementia will not be able to complain about the quality and quantity of food being given to them, therefore they will need regular monitoring to confirm they are receiving adequate food.

Resident aversive behaviours that affect feeding

Feeding is the act of moving food from a receptacle to the mouth. The ability to self-feed is the first activity of daily living (ADL) to be mastered and the last ADL to be lost as dementia progresses. Aversive behaviours associated with feeding are present well before the advanced stages of dementia are being experienced. In the final stages of dementia, residents may develop the following aversive behaviours relating to the intake of food:

- refusing to eat, turning the head away, refusing to open the mouth;
- spitting out food;
- leaving the mouth open so food drops out;
- refusing to swallow.

These aversive behaviours are cumulative. To uneducated carers and family members the resident may appear to have no manners. Refusing to eat, for example by leaving the mouth open, may appear to contaminate the food, leaving the impression that the resident is dirty. It is important for nurses and care staff to understand that the behaviour is a result of the disease process, and not a deliberate attempt by the resident to be ‘naughty’. It is equally important for everyone involved in feeding the resident to remember that because the resident is unable to communicate the reasons for his or her aversive behaviour, those reasons will never be able to be verified.

Table 5 shows a framework for possible physical, psychological and social causes of aversive behaviours.

Nurses, care staff and other people involved in feeding a dependent resident may hold an idealised vision of what to expect as they undertake feeding, based on their experiences especially involving feeding an infant. There may be an expectation that the task will be mutually enjoyable. If the resident exhibits an aversive behaviour such as not swallowing his or her food, then the expectation that feeding will be a pleasurable experience will be challenged. Feeding may become distasteful to the carers. Psychological stress and burnout can occur unless education and support are offered to those undertaking the feeding.
Table 5. Framework of causes of aversive behaviour and domains of functioning

<table>
<thead>
<tr>
<th>Causes</th>
<th>Physical</th>
<th>Psychological</th>
<th>Social</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not able to eat / drink</td>
<td>• Difficulty in swallowing;</td>
<td>• Grief;</td>
<td>• Distracting environment;</td>
</tr>
<tr>
<td></td>
<td>• Paralysis;</td>
<td>• Apathy;</td>
<td>• Insufficient time for feeding</td>
</tr>
<tr>
<td></td>
<td>• Acute illness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not understanding the need to eat</td>
<td>Visual and audio problems</td>
<td>• Apraxia (inability to carry out learned</td>
<td>Insufficient nursing skill</td>
</tr>
<tr>
<td>to drink</td>
<td></td>
<td>movements);</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Agnosia (inability to recognise objects).</td>
<td></td>
</tr>
<tr>
<td>Not wanting to eat / drink</td>
<td>• Condition deteriorating;</td>
<td>• Not wanting to live any longer;</td>
<td>Unpleasant environment</td>
</tr>
<tr>
<td></td>
<td>• Afraid of choking</td>
<td>• Disliking food.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
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</tbody>
</table>

Adapted from: Pasman, The, Onwuteaka-Philipsen et al 2003 p 311 79

Dysphagia

Dysphagia is difficulty in swallowing. There are four phases to swallowing 80:

Pre-oral phase, when hunger and anticipation of food trigger salivation;
Oral phase, when food is chewed and mixed with saliva to form a bolus (ball of food) that is moved to the back of the mouth;
Pharyngeal phase, when swallowing is started and the airway is automatically protected to prevent aspiration;
Oesophageal phase, when the bolus is moved through the oesophagus by peristalsis into the stomach.

In older people, swallowing is affected by decreased muscle strength that affects the lips, tongue, and jaw movements. The pharyngeal phase of swallowing is slower to start in older people.

Dysphagia is extremely common among institutionalised residents with dementia. Feinberg et al (1992) 81 found during a study of 131 residents that only 7% had normal swallowing. Oral-stage dysfunction was found in 93 residents (71%); pharyngeal dysfunction in 56 residents (43%); and pharyngoesophageal-segment abnormalities in 43 residents (33%).

Dysphagia can cause aspiration, dehydration and undernutrition; can lead to depression; and diminishes the quality of life of the individual 82.

The basis of oropharyngeal dysphagia (difficulty in initiation of swallowing and impaired transfer of food from the oral cavity to the oesophagus) is commonly
neurological disease, especially stroke; advanced dementia; and Parkinson’s disease, which account for 75% of all cases of oropharyngeal dysphagia. It is more common with advanced age.

Initial signs of dysphagia include reduced chewing and behavioural problems affecting eating. Other symptoms of dysphagia include:

- food sticking in the throat;
- coughing before, during or after swallowing;
- choking on food or fluids;
- nasal or oral regurgitation;
- needing to swallow 3 or 4 times with each bolus;
- frequently clearing the throat;
- hoarse, breathy or wet-sounding voice;
- drooling or dribbling of food, fluid or saliva;
- difficulty chewing or manipulating the bolus;
- pooling of food in the mouth;
- difficulty starting to swallow;
- gurgly or ‘wet’ sounding respiration;
- shortness of breath during meals;
- protruding tongue movements;
- increased time to finish a meal.

Oesophageal dysphagia is usually due to an obstruction. Common factors causing oesophageal dysphagia include tumours, reflux oesophagitis, candidiasis, and medications.

People with dementia may experience a range of swallowing difficulties throughout the dementia trajectory. During the early stages, taking impulsive large bites of food and gorging on food may cause problems. In the middle stages, the person may have a preference for sweet or salty foods, and have slower oral movements and a delayed swallowing reflex. Finally, as dementia reaches end stage, issues like pooling (also called ‘pouching’ and ‘squirrelling’) of food in the cheeks and mouth, and reduced co-ordination of the muscles, can lead to swallowing difficulties.

The ‘Guidelines for a Palliative Approach in Residential Aged Care’ recommendations for dysphagia state:

Guideline 29: A formalised multidisciplinary management program that includes input from a speech pathologist is beneficial in promoting early recognition, appropriate management and prevention of complications associated with dysphagia.

Aspiration

Residents with advanced dementia often vocalise when they are eating, due to reduced awareness that they have food in their mouth; not chewing and swallowing effectively; poor concentration, and fluctuating levels of consciousness, placing them at great risk
of aspiration. Aspiration occurs when food and fluids enter the larynx and lower respiratory tract.

Aspiration of oropharyngeal secretions can occur naturally, and about half of healthy adults regularly aspirate saliva when they are sleeping, but because healthy adults have strong immune systems, and the amount of aspirate is small, no pathological consequences result.

However, older residents with dementia have impaired immune systems, and dysphagia, making them at high risk of aspiration pneumonia. Aspiration pneumonia is an infectious process caused by inhalation of oropharyngeal secretions colonised by bacteria.

Aspiration may be either ‘silent’ or ‘audible’. ‘Silent’ aspiration can occur with no cough triggered, and the only symptom being deterioration in the oxygen saturation level and a fever. The right lower lobe of the lung is commonly affected and may be congested. ‘Audible’ aspiration can be identified because the resident coughs in response to being fed or given fluids.

Preventative treatment options for aspiration are limited. They include putting the resident on nil by mouth, modifying the diet, performing oral hygiene, and correctly positioning the resident.

One innovative approach to the management of dysphagia and aspiration was reported by Summersall and Wight (2006). They devised a three-level swallowing protocol, and provided intensive training to senior nurses in aged care facilities in their area in the use of the protocol. Additional training in accurate documentation and correct feeding for residents with dementia were also provided, with great success. The protocol is described in detail on page 106 of ‘Palliative Care in Severe Dementia’. In brief, residents with swallowing problems are assessed, preferably in the presence of a senior key nurse, then categorised into one of three levels. Interventions and a management plan are developed based on the level that the resident is categorised into:

Level 1: residents whose dysphagia can be satisfactorily managed, by modifying the diet, correct positioning, or feeding strategies;

Level 2: residents who are at high risk of possible aspiration because of factors such as fluctuating levels of alertness or vocalising during feeding. These residents are discussed with their family members, as the risks associated with aspiration remain despite the best possible care being given;

Level 3: residents who are aspirating. These residents have overt or chronic signs of aspiration, such as recurrent chest infections, coughing or choking, ‘wet’ voice or respiratory distress when being fed. These residents are discussed extensively with all members of the multidisciplinary team and family members. A decision is made on an individual basis whether or not to continue to feed the resident, despite the aspiration. The decision is based on the quality of life of the resident; any views he/she may have expressed in the past; and whether he/she shows pleasure or distress when being fed.
Residents who are fed despite known repeated episodes of aspiration need to have their goals of care clearly documented. The benefits and burdens associated with the use of antibiotics, and the site of care, should be discussed in full with the person responsible, care team, and other family members. This will prevent unnecessary transfer to hospital for treatment that is not in the best interests of the resident, and are contrary to the goals of care.

The Centre for Education and Research in Ageing (CERA), based in Concord NSW have a resource available called ‘Swallowing...on a Plate’ which is a training package for use in aged care facilities aimed at improving the quality of care of residents with swallowing problems. The resource can be ordered from CERA. Email to cera@medicine.usyd.edu.au or telephone 02 9767 7212 for further information.

Gillick and Mitchell (2002) 87 succinctly note that:

“Everyone needs to realize that eating problems are a signpost along dementia’s path, a signpost that indicates that death is approaching”. (Gillick & Mitchell (2002) 87 p231

For any resident with dysphagia / aspiration, a consultation with a speech pathologist to obtain individualised management suggestions is recommended.
SECTION FOUR: ASSESSING AND MONITORING RESIDENTS FOR WEIGHT LOSS AND FEEDING DIFFICULTIES

Residents with advanced dementia require assessment and monitoring of weight loss, and individualised nutrition care plans based on the goals of care determined for each resident. It is imperative that persons’ responsible and family members receive information and support as they consider issues relating to weight loss in advanced dementia, so that there is consensus agreement about how weight loss will be managed.

Assessment on admission

Nutrition needs and the common causes of weight loss:

Every facility has policies and procedures in place to assess a resident’s food intake and nutritional status on admission. Check to make sure your facility is following best practice guidelines by addressing each of the following issues:

- clarify with the resident/family member’s the resident’s food preferences, size of portions, and the timing and number of meals usually eaten;
- check the resident’s ability to self-feed. Look for tremors; ataxia; weakness in the hands and arms; joint pain;
- observe the resident while eating, especially for evidence of swallowing problems. In particular watch for coughing before, during or after swallowing; the need to swallow 3 to 4 times with each bolus; frequently clearing the throat; hoarse, breathy or wet voice; gargling while breathing; protruding tongue movements; sensation of something being caught in the throat; drooling or dribbling; or holding food in the cheeks. Referral to a speech pathologist is necessary if dysphagia is suspected;
- assess the resident’s mouth for tongue lesions, mouth sores, dental caries, gum disease, or poorly fitting dentures;
- observe the resident’s food intake for 1-3 days, and report the amount of food eaten from each food group eg protein, vegetables, sweets etc so that a nutrition plan can be developed based on the resident’s preferences. An example food and fluid chart is attached to this document;
- question the resident and/or person responsible and family members about recent weight loss or changes to appetite;
- check the condition of the resident’s skin for evidence of pressure ulcers;
- assess the resident for depression;
- document all medications and review for their potential to affect appetite or weight;
- assess for nausea, vomiting, constipation and diarrhoea which will affect food intake and weight;
- observe for fluid retention and oedema;
- assess for possible intercurrent infections that may affect appetite and weight.
Assessing residents for feeding difficulties

The Edinburgh Feeding Evaluation in Dementia (EdFED-Q) Scale can be used to assess feeding difficulties in residents with advanced dementia. This is a Mokken scale: residents who display a particular behaviour at one point on the scale will also display all the behaviours below that on the scale. For example, residents who spit out their food (No 7 on the EdFED-Q scale) will also turn their head while being fed (No 6); refuse to eat (No 5); and leave food on the plate (No 4) etc.

Estimating the amount of food eaten

Residents who regularly eat less than half their food are at greater risk of weight loss. It is very important that care staff and other people assisting with feeding residents can reliably estimate the amount of food being eaten and report residents who aren’t eating at least half of their meals.

Studies undertaken overseas have shown that nurses and care staff have difficulty estimating the amount of food eaten by residents. Pokrywka et al found that nursing assistants frequently overestimated the amount of food eaten. In the most extreme instances, estimates were up to 63% incorrect, leading to failure to recognise residents at risk of weight loss due to undernutrition. One-third of residents at risk of undernutrition and weight loss were not identified.

Simmons & Reuben (2000) reported similar results. They compared different methods of estimating the food and fluid intake of 56 residents in one facility. They found that the facility documentation reflected a significant overestimate (22%) of residents’ total intake; and over half (53%) of residents participating in the study whose intake was reduced by 25% or more were not identified.

Pierson found that nursing assistants calculated the amount of food eaten by residents based on the perceived nutritional quality of the food, rather than the actual amount consumed. Therefore, if a resident ate all the protein (meat) for example it was recorded that half the meal was eaten, when in reality only one-third of the food offered was consumed. Simmons & Schnelle (2003) recommend using an experienced senior staff member to identify residents in need of nutritional interventions, due to the problems with the unreliable reports from nursing assistants.

Solutions to this problem include using photographs of meals to train nursing assistants to calculate the proportion of food consumed. Typical meals can be photographed with varying quantities of food items removed. Standardised training programs can be held regularly to ensure all new staff understand how to accurately record the amount of food eaten. Collecting data immediately after the meal is finished can make the data more reliable. Finally, only keeping records for a few days can improve the attention to detail.

Residents requiring an assessment of their food consumption should have a record kept for 24 - 72 hours.
Assessing for undernutrition

A variety of tools have been developed to assist clinicians assess residents for undernutrition. However, systematic reviews 73, 96, 97 of the relevant literature have highlighted that many tools used to screen or assess for risk of weight loss and undernutrition have not been subjected to validity and/or reliability testing, and may not be sensitive or specific enough for clinical use.

One tool, the Mini-Nutritional Assessment (MNA) 28, 98 has been extensively tested for validity and reliability, and the sensitivity and specificity have been examined 96. The MNA contains two parts, an initial six-question screening section, followed by an assessment section if the screening indicates the resident is at risk of undernutrition. Unlike some other tools, no pathology screening measures such as albumin or prealbumin are required to complete the MNA 99.

The Mini Nutritional Assessment Tool (MNA)® can be retrieved from the following website for use when assessing nutrition status: http://www.mna-elderly.com

An alternative tool suitable for use is the Nutritional Risk Screening System (NRS). The NRS was developed and tested in Australia, and is suitable for care staff with minimal skills to use. For ordering information, contact:

Ms Yvonne Coleman
Nutrition Consultants Australia
PO Box 16
Hawthorn VIC 3122

Email: vcoleman@nutritionconsultantsaustralia.com.au
Website: http://www.nutritionconsultantsaustralia.com.au

Weighing the resident

Residents should be weighed within 7 days of admission, then weekly for three weeks to establish a baseline weight and see if the weight is stable 43. The resident should be weighed on the same scale, at the same time of day, wearing similar clothing each time, and preferably before breakfast, although weighing the resident immediately before bathing or showering is also acceptable. The scales need to be calibrated regularly: monthly, or when they are moved 43.

Measuring the resident’s height

Measure the height of the resident. Do not rely on self-report or family member’s memory 43. If the resident is unable to stand to be measured, then calculate the height, using the formula provided, based on the length of the lower leg.

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1 MNA is a registered trademark of the Société des Produits Nestlé S.A.
To measure the length of the lower leg from the bottom of the heel to the top of the knee cap: sit the resident in a chair with bare feet flat on the floor. The knee joint should be at a right angles to the floor. Measure from the bottom of the heel on the floor to the top of the kneecap. Calculate using this formula:

For females:
\[
84.88 - (0.24 \times \text{age}) + (1.83 \times \text{knee height in cm})
\]

For example, Mrs Smith is an 82 year old. Her knee height is 47cm.
\[
(0.24 \times 82 \text{ (age)}) = 19.68.
\]
\[
(1.83 \times 47 \text{ (knee height)}) = 86.01
\]
\[
84.88 - 19.68 + 86.01 = 151.2 \text{ cm}
\]
Mrs Smith is 151.2 cm tall.

For males:
\[
64.19 - (0.04 \times \text{age}) + (2.02 \times \text{knee height in cm})
\]

For example, Mr Johnstone is 91 years old. His knee height is 55cm.
\[
(0.04 \times 91 \text{ (age)}) = 3.64.
\]
\[
(2.02 \times 55 \text{ (knee height)}) = 111.1.
\]
\[
64.19 - 3.64 + 111.1 = 171.6 \text{ cm}
\]
Mr Johnstone is 171.6 cm tall.

Calculating the resident’s body mass index (BMI)

Be aware that BMI measures are often inaccurate. Resident’s may have a BMI calculated that is within the ‘acceptable’ range, yet have lost significant weight, so do not rely on this measure alone. A slow decrease in BMI over time, until it is less than 19, may be a key indicator of undernutrition requiring assessment and discussion with the person responsible.

The BMI is calculated by dividing weight in kilograms by height in metres squared (m²).

For example, Mrs Smith (above) weighs 50kg, and is 1.51 metres tall.
\[
1.51^2 = 2.28.
\]
\[
50 \text{ (kg)} / 2.28 = 22 \text{ (21.9 rounded to next highest figure)}. \text{Mrs Smith has a BMI of 22 and is within the healthy weight range.}
\]

Mr Johnstone (above) weighs 53kg, and is 1.71 metres tall
\[
1.71^2 = 2.92.
\]
\[
53 \text{ (kg)} / 2.92 = 18. \text{Mr Johnstone has a BMI of 18 and is very underweight. He requires immediate assessment to understand the causes of his weight loss.}
\]

Numerous internet sites provide BMI calculators to instantly calculate a BMI. One site is:

Enter the height (in metres) and the weight, the BMI will be calculated for you.
Further assessment of unintentional weight is lost

If unintentional weight loss occurs then a more in-depth assessment is required, unless the agreed goals of care for the resident limit further assessment. Reversible causes of weight loss include fluid and electrolyte imbalance, depression, medications known to cause weight loss, chronic infections, hyperthyroidism, pain, and constipation which affects appetite.

Criteria for when to assess further are listed on the next page. Guidelines for monitoring and assessing weight loss are provided with this document. Consult the general practitioner at any time that weight loss continues despite any interventions you apply. An assessment for irreversible weight loss due to cachexia may be necessary.

Establishing whether the resident is cachectic is important. Latham (2001) investigated how district nurses cared for cachectic patients at home, and found that many did not understand the metabolic disorders that caused cachexia. The care the nurses gave centred around telling the patient to eat more, which put the patients under unnecessary pressure from both nurses and carers, and left the patient feeling unsupported.

It is imperative that a family conference be held (if not already done) if a resident is cachectic, to make sure the person responsible and other family members understand the irreversible nature of the weight loss, and review the goals of care.
SECTION FIVE: CRITERIA FOR WEIGHT LOSS

All residents with advanced dementia are at HIGH risk of weight loss. They therefore require their weight and BMI checked monthly \(^{43,102}\), unless the goals of care contraindicate this.

Further assessment of weight loss is required when \(^{43}\):

- A weight change of 5% in one month is noted;
- There is a decline in food intake over several days. If the change is abrupt it may indicate a medication side effect or onset of an acute illness \(^{43}\);
- If the BMI has slowly decreased to <19;
- If there is persistent, unintended weight loss for 3 consecutive months.
SECTION SIX: FEEDING INTERVENTIONS

Environmental and social factors

A systematic review examining feeding interventions has recently been undertaken by Watson & Green (2006) 73. They found that most studies describing feeding interventions have reported positive effects, although small sample sizes and varied statistical analyses made the data unreliable, and no meta-analysis could be undertaken. They concluded, however, that environmental factors are important when assisting a person with dementia to eat. Primarily, the use of music to create a relaxing atmosphere looks like it may be a promising intervention. Music with a ‘slow and soothing’ tempo is best. Watson & Green further suggested that seating arrangements and table layout could be reviewed to enhance the dining experience. Desai et al (2007) 103 trialled serving meals from bulk containers rather than a tray-service delivery style, and found that cognitively impaired residents with low BMI benefited most from the changed food service and physical environment, with their consumption of carbohydrates and protein increased.

Other suggestions to alter the environment and social interaction include 41, 43:

- ensuring that the environment in the room where meals are served is pleasant and conducive to eating, by trying to reduce noise, confusion, and distractions;
- having comfortable chairs and the table at the right height;
- having more than one meal sitting. Try multiple sittings for smaller groups of residents. Residents who are alert and can eat independently can be asked to help residents who need verbal cues to encourage them to eat. Having more than one meal setting will assist feeding as more staff will potentially be available for less residents;
- support residents with dementia to eat in ways that confirm their dignity and do not further isolate them. Mealtimes can cause great tension as non-demented residents may find the eating behaviours of people with dementia intolerable 74, leading to further social exclusion of residents with dementia. Socially isolated people eat less;
- using non-nursing staff and volunteers at meal times to help set up trays and enhance socialisation at mealtimes. This frees nursing staff to assist residents who need the most help with eating and those who can feed themselves if they receive verbal cues. Training family members to help feed selected residents may be useful. However, only properly trained people should feed residents with swallowing disorders;
- consider holding a happy hour before dinner, when residents may congregate and have an alcoholic beverage or other drink before their meal;
- using the smell of freshly cooked food as an enhancement to eat. For example, consider operating a bread-making machine in the dining area;
- having the residents well dressed and groomed, with seating to facilitate interaction;
- residents known to be agitated at meal times should be seated so that their area is defined and other residents do not impinge on it 104.
Individualise the resident’s meal as much as possible

Resident’s need to be offered nutrition that follows the 13345+ a food plan. Include daily:
1 serve meat, fish, poultry or eggs;
3 serves dairy foods (+/- fat);
3 serves fruit (fresh, canned, dried, stewed);
4 serves vegetables (fresh, canned, dried, stewed);
5+ serves bread or cereals (preferably high fibre);
6-8 cups fluids;
2+ serves indulgences (cake, wine, ice cream).

Simmons et al (2003) 105 surveyed the family members of 103 residents in 3 aged care facilities in California to find out what interventions they preferred for increasing the food and fluid intake of their loved ones. The top 3 interventions the family members preferred were to improve the quality of the food and fluids offered first; then improve the quality and quantity of feeding assistance as the second intervention; then offer multiple small meals throughout the day instead of 3 larger meals.

Other suggested ways to individualise the meals for residents are 41, 43:

• making every effort to ensure that all foods offered are attractive and palatable. Use garnishes, seasonings, and sweets, as appropriate, to enhance the appearance and taste of dishes;
• providing extra food at breakfast, when many cognitively impaired residents are more alert. Young & Greenwood (2001) 106 found that people with Alzheimer’s disease have a shift in their circadian rhythms, and consume most of their energy needs at breakfast time. Li (2002) 107 found that some people with dementia were more alert at lunchtime. Therefore, each resident needs reviewing and food offered to maximise their most alert times;
• offer the option of small, medium, and large portions at each meal;
• if possible, offer some flexibility for the times meals and snacks are offered. Scheduling meals and snacks at approximately 3-hour intervals between 6 a.m. and 9 p.m. allows residents to eat at the times they prefer;
• allowing residents to eat at their own pace;
• offering foods that satisfy the resident’s ethnic, regional, and personal preferences as well as their preferences for sweet, salty, or spicy foods;
• providing foods of a consistency and texture that allows comfortable chewing and swallowing;
• offering finger-foods, for example, chicken nuggets instead of fillets, potato chips (french fries) instead of mashed potatoes.

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Facilitating feeding at meal times

In a study reported by Amella (1999), specific behaviours shown by residents with dementia, such as being interested, involved, relaxed and co-operative, resulted in a reciprocal bond being formed with the nurse feeding the resident. As a result of this bond the resident received more food. Nursing assistants tended to be task-focussed, and not engage in processes that might encourage a reciprocal bond, such as bantering with residents and talking about their concerns. The more task-focussed the nurse was, the less food was consumed. In another study, Kayser-Jones & Schell (1997) found that nursing assistants changed their behaviour if they expected a resident would not be able to feed him/herself. The nursing assistants acted in a way that did not promote adequate intake or resident dignity.

To assist feeding difficulties for people with dementia, Amella (2004) suggests:

- use timing and pacing to respond to potentially negative behavioural cues. Provide meals when the resident is rested. Watch for fidgeting, restlessness, turning head or coughing. Watch that the resident swallows;
- optimise sensory input by using touch to redirect the resident if distraction is a problem. Remind the resident with dementia to keep the mouth closed, chew and swallow;
- make sure the resident is wearing his/her eye glasses and hearing aide;
- demonstrate expected activities, such as offering utensils and food in an unhurried way, lean forward while assisting the resident, then lean back after a few mouthfuls so the resident can rest. Model the behaviour you want by opening your mouth while feeding or assisting the resident to feed. Praise the resident, smile, keep conversation focused on the here and now;
- avoid traffic through the dining area, use solid plain plates on a plain darker coloured tablecloth to simplify the sensory input for the resident;
- position residents so they are sitting straight up with their heads tilted slightly forward;
- minimise time in the supine position straight after meals;
- for residents being given antipsychotic medication which dries the mouth, moisten foods with gravy or sauces;
- if the resident has a ‘sweet tooth’ and enjoys a treat like icecream for example, offer it at every meal. Try alternating a spoonful of icecream with a spoonful of other foods, or put a little icecream on the tip of the spoonful of meat or vegetables;
- residents with very advanced dementia may only want to eat the sweeter foods. If that’s the case, then provide these to them. The aim is to give food for comfort and pleasure, not to try to maintain a nutritionally balanced diet.

Individualising feeding assistance for residents

Ethical decisions relating to feeding may be required each time a person with dementia is approached at meal time. Residential aged care facilities often adopt different ‘cultures’ in relation to feeding issues, because they have no clear guidance or knowledge about the issues associated with feeding. It is necessary for each facility
to decide what constitutes ‘assisting a resident to eat’ and what constitutes ‘force feeding’, so nurses are clear about the care they are giving.

Manthorpe and Watson suggest reframing a subjective idea such as ‘refusing to eat’ into a more objective idea, based on the resident’s disease process. In this case, the care plan could be changed, so that the subjective issue ‘refusing to eat’ becomes the more objective concept of ‘the inability to translate a reflex or desire into swallowing of food’.

From their systematic review of feeding and dementia, Watson & Green concluded that no one single intervention will be applicable to all residents due to the distinct and cumulative pattern of feeding difficulties associated with dementia.

Simmons and Schnelle have found that approximately 50% of residents with low oral intake DO NOT increase their intake even when given appropriate feeding assistance at meal times. These residents respond better to being given between meal snacks. The researchers suggest a 2-day feeding trial to see which residents respond best to feeding assistance at meal times. During six meals (ideally breakfast, lunch and dinner on 2 consecutive days within the same week) residents should be given assistance as needed with their meals. If they do not improve their intake by at least 15%, they should be trialled with an intervention of increased snacks between meals.

Bear in mind that the resident has the right to refuse food eg by turning his/her head away. This is an expression of autonomy; the behaviour needs to be interpreted carefully. This behaviour is only of concern if the resident repeats it frequently and is losing weight.

Pasman et al studied nurses feeding people with dementia in residential aged care facilities. They observed that it was rare for nurses to discuss any feeding difficulties together with their colleagues. Therefore, each nurse interpreted aversive behaviour differently. Some stopped feeding when aversive behaviours were seen, while others continued trying to feed the resident. The authors recommend discussing the aversive behaviour with the family members as well as other facility staff, to try to determine the likely cause and how to manage the situation then consistently follow the management plan.

**Enriching foods and nutritional supplements**

For residents unable to eat large amounts, the best first option is to increase the energy content of the daily foods.

A consultation with a dietitian to develop a high-energy diet option to be served in the facility for residents at risk of weight loss is recommended. The cook and other kitchen/servery staff should be consulted during the development of the diet to ensure that the recommendations can be sustained. Developing a list of snacks with their energy content listed so that high-energy options can be chosen for residents at risk of weight loss is also useful.

Simple ideas for increasing the energy content of foods include:
• adding extra butter or margarine to mashed potato and other vegetables;
• adding cheese to mashed potato, pasta, casseroles, scrambled eggs;
• adding cream to desserts and porridge;
• adding skim milk powder to milk, soup, porridge, white sauce, cheese sauce, baked custard;
• offering additional finger foods.

A dietitian can provide suggestions that are appropriate for individual residents.

If these strategies are not successful in halting a resident’s weight loss, then commercially prepared oral liquid nutrition supplements can be trialled. A study by Young et al 111, 112 using nutrition supplements in residents with Alzheimer’s disease concluded that residents with low BMI are less likely to benefit from supplements than those with higher BMI; and residents who are more cognitively intact benefit more than residents with greater cognitive impairment. While the reasons for this finding is not clear, the key point is that if these supplements are to be used, they should be commenced early in the disease trajectory when weight is being lost, and not left until the resident is cachectic.

Systematic reviews of the literature relating to oral nutritional supplements have been completed in 2008 113, 114. Most studies reviewed were of poor quality. The authors found that frequently supplements were not given as prescribed; weight loss is not investigated before starting the supplements; supplements should usually be given between meals; and the supplements may cause a reduction in the amount of normal food consumed. These authors 114 recommend:

• investigating the causes of weight loss before commencing oral liquid supplements;
• include family members in the discussions about commencing oral supplements;
• nursing staff should provide assistance and encouragement to residents as they consume the supplements;
• monitor the response to the supplement: weight gain or loss, normal diet intake, bowel movements, wastage of the supplements.

Drinking and fluids

Providing fluids regularly as part of social activities as well as at meal times will increase the amount of fluids a resident drinks 2. Fluid can be provided in the form of soups, fruit juices, jelly, yoghurt, milkshakes and smoothies, chocolate drinks such as Ovaltine, Milo and Aktavite, and soup-in-a-cup 115.

Tips for increasing fluid intake 116:

• for residents who do not recognise a cup or glass placed on the table, put the glass in the resident’s hand and show him/her what needs to happen;
• milk and fruit drinks are more easily seen in clear drinking glasses;
• use small cups or tumblers, they are easier to manage;
• prompt the resident to remind him to drink regularly;
• develop strategies to promote hydration tailored to assist the staff giving care. eg if a staff member is undertaking an activity with residents, then incorporate regular drink breaks into the activity;
• cognitively impaired residents might respond better if they are offered a choice of drinks when being prompted to drink;
• use a colourful beverage cart to attract the attention of residents;
• frequent small sips of fluid can reduce the resident’s sensation of thirst and oral discomfort that is associated with dehydration.

Texture-modified foods and fluids for residents with dysphagia

When the texture of the diet needs to be changed the following aspects should be considered:

• residents with some swallowing problems may prefer finely chopped food instead of the more unpalatable pureed food. Discuss whether this is possible with the speech pathologist;
• a resident who is just starting to have swallowing problems may be able to tolerate a normal-textured diet in the morning, but by the evening when he/she is tired, may need to have a pureed meal;
• a resident who has difficulty swallowing may reject pureed or artificially thickened foods but may eat foods that are naturally of a pureed consistency, such as oatmeal, ice cream, yogurt, mashed potatoes, and puddings;
• residents receiving a texture-modified diet are often not offered between meal snacks eg while others are given scones they may not be offered an appropriate alternative, which contributes to their low energy consumption. Offer these residents snacks at the same times that other residents are offered them;
• refer to a speech pathologist for information relating to the correct feeding position for an individual resident with dysphagia, and the correct consistency of liquids required.

Logemann et al (2008) reported the results of a randomised controlled trial into three interventions for aspiration of thin liquids in 711 people with dementia or Parkinson’s disease (honey consistency liquids, nectar consistency liquids, and chin-down posture). Immediate elimination of aspiration on thin liquids occurred most often with liquids the consistency of honey, then on liquids the consistency of nectar, and finally a chin-down posture. People with the most severe dementia showed least effectiveness in all three intervention categories.

Full details of the Australian Standards for texture-modified foods and fluids are available from the Dietitians Association of Australia website: http://www.daa.asn.au/index.asp?pageID=2145849283
Decisions relating to stopping feeding

For some residents with very end stage dementia there may come a time that facility staff question whether they should continue feeding the resident due to the problems associated with either aspiration or aversive behaviours. This is an extremely complex ethical question. The whole care team: the person responsible and family members; facility nursing and care staff; general practitioner; and other consultants as appropriate including the speech pathologist, dietitian, palliative care services and other specialist consultants should be involved so that consensus is reached before feeding ceases. The wishes of the resident if known, his/her quality of life and other factors such as whether feeding still appears pleasurable, or causes distress, need to be considered.

Watson (2002) suggests that residents who are refusing to eat, or turning their heads away, should be gently encouraged to eat. However, residents who have reached the stage where they spit food out of their mouth, or allow the food to drop out, need to be discussed among the caring team. Continuing to feed this resident may be inappropriate. Encouraging a resident to eat, even though doing so distresses the resident, may constitute ‘force feeding’ and as such may be illegal as well as unethical.

Summersall and Wight (2006) use a pamphlet to describe the risks associated with swallowing problems, including the likelihood that the swallowing problems will become worse as dementia progresses, and will eventually become life threatening. In the event that a resident is assessed as level 3 in their scale of swallowing problems, and thus aspirating, the multidisciplinary team and family members meet to discuss whether small amounts of pureed food and thick liquids will be given orally, using maximum precautions. If this decision is made then deciding how, where, or if to treat the repeated chest infections that arise from aspirating is essential.

The alternative to continuing feeding is to place the resident on nil by mouth and implement an end of life management plan. Regnard and Huntley (2006), also writing in Hughes (2006) suggest that if it is thought that the resident will die within a few days then good mouth care to keep the mouth moist is sufficient care, as hunger is rare. They caution against stopping feeding too soon, as to do so may result in prolonged discomfort for the resident rather than a rapid deterioration towards death. The alternative to oral feeding is to use a medical intervention (treatment) and feed the resident via a nasogastric or gastrosomy tube.

Medical interventions to provide nutrition in end stage dementia

The issue of whether to provide enteral feeding to a person with advanced dementia having difficulties with feeding and swallowing should be raised with the person responsible and family members well before these problems arise, and discussions should continue on a regular basis. Making decisions during a crisis situation adds to the emotional burden for the person responsible or proxy decision-maker. Being pressured by time constraints can add to the dissatisfaction of the proxy decision-makers.
Enteral feeding via nasogastric tube, percutaneous endoscopic gastrostomy (PEG) tube or jejunostomy tube are medical treatments. In the context of end stage dementia decisions about medical treatments need to be made bearing in mind that the person with dementia has an incurable, terminal illness. The stage of dementia, likely prognosis, quality of life and benefits to the resident, previously expressed wishes of the resident, and the values of the resident need to be weighed against the burdens associated with the treatment.

Finucane et al (1999) reviewed the available evidence regarding the benefits and risks of tube feeding in people with advanced dementia. These authors found:

- no published studies suggesting that tube feeding can reduce the risk of aspiration pneumonia;
- uncertain evidence about whether tube feeding prevents undernutrition;
- no published studies suggesting that tube feeding can prolong survival in people with dementia and dysphagia;
- no published studies suggesting that tube feeding can improve pressure sore outcomes;
- no published studies suggesting that tube feeding can reduce the risk of infection in people with dementia and dysphagia;
- no published studies suggesting that tube feeding can improve function or reduce its decline in people with dementia and dysphagia;
- no published studies suggesting that tube feeding makes people with dementia and dysphagia more comfortable.

Furthermore, the presence of a feeding tube will strongly predict that the person will aspirate. Other literature reviews by Gillick (2000) and Garrow et al (2007) agree with the findings of Finucane et al, and suggest that careful hand feeding is a viable alternative to tube feeding. Hand feeding is more appropriate usually because the focus is on comfort rather than life prolongation. PEG feeding is usually not warranted in end stage dementia, and may interfere with the natural death process.

Risks associated with feeding tubes include peristomal infection; leakage; tube removal, displacement or migration; bleeding; gastric mucosal overgrowth or ulceration; metabolic and biochemical complications (eg refeeding syndrome: complications arising from giving nourishment to severely undernourished people); gastrointestinal symptoms such as nausea, abdominal cramps, constipation or diarrhoea; microbial contamination and infection of feed, and death.

Angus & Burakoff (2004) reviewed the literature relating to PEG tube placement in oncology, neurology and geriatric patients. They suggested that appropriate indications for inserting a PEG tube for these patients are:

- oesophageal obstruction (eg due to oesophageal cancer);
- neurologic aetiology of dysphagia without obstruction (eg post stroke, pseudobulbar palsy);
- prolonged refusal to swallow without evidence of concomitant terminal illness (eg protracted pseudodementia due to severe depression);
- supplemental nutrition for people undergoing chemotherapy or radiation therapy.
PEG tubes are not appropriate for use in anorexia-cachexia syndrome, and the health care team are under no obligation to offer this medical treatment. If tube feeding is to be started in a resident with advanced dementia then the best course of action is to limit the amount of time the feeding will be offered, so that it can be stopped if no benefits are seen. The decision to insert a feeding tube is ultimately the choice of the person responsible, who should act in the best interests of the resident. Family members are afraid that their loved one will experience hunger and thirst. Although it’s not known to what degree hunger and thirst are experienced by people in the final stages of dementia, studies with cancer patients have revealed that when they are dying they do not experience either hunger or thirst beyond that which can be relieved by mouth swabs or ice chips.

Lewis et al (2006) were interested in who made the decision to insert a tube when it occurred, and whether the family members received enough information. In over half (55%) of the cases the doctor made the decision. Lewis et al concluded that doctors may be justified in taking a more active role in feeding tube decisions. The family members want more information than is normally required to make an informed choice. Gillick & Volandes (2008) believe that some families and their treating doctors opt for artificial nutrition because the case for using a feeding tube is a moral one and not a scientific one. Families need to demonstrate their caring, and opt for a feeding tube as a way to symbolically show their concern and love for the person with dementia. Gillick & Volandes suggest acknowledging the symbolic value of nutrition for them, then find alternate means of satisfying their need to show their care than by feeding.

Mitchell suggests the following steps for decision-making if artificial feeding is being considered:

- clarify the clinical situation;
- establish the primary goal of care;
- present treatment options and the pros and cons of each choice;
- weigh the options against the values and preferences of the resident / family;
- provide additional and ongoing decision support.

A copy of the booklet ‘Making Choices: Long Term Feeding Tube Placement in Elderly Patients’ is available to download in PDF form from:

http://decisionaid.ohri.ca/docs/Tube_Feeding_DA/PDF/TubeFeeding.pdf

This booklet can be given to persons responsible and family members before a family conference to read so they are prepared to ask questions when a feeding tube is being considered for their loved one with dementia.
SECTION SEVEN: QUALITY IMPROVEMENT ACTIVITIES

Facility-wide strategies to improve the monitoring of weight loss and outcomes for residents with advanced dementia

In order to improve monitoring of weight loss and outcomes for residents, a number of strategies may be implemented by the facility. These include:

1. Form a weight loss working party to review ways of preventing weight loss and nutrition problems within the facility;

2. Build regular monitoring of weight loss strategies and evaluation into the regular quality improvement cycle in the facility;

3. Ensure staff have regular updates on weight loss programmed in to their regular education;

4. New staff need a comprehensive introduction to the weight loss philosophy and practice of the facility during their orientation. Give out policies and paperwork at this time, and ensure all staff are aware of their role in the prevention of weight loss and nutrition problems.

Standards of care:

1. Weigh residents every month unless they are losing weight. If losing weight, weigh weekly to monitor the interventions. Only stop weighing a resident if there has been a documented family conference, and the consensus opinion is that weight should no longer be monitored;

2. Review the nutrition care plan once a nutrition intervention has been trialled and evaluated;

3. All staff have a role in preventing weight loss, including ensuring residents receive sufficient fluids to prevent dehydration;

4. Family members can be encouraged to assist with feeding a resident and giving fluids, provided the registered nurse in charge is satisfied that they are able to safely do so;

5. Specify when a resident needs more comprehensive monitoring of their weight. For example, if a resident has had influenza, then additional weighing may be warranted for 2-3 weeks to ensure the weight is stable;

6. Menus should be varied and meals not repeated more than once every three weeks.
Education and Training:

- All registered nurses should be able to calculate the height of a resident unable to stand, and the resident’s BMI;
- All staff responsible for completing a food diary or weight loss chart should be trained in how to complete the form;
- All staff responsible for developing or implementing interventions used for weight loss should understand the interventions, and be competent in using them.

Quality improvement monitoring of nutrition care outcomes:

- All (100%) residents should have a nutrition needs assessment completed, and a review of the common causes of weight loss completed on admission prior to the nutrition care plan being developed.

Review and record at regular intervals:

- The % of residents who are losing weight, per the criteria listed in the framework;
- The % of residents who leave 50% or more of their meal;
- The % of residents who have been commenced on an oral liquid supplement without first having their weight loss investigated;
- The % of residents with advanced dementia who have their goals of care documented;
- The % of residents who have an advance care plan or documented discussion providing direction for how they want weight loss managed.

Quality Improvement (QI) audits

- Consider commencing auditing with a select number (eg 5-10) resident files per month;
- Summarise the results, determine whether additional education or training is required;
- If progress is satisfactory, change monitoring to quarterly and monitor a select number eg 15-20 resident files per quarter;
- If progress is not satisfactory, continue monthly audits until the results are acceptable;
- Continuously monitor and summarise the results, provide feedback and further education to the care staff as necessary.
SECTION EIGHT: CONSENT AND CAPACITY ISSUES

Refer to your facilities’ policies and procedures relating to consent and capacity.

Capacity to give informed consent.

Before medical or dental treatment is provided to a resident, there is professional and legal responsibility to obtain consent for the treatment. Verbal consent is required: in most instances involving advanced dementia, a proxy will be required to make substitute consent (see below). Ensure that clear documentation of the consent process is made in the resident’s records.

Key points relating to capacity to give informed consent:

- it is presumed that a person has the capacity to make their own healthcare decisions unless proven otherwise, (similar to the presumption of innocence until proven guilty);
- an abnormal Mini-Mental State Examination (MMSE) score alone does not equal incapacity;
- evidence of incapacity should not be based on ignorance. The individual whose capacity is being assessed must be given relevant information;
- careful documentation is required, especially for borderline cases;
- competency to consent to medical treatment by an individual is a legal concept and legal decision, made finally by a court of law. To assess the capacity of individuals to consent to their own medical treatment is a time-consuming but necessary process.

A person who has the capacity to give consent to medical treatment should be able to:

- express in his or her own words what the problem is;
- express in his or her own words what the treatment choices are, including “do nothing”;
- express in his or her own words what the foreseeable consequences of each treatment might be;
- all of the above must not be based on delusional ideas.

Incapacity is present if a person:

- does not know what the issue is; OR
- does not know the possible choices; OR
- does not appreciate the reasonably foreseeable consequences; OR
- the decision is based on a delusional construct; AND
- cognitive or mental impairment is present.
Substitute consent

In NSW, the Guardianship Act 1987 establishes who can give valid substitute consent if an individual is incapable of doing so. A substitute decision-maker can be the 'person responsible' or a guardian: either an Enduring Guardian appointed by the person when they had the capacity to do so, or a guardian appointed by the Guardianship Tribunal.

The Guardianship Act 1987 identifies four levels of treatment: urgent; major; minor; and special treatment. Urgent treatment (aimed at saving a person’s life) may proceed without valid substitute consent; all other treatment requires valid substitute consent. (See the Guardianship Tribunal website www.gt.nsw.gov.au for full details).

Key points relating to valid substitute consent:

- a ‘person responsible’ (in order of hierarchy) may be a guardian or enduring guardian who has the function of consenting to medical, dental or health care treatments; or the most recent spouse or defacto spouse with a close continuing relationship with the person; or an unpaid carer who is providing or was providing care to the person prior to admission to the residential aged care facility; or a relative or close friend who has close personal contact with the person;
- the ‘person responsible’, including an enduring guardian, cannot override a person’s objections to treatment if they are objecting;
- ‘persons’ responsible’ are required to act in the best interests of the person they are responsible for, and need to take the person’s previously expressed wishes into account but MAY act contrary to those previously expressed views if the action is in the best interest of the person;
- for minor treatment, if the person is NOT objecting, but the person responsible cannot be located, the doctor or dentist may treat without consent and clearly document in the resident’s notes that the treatment was necessary to promote the resident’s health and well-being, and that the resident did not object. Treatment may not proceed if the person is objecting.

A doctor may make an application to the Guardianship Tribunal to consider consent to a treatment if the guardian or ‘person responsible’ is objecting to the proposed treatment.

When is a person objecting to treatment?

Treatment may not be instituted if the person objects.

Key points:

- objection is considered to be continuous and strenuous refusal;
- the behaviour of the individual will need to be interpreted;
- if verbally refusing, while physically doing what is required eg accepting and swallowing oral medication, but saying “no”, then that is not considered to be continuous and strenuous refusal;
- if both verbally refusing to have the treatment (eg, saying “no, no, no”) AND physically resisting to the treatment (eg clenching mouth so medication cannot be given), then that is evidence of continuous and strenuous refusal.
TREATMENT MAY NOT PROCEED, EVEN IF THE PERSON RESPONSIBLE HAS GIVEN CONSENT. The Guardianship Tribunal will need to be contacted to consent to the treatment despite the objections.
SECTION NINE: FAMILY CONFERENCES AND DEVELOPING PLANS OF CARE

Planning care for a resident by holding a family conference has two-fold benefits. Firstly, by discussing the goals of care for the resident the outcomes for the resident may be improved. Secondly, relationships between all the caregivers may improve by having everyone meeting together. The general practitioner (GP) can be paid under Medicare Item Numbers 734, 736 or 738 if he or she organises and coordinates the conference, or items 775, 778 or 779 if he or she participates in a conference (not more than 5 in twelve months).

When to hold a family conference

- Newly admitted resident to determine the goals and plan of care;
- as part of the annual ACFI review;
- whenever an unforeseen significant change in the resident’s medical condition has occurred.

Tips for increasing the participation of the general practitioner in family conferences

Organising a family conference is time consuming, and it may be difficult for the GP to organise, or attend. To increase the chance that the GP will participate, the following tips may be useful:

- reduce the administrative burden on the GP. Contact the GP’s surgery and try to use the Practice Manager or Practice Nurse to assist with the planning;
- try to fit the family conference in at a time when the GP is already visiting the facility;
- always give the GP the option of participating when you are organising a family conference. If he or she wants to participate, try to work out any barriers to involvement so he or she can contribute;
- offer the GP different levels of involvement eg the GP may be willing to be involved in a 10-15 minute teleconference instead of attending in person;
- when contacting the GP’s office, remind the receptionist that you want to talk about one of their patients eg “I want to talk to Dr X about Mrs X”. Be specific, this may assist in getting past the 'gatekeeper';
- think about the care of the resident being the GP’s responsibility, so the Practice Nurse may be useful. If you tell the Practice Nurse about concerns you have about a particular resident, and the need for a family conference, the Practice Nurse may be willing to raise the issues with the GP on your behalf;
- define the GP’s role in the family conference, be very specific about what you want to achieve from the family conference. GP’s prefer family conferences when they occur at specific difficult points in the disease trajectory of a resident;
- make sure all the lines of communication are clear to both GP and facility staff.
Steps in holding a family conference

To ensure the GP is remunerated for his or her coordination of and/or participation in the family conference, the following steps are required to be performed:

1. Identify the resident’s need for a family conference;
2. Contact the GP’s Practice Nurse or Practice Manager to assist with coordinating the family conference, and be the single point of contact for all attendees;
3. The Practice Nurse or Manager will consult with facility staff and determine which health professionals will be involved. NB, there must be 2 other healthcare providers present at the family conference, as well as the GP. These providers can be a nurse and a diversional therapist from the aged care facility, but could be another health service provider such as a physiotherapist, or speech pathologist, palliative care specialist or geriatrician. The other health service providers may charge a fee for their attendance;
4. Arrange a time, preferably at least 4 weeks in advance for an annual review, or as soon as possible after an unforeseen significant change in the resident’s medical condition;
5. Develop an agenda and an introduction letter, the coordinator will then send these to participants;
6. The resident’s consent is required, or if unable to give consent, the person responsible’s consent. Verbal consent is all that is necessary. Ensure that the resident/person responsible understands there will be a Medicare charge generated for the GP’s involvement, and other health service providers may also charge for their time;
7. Conduct the family conference. All members of the family conference team must participate for the whole of the conference. The conference may be face to face, or via telephone, video link, or a combination. Issues to discuss include:
   - The resident’s medical history;
   - Review of the previous goals and plan of care;
   - Identify current multidisciplinary care needs;
   - Identify the outcomes to be achieved by members of the multidisciplinary care team;
   - Identify tasks that need to be undertaken in order to achieve outcomes and allocate tasks to team members;
   - Identify whether previously identified outcomes have been achieved.
8. A record of the family conference must be kept in the resident’s records, and a copy offered to the resident/person responsible, and other health service providers (with the consent of the resident/person responsible).

What to discuss during a family conference for a resident with advanced dementia

A number of decisions relating to the future care needs of a resident can be made in advance of their occurring, and can be included in a family conference discussion. One study of death from dementia has revealed that:
85% of people with dementia die before the very end stage of dementia is reached; death, regardless of when it occurs, is most commonly associated with cachexia/dehydration (35.2%), cardio-vascular disorders (20.9%), and acute pulmonary diseases such as pneumonia (20.1%); over half of residents who reach the very end stage of dementia will die of cachexia/dehydration; approximately 9% of people with dementia die of an unknown, acute cause.

Therefore, in discussing the goals and plan of care for a resident with advanced dementia, the following issues could be included on the agenda:

- the typical trajectory of dementia;
- the symptoms the resident is currently experiencing that are causing distress, and how they will be managed;
- the likelihood of symptoms that may occur in the future, and how each will be addressed;
- the benefits and burdens of any treatments should be clearly articulated so decisions made about current or future care are based on objective information:
  - urinary incontinence; repeated urinary tract infections;
  - gait disturbances that leave the individual at high risk of falls; injuries resulting from falls;
  - pneumonia;
  - swallowing problems: pouching of food, dysphagia;
  - feeding issues and aversive feeding behaviours;
  - weight loss due to cachexia;
  - dehydration;
  - risk of decubitus ulcers;
  - aspiration pneumonia;
  - anxiety, agitation, aggression, depression, psychotic symptoms;
  - loss of ability to communicate verbally, and how symptoms such as pain are recognised and treated;
- the family member’s role in care;
- the site of care: a palliative approach to care given in the facility; times when transfer to hospital may be necessary; curative treatments offered in hospitals;
- cardiopulmonary resuscitation (CPR);
- medically provided nutrition and hydration (PEG feeds, subcutaneous hydration);
- blood transfusions;
- antibiotic therapy: in the facility/ in hospital (via intravenous infusion), and whether or not to give antibiotics or/and palliate symptoms with analgesics, antipyretics, sedatives.

The person responsible needs to make decisions based on either the known or probable wishes of the resident; or what is in the ‘best interest’ of the resident: the relative benefits and burdens of a particular treatment choice in terms of the ability to relieve any suffering and maintain comfort and dignity and the best possible quality of
Nurses can assist persons responsible by reassuring and encouraging them to think of times when there were conversations about what the resident might have wanted, so that the known or probable wishes of the resident become clearer.

Conflicts are most likely to occur around two main issues - aspiration pneumonia and neurogenic dysphagia. Many clinicians and families find it harder to discontinue a therapy than to withhold it in the first place, so it is particularly important that the person responsible is aware of the burdens and benefits of medical interventions such as PEG feeds. In some instances, it may be easier to institute a trial intervention for a specific time frame eg a trial of oral antibiotics for one week for repeated urinary tract infections, which can be discontinued if unsuccessful. Research in NSW has shown some evidence that residents have an increased survival rate if their plan of care opts for them remaining in an aged care facility rather than transfer to hospital for care, compared to those without a plan of care.

Facility staff not involved in the development of the plan of care during the family conference need to be informed of the outcomes, and be given the opportunity to discuss any decisions they find ethically challenging, so that consensus about the goals of care are reached, and potential for conflict avoided.

**General practitioner contribution to a care plan**

A GP may contribute to the care plan of a resident, and be paid under Medicare item no. 731. The recommended interval between reviews is 6 months, but may be 3 monthly. To ensure the GP is remunerated, the following steps need to be undertaken:

1. Invite the GP to contribute to the ‘nursing and personal care plan’ of the resident;
2. The resident or person responsible need to be informed that the GP will be consulted, and consent recorded;
3. Provide the GP with the resident’s notes, to review alongside the GP’s own patient notes;
4. The GP will contribute to the care plan by discussing it with facility staff and giving any additions, changes or other recommended management;
5. The fact that the GP contributed to the care plan is documented on the care plan in the facility;
6. The GP is also required to document in the resident’s medical records that he or she has contributed to the care plan. The documentation may just be a date, signature, and comment that a contribution to the care plan has been made, but it is also recommended that the GP includes a brief summary of recommendations;
7. Facility staff may write detailed notes into the care plan after verbal discussion with the GP;
8. Once an Item 731 has been claimed by the GP, and it is documented that the resident requires Allied Health or dental services the resident may be eligible for access to up to 5 Allied Health and 3 Dental care services per year.
SECTION TEN: REFERENCES


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SECTION ELEVEN: ANNOTATED BIBLIOGRAPHY


A copy of this paper can be accessed for reading from: http://www.eatright.org/ada/files/Liberalizednp.pdf

This paper reviews the evidence relating to the use of therapeutic diets for residents in long-term care institutions, and recommends those diets that can be liberalized so the resident can enjoy a more normal diet. This paper would be useful to show general practitioners who may be hesitant to liberalise a resident’s diet; and to discuss with family members during your discussions about the provision of food and fluids to a resident.

2. Best Practice Information Sheet ‘Oral hygiene care for adults with dementia in residential aged care facilities’

3. Best Practice Information Sheet ‘Identification and Nursing Management of Dysphagia in Adults with Neurological Impairment’

A copy of these information sheets can be accessed from the Joanna Briggs Institute website: http://www.joannabriggs.edu.au/pubs/best_practice.php

Joanna Briggs Best Practice Information Sheets provide up-to-date summaries of the available best-practice evidence, suitable for nurses. They are useful to review when planning inservice education for nurses and care staff.


This site contains a number of ‘Help Sheets’:

- See ‘Help Sheet No 3: Quality dining room service’ for further information regarding creating a pleasant environment for eating in residential aged care facilities;

- See ‘Help Sheet No 7: Appropriate meal sizes for residents’ for further information regarding meal sizes for residents in aged care facilities;
• See ‘Help Sheet No 15: Catering for people from culturally diverse backgrounds’ for additional information about providing culturally appropriate foods;

• See ‘Help Sheet No 9: Promoting independence at meal times’ for further information relating to individualising feeding assistance;

• See ‘Help Sheet No 14: Drinking and fluids: maintaining hydration’ for further information regarding fluids and hydration;

• See ‘Help Sheet No 13: Catering for residents with swallowing problems: texture-modified diets’ for further information about catering for residents with swallowing problems.

These Help Sheets will be useful for many different staff in residential aged care facilities. They are clear, concise and provide useful tips to improve the quality of life of the resident.


This paper describes a feeding trial to determine which residents respond best to feeding assistance at meal times. The trial is described in sufficient detail that a facility could copy the procedure. This paper would be useful for a quality improvement team to review and possibly follow when considering food provision in a facility.


These guidelines provide comprehensive information to assist doctors and nurses discuss prognosis and end of life issues with people with eventually terminal conditions, and their caregivers. These guidelines would be very useful to use as part of education sessions relating to communicating difficult issues. Topics included in the guidelines are timing of discussions, preparation, setting, how to discuss prognosis and end-of-life issues, facilitating hope, commencing or changing treatments, discussing future symptom management, discussing the process of death and dying, managing conflict, and discussing medically futile treatments.

The guidelines can be retrieved for use from:

7. North West Melbourne Division of General Practice. GP and Residential Aged Care Kit. Clinical Information Sheet: Pneumonia; and


These information sheets were written to assist general practitioners and nurses in residential aged care facilities involved in the care of residents with two common causes of infection in aged care facilities: pneumonia and urinary tract infection. The information contained in each sheet includes background information about the issue, assessment, investigations and management of the infection. Information enabling the clinician provide palliation of symptoms is also included.

The information sheets can be retrieved for use from:

http://www.nwmdgp.org.au/pages/after_hours/GPRAC-CIS-12.html (pneumonia) and