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Mealtime Management for Nurses -Practice Package

Summary: The package has been designed to provide information on the Mealtime Management for Nurses that guides nurses when working with people with disability in order to promote consistent and efficient best practice. It outlines current principles around good practice in the Mealtime Management for Nurses.

Document approval

Mealtime Management for nurses has been endorsed and approved by:

Signature on file David Coyne Executive Director Approved: 7 October 2014

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1. INTRODUCTION

1.1 Introduction and purpose

Welcome to the Mealtime Mangement for Nurses Core Standard. This resource was developed by Clinical Innovation and Governance, within Ageing, Disability and Home Care, Department of Family and Community Services, New South Wales, Australia (FACS).

This practice package has been developed to support nurses who are working with people and their families who support people with a disability. It has been designed to provide information on the Mealtime Management for Nurses that guides nurses when working with people with disability in order to promote consistent and efficient best practice. It outlines current principles around good practice in the Mealtime Management for Nurses. This practice package is designed to complement organisations policies and procedures, rather than replace them.

This practice package can be used in a number of different ways:

- As a basis for self directed learning
- As part of core standards learning
- For reference and clarification
- For part of the induction of new staff
- In conjunction with professional supervision
- With student nurses in placements
- With other professions and disciplines

This practice package forms part of the supporting resource material for the core standards program developed by Clinical Innovation and Governance. Please note that some of the information contained in this package is specific to all practitioners working with people with a disability in New South Wales, Australia.

1.2 Common core standards

FACS has developed four practice packages that support the common core standards for practitioners who provide support to people with a disability. These are located on the FACS/<u>ADHC website</u>.

The common core standards cover the following areas for practitioners who support people with a disability:

- Professional Supervision
- The Working Alliance
- Intellectual Disability: Philosophy, Values and Beliefs
- Service Delivery Approaches.

1.2.1 Nursing and Health Care Practice Packages

The following Nursing and Health Care practice packages have been organised according to the order they should be read. The information is further organised according to domains of practice within those standards as follows:

- Person-Centred Health Care Assessments and the Development of Health Care Plans Practice Package
 - Health Assessment
 - Health Planning
- Communication and Behaviour Support Practice Package
 - Communication
 - Behaviour Support
- Working with People with Chronic and Complex Health Care Needs Practice Package
 - Health Care and Support
 - Teaching and Coaching
 - Advocacy and Co-ordination
 - Education, Research and Evaluation
- Mealtime Management Practice Package for Nurses
 - Nutrition for Health and Wellbeing
 - Managing Dysphagia
 - Enteral Nutrition

These core standards represent fundamental areas of knowledge, skills and attitudes required by Registered and Enrolled Nurses when working with people with disability, their families and carers. The standards are not intended to restrict practice nor imply boundaries. Rather, they are intended to enhance core skills that underpin practice. Information presented in this practice package provides access to key information and resources thus contributing to FACS's knowledge translation program.

The Nursing and Health Care Core Standards are intended to provide information that is particularly useful to Registered and Enrolled Nurses new to the area of practice in disability. These may include:

- FACS staff
- NSW Health staff
- non-government agency staff (NGO)
- practice nurses working with GPs
- nurses working in specialist clinics
- private agency staff
- nursing students.

Practice contexts include:

- family homes
- general practitioner surgeries (GPs)
- residential/accommodation services
- community health services
- specialist teams
- hospitals
- nursing hom

1.3 Copyright

The content of this package has been developed by drawing from a range of resources and people. The developers of this package have endeavoured to acknowledge the source of the information provided in this package. The package also has a number of hyperlinks to documents and internet sites. Please be mindful of copyright laws when accessing and utilising the information through hyperlinks. Some content on external websites is provided for your information only, and may not be reproduced without the author's written consent.

1.4 Disclaimer:

This resource was developed by the Clinical Innovation and Governance Directorate of Ageing, Disability and Home Care in the Department of Family and Community Services, New South Wales, Australia (FACS).

This practice package has been developed to support practitioners who are working with people with a disability. It has been designed to promote consistent and efficient best practice. It forms part of the supporting resource material for the Core Standards Program developed by FACS.

This resource has references to departmental guidelines, procedures and links, which may not be appropriate for practitioners working in other settings. Practitioners in other workplaces should be guided by the terms and conditions of their employment and current workplace.

Access to this document to practitioners working outside of FACS has been provided in the interests of sharing resources. Reproduction of this document is subject to copyright and permission. Please refer to the website disclaimer for more details.

The package is not considered to be the sole source of information on this topic and as such practitioners should read this document in the context of one of many possible resources to assist them in their work.

Whilst the information contained in this practice package has been compiled and presented with all due care, FACS gives no assurance or warranty nor makes any representation as to the accuracy or completeness or legitimacy of its content. FACS does not accept any liability to any person for the information (or the use of such information) which is provided in this practice package or incorporated into it by reference.

2. The Definition of Disability

In order to understand how the conceptualisation of disability has changed, it is first important to define what disability is.

<u>The Disability Discrimination Act 1992</u> (Australasian Legal Information Institute, 2010) defines disability as:

- total or partial loss of the person's bodily or mental functions
- total or partial loss of a part of the body
- the presence in the body of organisms causing disease or illness
- the malfunction, malformation or disfigurement of a part of the person's body
- a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction
- a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment, or that results in disturbed behaviour and includes a disability that:
 - presently exists
 - previously existed but no longer exists
 - may exist in the future
 - is imputed to a person (meaning it is thought or implied that the person has disability but does not). (AustLII, 2010)

Please note that the target group of people with disability is under review in the Disability Inclusion Bill (2014).

There are many different causes of disability for example accidents, illness or genetic disorders. A disability may affect a person's movement, their ability to learn, or their ability to communicate. Some people have more than one disability. Although some people are born with disability, many people acquire a disability. Not all disabilities are permanent and conditions which cause disability increase with age (Australian Network on Disability, 2013).

2.1 The definition of intellectual disability

A person has an intellectual disability if they have the following:

1. An IQ that is 2 standard deviations (SD) below the mean (approx. 70, as average IQ is 100 and the SD is 15) and:

2. A significant deficit in at least one area of the following domains of adaptive functioning:

- conceptual domain- reading writing, reasoning and knowledge
- social domain empathy, social judgement and making friendships
- practical domain personal care, daily living skills.

3. These problems must be manifest in the developmental period.

(American Psychiatric Association, 2013)

Based on the functional deficits, intellectual disability can be mild, moderate or severe and factors such as personality, coping strategies and the presence of other disabilities (motor, social or sensory) will influence a person's requirement for support with daily living.

(Centre for Developmental Disability Health, 2013)

3. Mealtime Management

Mealtime Management is essential to health care practice in the field of intellectual disability because of:

(i) the prevalence of malnutrition that results in underweight and obesity, and lack of nutrients, and

(ii) the incidence of dysphagia that results in high rates of aspiration, pulmonary infection and death.

The Nursing and Health Care Standard, Mealtime Management, is addressed under the domains of:

- Nutrition for Health and Wellbeing
- Managing Dysphagia.
- Enteral Nutrition

3.1 Nutrition for Health and Wellbeing

Good nutrition is essential for growth and development, for cell and tissue repair, for daily activities, and to keep people healthy, happy and well.

Nutrition refers to taking in and using fuel in the body. It is a complex, three-part process where:

- 1. food and drinks are consumed (eating and drinking)
- 2. the body breaks down food and drink into nutrients (digestion)
- 3. nutrients travel through the blood stream to body tissues and organs to be used as energy, and for growth and repair (absorption).

Nutrition then refers to more than just food and drink.

For effective nutrition to occur, people:

- must take in food and fluids that will provide enough energy and key nutrients for growth and repair
- must have a digestive system that works properly
- need healthy body systems to transport and absorb nutrients to be used by the body.

Good nutrition is also related to enjoyable sensual and social experiences, and is dependent on socioeconomic factors.

3.1.1 Nutritional Risks for People with Disability

Refer also to the Working with People with Chronic and Complex Health Care Needs - Practice Package. Section 3.1.1 Management of Dysphagia for complementary information.

People with disability frequently have associated disorders that interfere with nutrition in terms of intake, digestion or absorption of nutrients. They often require

assistance from others for nutritional planning, and some are dependent on others for eating and drinking. They also confront lifestyle risks, especially when mobile and having greater levels of functional independence.

The incidence of obesity is higher, particularly and when mental illness, intellectual disability, and limited mobility interact.People with Down syndrome and women are more likely to be obese. However, undernutrition is also a significant risk particularly for people with dysphagia and severe physical limitations such as spastic quadriparesis. Vitamin and mineral deficiencies (e.g., iron, vitamin D, folate) are common.

The relationships between intellectual disability, mental illness, complex medical conditions, nutrition, wellbeing, illness, and quality of life are multifaceted. However, greater understanding of the centrality of nutrition for health and wellbeing, along with improved technologies for nutritional support, have the potential to reduce the chance of people with disability being severely underweight or obese.

Following are some common nutritional problems and risks for people with disability.

Appetite problems. *Anorexia* (poor appetite) – may be associated with illness, medications, pain, constipation, disease, depression, grief, oral problems, stressful environment, and many other factors.

Polyphagia (big appetite) – may be associated with medications, Prader-Willi syndrome, enjoyment of food, stress and anxiety, boredom, poorly controlled diabetes, and many other factors.

Problems with the regulation of appetite may lead to:

- malnutrition
- lack of energy, lethargy, etc.
- obesity
- type 2 diabetes
- binge eating
- bulimia nervosa (binge eating and purging)
- anorexia nervosa (obsessive fear of gaining weight)
- cachexia (a wasting of the body seen in cancer, chronic lung disease and other diseases).

Undernutrition occurs when the body does not get enough energy or nutrients for good health, or is unable to utilise energy or nutrients because of digestive problems or illness. Undernutrition (malnutrition) may result in starvation.

Causes of undernutrition include:

- increased energy requirements e.g., hypertonia (spasticity); excessive drooling; following illness, etc.
- digestive problems digestive chemicals (saliva, enzymes, etc.); delayed gastric emptying (GORD, nerve damage, smooth muscle disorders, medications, diabetes, inflammation, etc.); problems with peristalsis (too slow; too fast)

- absorption problems malabsorption (of food or specific nutrients) occurs with coeliac disease, lactose intolerance, Crohn's disease, liver disease, parasite infection (e.g., *Giardia*), some medications
- swallowing problems
- poor food variety and balance
- high kilojoule, low nutrient foods (junk foods) people can be obese but malnourished at the same time.

Medications are a risk factor for poor nutritional status. They may influence food intake, as well as the digestion, absorption and metabolism of nutrients.

Overnutrition and obesity. Overnutrition may result in overweight and obesity, as well as other disorders related to specific nutrients, such as cardiovascular disease (linked to high dietary fats) and type 2 diabetes (linked to excess refined carbohydrates).

People with disability have a higher prevalence of overweight and obesity than the general community. This places them at even greater risk for further health problems such as cardiovascular disease, osteoarthritis, sleep apnoea, type 2 diabetes, reproductive problems, psychological problems.

Neurological impairments that affect eating and drinking will have an adverse impact on nutrition. Neurological impairments may affect:

- muscle tone and movement posture, hand grip, intentional movement, drooling
- oral-facial hypersensitivity
- chewing and swallowing problems dysphagia and aspiration

Reflux and gastro oesophageal reflux disease (GORD) are common and have a significant impact on nutrition. Oral and peptic ulcers are often associated. Pain and discomfort may cause loss of appetite or sometimes wanting to eat all the time.

Adverse food reactions. Food intolerance and food allergy, along with autoimmune disorders, have an impact on the digestion and absorption of nutrients. These include:

- GI problems
- pharmacological reactions, e.g., salicylates (tomatoes, strawberries), amines, preservatives
- metabolic disorders, e.g., PKU, lactose intolerance
- coeliac disease an autoimmune disorder resulting in gluten intolerance.

People on restricted diets because of adverse food reactions need to be especially careful to eat a balanced diet to maintain good nutrition.

Physiological digestive disorders include:

- irritable bowel syndrome (IBS)
- inflammatory bowel disease (IBD) includes Crohn's disease and ulcerative colitis.

Weight loss and malnutrition can be dramatic.

Communication problems and dependence on others lead to problems with the communication of hunger and thirst, as well as information about food preferences. People with disability are dependent on others to a greater or lesser extent. Nutritional support may vary from guidance and assistance with healthy food choices and preparation to total dependence on others who need to ensure adequate nutrition and hydration.

Lack of education and knowledge about healthy nutrition on the part of support staff have been identified as significant factors contributing to obesity rates of people with disability living in supported accommodation.

The <u>NSW Ombudsman's Reviewable Disability Deaths Team</u> has documented cases of preventable deaths associated with inadequate nutrition and hydration. These deaths of people with disability in accommodation services have been attributed to staff and systemic neglect.

3.1.2 Outcomes of Poor Nutrition

There are many adverse outcomes of poor eating and drinking practices and inadequate nutrition. Such outcomes apply to the general population, but are prevalent in people with disability who experience poorer health than the general population.

Outcomes of poor nutrition include:

- failure to thrive
- compromised growth and development
- malnutrition
- undernutrition
- obesity
- metabolic syndrome
- nutrient deficiencies
- impaired immunity and increased susceptibility to infection
- type 2 diabetes
- hyperlipidaemia
- hypertension
- cardiac disease
- stroke
- cancers

- diarrhoea
- constipation
- urinary tract infections
- oedema
- osteoporosis
- musculoskeletal disorders
- reduced respiratory muscle function
- sleep apnoea
- infertility
- oral problems
- eye problems
- decreased energy, reduction in participation
- psychological problems

Some of these health conditions are not necessarily always caused by nutritional problems – some people will develop the conditions even though they eat well and lead very healthy lives. However, the associations are strong. The development of many of the listed problems is the result of a complex interaction of genes and the environment. Many people have a genetic predisposition to a specific health condition (e.g., type 2 diabetes, hyperlipidaemia) which will become a problem in a particular environment such as poor nutrition.

3.1.3 Assessment of Nutrition

A multidisciplinary approach is often needed to asses nutritional problems in people with disability.

Body (anthropomorphic) measurements are the first steps in establishing underweight or overweight. These include:

- weight
- height
- BMI
- waist circumference
- skinfold thickness

When height cannot be measured accurately, BMI cannot be calculated. However, subcutaneous fat indicates significant underweight or obesity. Waist circumference and skinfold thickness provide information. *Serial measurements and recording*are an essential tool in assessing weight loss and gain, and for assessing the efficacy of interventions. In many circumstances, Nurses are responsible for ensuring this is done.

GP assessment includes identification of clinical disorders that may be associated with undernutrition or overnutrition, e.g., GORD, malabsorption, depression, constipation, anaemia, reduced immunity, insulin resistance, type 2 diabetes, pain.

Blood biochemistry assists in the assessment of nutritional disorders. For example, people at risk must be monitored for low calcium and vitamin D which is associated with osteoporosis, and low iron and haemoglobin (Hb) which are associated with anaemia.

Medication assessmentmay help in identifying sources of weight gain. Some drugs used by people with disability induce weight gain (e.g., some AEDs and antipsychotics).

DEXA (dual energy X-ray absorptiometry) scans measure bone mineral density. Low bone density indicates osteoporosis that may be related to nutritional problems.

Endoscopy visualises the gastrointestinal tract and may assist in the diagnosis of disorders such as GORD, ulcers, ulcerative colitis, etc.

Dietary assessment by a Dietitian for nutritional and energy (kilojoule intake).

Swallowing assessment by Speech Pathologist who will advise about additional investigations.

Positioning, support and eating technique assessment by Physiotherapist, Occupational Therapist, Speech Pathologist to ensure optimal positioning, support and equipment for effective and safe eating and drinking.

Assessment of physical activity by Physiotherapist to assist with estimates of energy requirements. Dietitian can then make any necessary adjustments.

Dental assessment to address oral concerns, e.g., gingivitis and sore gums often prevent eating and adequate nutrition.

3.1.4 Healthy Nutrition

Variety and balance are the keys to healthy nutrition and enjoyable eating. Nutrition must be based on the recommendations in the NHMRC's <u>Australian Dietary</u> <u>Guidelines (2013)</u>. The website has useful information and resources for healthy eating across the lifespan. The <u>Australian Guide to Healthy Eating Poster</u> is available from the website and is a useful reminder for staff and for people living in supported accommodation. Community staff can direct families to the resources available there.

Comprehensive guidance regarding nutrition, eating and drinking, and food management, is available in the <u>FACS:ADHC Nutrition in Practice Manual</u>. This manual assists support staff to develop simple eating and drinking plans for people with minimal eating and drinking problems.

An excellent resource, <u>Good Food</u>, <u>Good Living: Nutrition for People with Disabilities</u> <u>Living in Supported Accommodation</u>, is available from <u>Greystanes Disability</u> <u>Services</u>. This resource shows how to put the 'Australian Dietary Guidelines' and the 'Nutrition in Practice Manual' into practice. It is an interactive guide and learning package for support staff and people with disability that covers the following areas:

- Nutrition for Health and Wellbeing
- Problems with Nutrition
- Who's Who in Nutrition (Professional Roles)
- Strategies to Improve Nutrition and Wellbeing
- Food Management
- Food and Kitchen Safety.

Some people living in supported accommodation will have a nutrition plan and/or a mealtime management plan. In the absence of individual plans, healthy nutrition is achieved by providing meals in line with the Australian Dietary Guidelines. Food and Nutritional Health for Adults: Risk Screening and Monitoring Outline is a brief and easy to use tool that assists in risk identification and monitoring for people living in the community.

3.1.5 Nurses and Nutrition

It is essential that Nurses have an understanding of risk factors and adverse outcomes related to poor nutrition of people with disability. Nurses are responsible for the assessment of risk factors and nutritional screening. Referral to an **Accredited Practising Dietitian** is indicated for full nutritional assessment and planning. Dietitians develop individualised nutrition plans for people with specific needs. The <u>Practice Package for Dietitians</u> (available only on FACS intranet) may be a useful resource for some Nurses. Referral to other members of the multidisciplinary team may also be necessary

Nutritional problems for people with an intellectual disability are often complex. Management may require a multidisciplinary approach, e.g., GP, Dietitian, Speech Pathologist, Gastroenterologist), and the close involvement of families, carers, and support staff.

Nurses are responsible for:

- ensuring that weight is monitored and documented
- monitoring of excessive weight gain or loss
- monitoring for dehydration
- monitoring growth and development of young people
- the assessment and documentation of nutritional risk factors
- the assessment and documentation of adverse nutritional outcomes
- elimination management
- referral to other professionals as required, e.g., Dietitian, GP, Speech Pathologist, Dentist
- being alert to the necessity for specialist investigations and consulting with GP re referrals
- development of strategies to minimise risk factors and adverse outcomes (in consultation with other professionals when necessary)
- overseeing and monitoring healthy eating and drinking practices
- overseeing the implementation of nutrition plans
- education of families, carers and support staff.

(Sources used for 6.1 – 6.1.4: Barr, Gilgunn, Kane & Moore, 1999; Bhaumik*et al,* 2008; Burton, Cox & Sandham, 2009; DIISRET, 2013; Hove, 2004; NSW Ombudsman, 2013; Roberts, Stewart, Cole, Farmer & Patrick, 2002; Robertson, *et al*, 2000; Somerville*et al*, 2008; Stewart, Beange&Mackerras, 1994; Therapeutic Guidelines, 2012; Vanlint, Nugent, Durvasula, Downs & Leonard, 2008.)

3.2 Managing Dysphagia

Many people with disability have swallowing difficulties which make them vulnerable to risks from aspiration and choking, along with respiratory disease related to aspiration. Prevalence in adults with multiple disabilities is estimated to be as high as 76% (Therapeutic Guidelines, 2012). The NSW Ombudsman (2013) identified adverse events arising from dysphagia as a major area of preventable deaths of people with disability.

3.2.1 Dysphagia

Refer also to the Working with People with Chronic and Complex Health Care Needs Practice Package Section 3.1.1 Management of Dysphagia for complementary information. The severity of dysphagia ranges from mild to severe. **Eating difficulties** related to dysphagia may be affected by the following:

- environment
- alertness
- positioning and posture
- breathing
- neuromuscular control of mouth and throat
- ageing

- teeth
- dentures
- cough
- voice
- gag
- compensation

See the <u>FACS:ADHC Nutrition in Practice Manual</u> for further detail.

Consequences of dysphagia include:

- death from choking
- aspiration and its complications
- compromised nutrition (malnutrition and dehydration)
- changes to usual patterns of oral intake
- social isolation
- negative psychosocial effects, e.g., anxiety related to coughing and choking, depression.

3.2.2 Aspiration

Aspiration is the entry of material (food, liquid saliva) into the airway below the level of the true vocal cords. Aspiration is classified as:

- silent aspiration no observable symptoms such as cough or clearing of the throat
- prandial aspiration food is aspirated as it passes into airway on the way to the stomach
- salivary aspiration aspiration of saliva
- gastric aspiration gastric contents may be aspirated when reflux is severe.

Aspiration occurs in healthy people, but the airway is cleared by coughing.

Aspiration presents the greatest risks in people who:

- have a poor cough
- cannot swallow their saliva
- have problems sitting up and holding the head up
- have a weak or breathy voice
- are gurgly when they speak or breathe
- are drowsy
- have GORD.

Aspiration may lead to pulmonary inflammation, infection, pneumonia and chronic lung disease, wheezing and night time coughing. Some of these symptoms may be masked by, or mistaken for asthma. Aspiration pneumonia is one of the most common causes of death in people with an intellectual disability (Therapeutic Guidelines, 2012).

3.2.3 Screening for Dysphagia

Screening tools assess for risk. If risks are identified, close monitoring is essential and further assessment is indicated. A number of dysphagia screening tools for use by Nurses have been developed for acute stroke care. Following are the dysphagia and risk screening tools developed for use with people with disability.

Nutrition and Swallowing Risk Checklist

This comprehensive and detailed tool includes valuable information. It has been developed specifically for adults with disability and is recommended for use in all FACS/ADHC funded services. All people using FACS/ADHC residential services must have the checklist completed at their initial assessment, and updated annually by Nurses, support workers, or case managers.

The Checklist is included in the <u>Nutrition in Practice Manual</u> (FACS:ADHC, 2012) which can be found on the department's website at:

http://www.adhc.nsw.gov.au/ data/assets/file/0019/228124/Nutrition Practice Manual July2012.pdf

Functional skills deteriorate as people age. Swallowing function in some people with disability deteriorates after the age of 30 years. Therefore, **regular review of swallowing ability and oral intake is essential.**

Nurses need to be alert to the signs of dysphagia in people they are responsible for. Examples of **dysphagia warning signs** include:

- coughing
- wheezing
- wet respiratory quality
- excessive drooling
- pocketing of food in mouth
- sudden changes in colour around mouth and lips
- refusal of food and fluids
- watering eyes
- gagging
- grimacing
- fatigue during eating
- residual food left in mouth

3.2.4 Assessing Dysphagia

Referral to a Speech Pathologist may be necessary for further screening and assessment.

The Dysphagia Disorders Survey (DDS) and The Dysphagia Management Staging Scale (DMSS)

These are standardised screening tools for feeding and swallowing disorders in children and adults with disability. Speech Pathologists administer these tools following training and accreditation.

See <u>http://www.nutritionalmanagement.org/dds_dmss.htm</u> for further information.

The Speech Pathologist will advise the person's GP and other professionals about what additional investigations are needed. These may include the following

<u>Modified barium swallow (MBS)</u> is an X-ray examination of swallowing function. It is conducted by a Radiologist and a Speech Pathologist following oral intake of barium-coated foods and liquids of different consistencies. Chewing and swallowing motions are X-rayed and videoed. Aspiration of food and fluids can be visualised.

CT scans allow visualisation of internal organs. They can be useful for assessing damage caused by swallowing problems and aspiration.

Dysphagia Clinics. Specialist dysphagia clinics are available at the Children's Hospital at Westmead, Sydney Children's Hospital, and at Westmead and St. George Hospitals. They provide comprehensive assessment of dysphagia and nutrition problems for children and adults with complex medical conditions and disabilities, as well as ongoing support and management. See the Dysphagia and Nutrition Clinic at CHW

Nursing judgment is crucial in avoiding aspiration in people who are at risk. Nurses must always be sensitive to signs such as gurgling, wet cough, wheeziness, breathlessness during eating, choking, etc.

For further information see:

Living with Dysphagia. Booklet that presents general information about dysphagia. http://www.stgeorgeswallowcentre.org/Patient%20Information/LivingwithDysphagia.pdf Clinical Guidelines: Dysphagia. Speech Pathology Australia http://www.speechpathologyaustralia.org.au/library/Clinical_Guidelines/FINAL%2015062012%20Dysp hagia%20Clinical%20Guidelines.pdf Safe Swallowing. Information, resources and products. http://www.safeswallowing.com.au/ Dysphagia and Swallowing Resource Centre http://www.dysphagia.com/ Dysphagia Research Australia. Useful information and links. http://www.dysphagiaresearchaustralia.com/index.html

Following assessment and diagnosis of eating and drinking problems, the Speech Pathologist will develop an individual eating and drinking plan (sometimes called a Mealtime Management Plan). This plan may be developed with other members of the multidisciplinary team and will be implemented along with a person's nutrition plan.

Sometimes, recommendation for eating and drinking via a gastrostomy will be made if it is considered that a person with a disability aspirates regularly and is at high risk of complications, or if nutrition is inadequate.

3.2.5 Eating and Drinking with Dysphagia

Safe eating and drinking for healthy and enjoyable oral intake are the goals for people with swallowing difficulties.

Eating and drinking plans specify strategies to reduce the risk of choking and aspirating, and increase the efficiency of oral intake. Strategies include:

- food and fluid consistencies
- mealtime equipment needed
- seating and positioning requirements
- supportive techniques
- environmental considerations

3.2.5.1 Food and Fluid Consistencies

Thickened fluids and texture-modified foods are provided for the therapeutic management of dysphagia. Inconsistent labeling and descriptions of modified foods and fluids threatens interprofessional and family and support staff communication, as well as the safety of people with dysphagia. Therefore, the Dietitians Association of Australia and The Speech Pathology Association of Australia (2007) have developed consensus standards for scales of modified foods and fluids that specify levels, labels and definitions to be used throughout Australia.

The <u>Australian Standards for Texture Modified Food and Fluids</u>specify the following: **Fluid:**

- Mildly Thick (Level 150) fluid runs freely off spoon but leaves a mild coating on spoon
- Moderately Thick (Level 400) fluid slowly drips in dollops off the end of the spoon
- Extremely Thick (Level 900) fluid sits on the spoon and does not flow off it.

Food:

- Texture A (Soft) food may be naturally soft or may be cooked or cut to alter its texture
- Texture B (Minced and Moist) food is soft, moist and easily mashed with a fork; lumps are smooth and rounded
- Texture C (Smooth Pureed) food is smooth, moist and lump-free; may have a grainy quality.

The <u>Australian Standards for Texture Modified Food and Fluids Poster</u> should be readily available to all staff involved in food preparation and assisted nutrition for people with dysphagia (suggest: inside pantry or other kitchen cupboard).

3.2.5.2 Adaptive Equipment

Adaptive eating and feeding equipment suited to the needs of an individual with dysphagia is recommended and organised by Speech pathologists and Occupational Therapists.

Examples of adaptive equipment include:

- Spoons, knives and forks. These may be made of rubber or plastic to prevent biting down too hard. Weighted cutlery with or without thick handles and/or an angled head promote grip and make food transfer easier. Spoons should have a small bowl.
- Strawsare used for people with dysphagia if they have problems with cup use because they allow drinking with the chin tucked down. <u>Warning:</u> Straws reinforce the sucking reflex, so are used only on the advice of a Speech Pathologist and with regular pauses.
- Cups with spouted lids and/or dual handles.
- **Plates** with raised edges assist some people with independent eating.

3.2.5.3 Positioning and Seating

Proper body positioning during eating and drinking is essential for safe swallowing. Incorrect posture increases the risk of choking and aspiration. Head position influences swallowing ability and airway safety. The ideal position for eating and drinking is sitting upright in a chair with both feet on the floor, hips back in the chair, head facing the front and chin slightly forward.

If unable to sit in a chair, assistance is provided to promote an upright position in a wheelchair or bed (if ill). People who cannot sit in a chair need an individualised, supportive wheelchair with appropriate trunk and head supports as prescribed by a Physiotherapist or Occupational Therapist.

When eating and drinking in a wheelchair:

- the back of the chair should be upright
- knees should be at right angles to the hips
- feet should be on footplates
- head, trunk and limbs should be well supported allows coordination of breathing and swallowing and promotes expulsion of particles from airway during coughing.

If these positioning principles cannot be implemented due to severe physical disability, proper positioning, seating and supports required for the individual are specified in a **seating plan**.

People need to **remain upright for at least 30 minutes** following eating and drinking. This reduces the risk of reflux and aspiration.

3.2.5.4 Supportive Techniques

An individualised eating and drinking plan will specify any techniques required to support safe swallowing. These may include:

- food to be taken in small mouthfuls
- allow ample time for chewing and swallowing before taking another mouthful
- do not rush
- if feeding, sit in front of the person
- give a dry spoon between every three-four mouthfuls of food to promote swallowing
- gently support jaw to ensure mouth closure

Support staff may need guidance and modeling from Nurses to effectively implement some techniques. Ensure that only person is fed at a time,

3.2.5.5 Environmental Considerations

A calm and relaxed eating and drinking environment is important for everyone. It is essential for people with dysphagia whose swallowing risks are increased in environments that cause hurrying or distraction. Noise levels, loud noise, distractions, unfamiliar people, unfamiliar environments, room temperature, comfort all have an impact on eating and drinking.

3.2.6 Hydration

People with dysphagia, particularly those on thickened fluids, often drink less. As people age, they drink less. People with communication impairments may have difficulty communicating thirst. Attaining adequate hydration can present problems in people with dysphagia, especially when they are dependent on others for drinks.

Nurses are responsible for monitoring the symptoms of dehydration which include:

- dry, sticky mouth
- thirst
- low urinary output
- concentrated urine

- dry skin
- headache
- constipation
- lightheadedness, dizziness

When indicated, nurses are responsible for organising the recording of daily fluid intake (and output if necessary). Fluid balance are tallied at the end of 24 hours and negative or positive balances are recorded in the person's notes. Fluid requirements are usually calculated as 30ml per kg body weight or 6-8 cups of fluid a day

Strategies to increase hydration include:

- Communicate the importance of hydration to all team members and educate individuals, families, carers and support staff.
- Encourage and remind people to drink as per plan.
- Offer small drinks regularly and frequently.
- Replace disliked fluids with drinks that are acceptable.
- Fluids are obtained from a wide range of sources (which may need thickening as per plan) – milkshakes, smoothies, tea, coffee, soups, jellies, custard, yoghurt. <u>Warning</u>: ice cream, sorbets, ice blocks, some jellies melt in the mouth and become thin fluids
- Fruit and vegetables are a good source of fluid, especially those with a high water content like watermelon and tomatoes. Be cautious and re textures and add watermelon and other fruits to smoothies. Use tomatoes in cooking.
- Encourage fluids with medication when feasible
- Closely monitor and record on a fluid balance chart all episodes of diarrhoea and vomiting.

3.2.7 Medications and Dysphagia

Some medications may affect swallowing by interfering with oesophageal muscle control (e.g., Cogentin), or by causing a dry mouth (e.g., ACE inhibitors, diuretics).

Some medications are difficult to swallow and may be a problem for people with swallowing difficulties. However, a number medications cannot be crushed or dissolved to be given as a liquid, particularly when they are sustained-release or have an enteric coating.

Nurses should speak with a Pharmacist regarding information about crushing and dissolving medication. Always ensure that prescribing GPs, Specialists and Dentists are aware of a person's swallowing difficulties when prescribing medication. Occasionally, in the absence of a suitable alternative, the Doctor will prescribe an essential medication that will have to be crushed or dissolved (even though this is not ideal).

Staff working in an organsiation should refer to their Medication Policy and Procedures (FACS staff on FACS intranet only).

3.2.8 Oral Health and Dysphagia

Poor oral health results in high levels of plaque and bacteria in the oral area. This has been implicated as a significant factor in the development of aspiration pneumonia. Oral health is essential in the prevention of complications of dysphagia. Refer also to the Working with People with Chronic and Complex Health Care Needs Practice Package Section 3.10 Oral Health for information on the management of oral health.

For further information see:

<u>Dysphagia.</u> Hunter New England Local Health District. Excellent site with links to numerous resources about, dysphagia, eating and drinking, modified textures, etc. <u>http://www.hnehealth.nsw.gov.au/allied_health/dysphagia</u>

Australian Standards for Texture Modified Food and Fluids Poster

[http://www.speechpathologyaustralia.org.au/library/Poster.pdf]

<u>Medicines Optimisation in Patients with Dysphagia.</u> UK website that provides practical guidance on the administration of medications to people with dysphagia. <u>http://dysphagia-medicine.com/</u>

Ensuring Safer Practice for Adults with Learning Disabilities who have Dysphagia. UK NHS site with numerous resources.

http://www.nrls.npsa.nhs.uk/resources/?entryid45=59823

Cornish, P. (2005). <u>'Avoid the crush': hazards of medication administration in</u> patients with dysphagia or a feeding tube.*CMAJ*, 172 (7).

[http://www.cmaj.ca/content/172/7/871.full]

<u>Understanding Dysphagia, Nestle Healthcare</u>. YouTube Presentation [<u>http://www.youtube.com/watch?v=jK1o3LSQmB0</u>]

'Swallowsafe' DVD – a guide to effective and safe swallowing for people with developmental disabilities. Available from the Gastroenterology Clinic, the Children's Hospital at Westmead.

Following resources are available:

Contact your Manager or Nursing and Health Care Practice Leader regarding access.

FACS ADHC <u>Mealtime Management Modules</u> are an excellent e-learning resources that cover the complex issues related to mealtimes and people with disability. They expand on material covered in this practice package. At the time of developing this Practice Package, the Modules are being rewritten. The web link will change.

FACS ADHC Practice Packages: Speech Pathology Dietitics Physiotherapy Occupational Therapy

(Sources used: FACS:ADHC, 2012; Therapeutic Guidelines, 2012)

3.3 Enteral Nutrition

Refer also to the Working with People with Chronic and Complex Health Care Needs Practice Package 3.10 Oral Health Section for information on the Management of Oral Health.

When people are unable to take in food or fluids orally, non-oral feeding may be indicated.

Non-oral feeding falls into two main categories:

1. Enteral nutrition (sometimes called tube feeding):

- via nasogastric (NG) tube tube passes up through the nose, to throat and down to the stomach. Usually used as a short-term measure during illness, etc.
- gastrostomy tube goes through abdomen into the stomach. Usually this is a percutaneous endoscopic procedure (PEG tube)
- jejunostomy tube through abdomen into the small intestine. May be placed using percutaneous endoscopic jejunostomy (PEJ, sometimes called J tube)

2. **Parenteral nutrition**delivers nutrients directly into the bloodstream so as to bypass the gut. This is less common and managed by the medical team in hospital

The focus in this package is on enteral nutrition, especially via gastrostomy, because this is what is most commonly encountered in disability nursing practice.

Enteral nutrition support refers to the introduction of nutrition directly into the stomach or small intestine via a tube. Such nutrition is usually a complete nutritional formula. However, sometimes thickened fluids or a fortified drink might be given into the stomach to supplement inadequate oral nutrition.

3.3.1 Reasons for Enteral Nutrition

Enteral nutrition is considered when an individual is:

- not safe for oral intake
- or when oral intake is not enough to meet nutritional requirements.

These problems are often associated with:

- neuromuscular problems that affect chewing and swallowing coordination that may result in aspiration (e.g., dysphagia associated with cerebral palsy, motor neurone disease, brain injury, Huntington's disease, stroke)
- medical problems and/or structural abnormalities of the gastrointestinal tract, e.g., inflammatory bowel disease, cancers, hepatic, renal or respiratory failure, anorexia, HIV/AIDS.
- cognitive impairments that affect capacity to coordinate chewing and swallowing safely
- fatigue associated with illness
- failure to thrive or severe reflux in infants
- reduced level of consciousness

If safety is a major concern, such as in the case of severe dysphagia and chronic aspiration, all nutrition and hydration will be administered via tube. Gastrostomy tube insertion has sometimes been combined withfundoplication to reduce reflux and

aspiration. However, a person who has had both procedures may still aspirate saliva, so correct posture and positioning are still essential. Note that fundoplication is no longer recommended as best practice.

In some instances, tube feeding is a supplement to oral intake. This is more common in situations where intake is inadequate, but swallowing safety is a secondary consideration. It is preferable to maintain some oral intake where possible to maintain function and sensual enjoyment.

These decisions are made with persons and their families following assessment by a Speech Pathologist, along with other specialists, such as a Dietitian, Gastroenterologist, Paediatrician

3.3.2 Making Decisions about Enteral Nutrition

Making decisions about permanent gastrostomy placement is fraught for individuals and their families. Mothers in particular are faced with anxiety and guilt about not being able to adequately feed their children. Families and carers worry about causing unnecessary pain and distress and are also concerned about the loss of sensual and social pleasure derived from eating experiences. Families sometimes feel rushed and coerced by professionals to make decisions about tube feeding (Brotherton& Abbott, 2012; Sleigh, 2005).

It is essential that families are supported during the decision-making processes related to gastrostomy placement. Decisions must be person-centred to enable families feel they are making a true choice in the interest of the child or person for whom they are responsible.

An ethical decision-making framework is helpful when assessing and managing dysphagia in people with disability. *Therapeutic Guidelines, Developmental Disability* (2012, p.192) provides an example of a framework that considers swallowing function, along with potential harms and benefits to the person in the broader psychosocial context.

3.3.3 Delivering Enteral Nutrition

Decisions about methods of enteral feeding are made by the person, family and members of the multidisciplinary team in consultation with a Dietitian.

Enteral feeds may be delivered in the following manner:

- Bolus Feeding. Nutrition and fluids are delivered by gravity. This is the simplest method and requires minimal equipment. It allows for regular mealtime feeding regimes. However, it increases the risk of adverse gastrointestinal (GI) symptoms, e.g., 'dumping' leads to vomiting; diarrhoea.
- Intermittent Feeding. Involves smaller amounts by gravity or pump. Allows time free from feeding, but increases risk of GI problems.
- Continuous Feeding. Delivered by pump in small amounts. Decreases risk of GI symptoms but person is connected to system and mobility may be reduced.

The Dietitian calculates formula feed requirements and fluid intake. These calculations consider body weight, nutrition and energy requirements. Fluid intake includes water needed for flushes and medication administration. These requirements are documented on a nutrition care plan. Regular reviews (usually six monthly in the absence of change) by the Dietitian are necessary to ensure adequate intake of fluid, energy, protein and micronutrients.

Appropriate posture and positioning during feeding and for 30 minutes afterwards are essential to prevent reflux and aspiration.

3.3.4 Enteral Nutrition – Some Practical Considerations

Diarrhoea is a risk for people receiving enteral nutrition. Causes of diarrhoea include:

- intolerance to the formula
- some medications, e.g., antibiotics
- feeding the formula when it is too cold, i.e., straight from the fridge
- feeding the formula too fast
- using formula at room temperature for more than four hours
- contamination by poor hygiene practices, e.g., poor hand washing, hanging feeds for too long, water flushes not cleaning tubing adequately.

Information about practical issues such as:

- feeding tubes care and management
- feeding tubes trouble shooting
- feeding and nutrition plans
- HEN resources

Is readily available. Many sources are listed in the box below. The Agency for Clinical Innovation (ACI): Nutrition is a good place to start. Go to Resources for Clinicians.

The sensual and social aspects of eating and drinking are important for people receiving enteral nutrition. Where possible the Speech Pathologist and Dietitian will incorporate some minimal oral intake if safe. This can be taken at regular meal times with other people. If not safe, consult with members of the multidisciplinary team regarding strategies to enhance nutritional enjoyment.

For further information see: Agency for Clinical Innovation (ACI): Nutrition http://www.aci.health.nsw.gov.au/networks/nutrition Australasian Society for Parenteral and Enteral Nutrition (AuSPEN) http://www.auspen.org.au/ AuSPEN. Clinical Practice Guidelines: Home Enteral Nutrition in Australia http://www.auspen.org.au/assets/Uploads/Documents/guidelines-2/AuSPEN-Home-Enteral-Nutrition-Guidelines.pdf Dysphagia. Hunter New England Local Health District. Excellent site with links to numerous resources about, dysphagia, eating and drinking, modified textures, etc. http://www.hnehealth.nsw.gov.au/allied_health/dysphagia Enteral Nutrition Manual for Adults in Health Care Facilities. Dietitians Association of Australia, Nutrition Support Interest Group. http://daa.asn.au/wp-content/uploads/2011/11/Enteral-nutrition-manual-Oct-2011.pdf Gastrostomy Information and Support Services (GISS)

http://www.scopevic.org.au/index.php/site/resources/gastrostomies

GISS (NSW) Membership Contact

http://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0006/159909/join_giss_nsw_mailing_list.pdf Guidelines for Home Enteral Nutrition (HEN) Services. GMCT, now ACI.

http://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0007/154663/hen_guidelines_2007_05_28.p

Home Enteral Nutrition (HEN) Equipment Forms and Guidelines

http://www.enable.health.nsw.gov.au/home/forms-and-guidelines/hen

HEN Feeding Plan

http://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0004/154777/feeding_plan.pdf#zoom=100 HEN Feeding Tubes – Troubleshooting

http://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0019/154801/feed_tube_troubleshooting.pdf# zoom=100

HEN Tubes – Care and Management

http://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0007/154807/tube_care_management.pdf#zo om=100

<u>Medicines Optimisation in Patients with Dysphagia.</u> UK website that provides practical guidance on the administration of medications to people with dysphagia. <u>http://dysphagia-medicine.com/</u>

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Cornish, P. (2005). <u>'Avoid the crush': hazards of medication administration in patients with dysphagia or a feeding tube.</u> *CMAJ*, 172 (7). http://www.cmaj.ca/content/172/7/871.full

'Swallowsafe' DVD – a guide to effective and safe swallowing for people with developmental disability. Available from the Gastroenterology Clinic, the Children's Hospital at Westmead.

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FACS ADHC Practice Packages: Speech Pathology Dietitics Physiotherapy Occupational Therapy

(Sources used: Burton, Cox &Sandham, 2009; DAA, 2011; FACS:ADHC, 2012; Pearce & Duncan, 2002; Somerville *et al*, 2008; Therapeutic Guidelines, 2012; Yates, 2013)

3.4 What does this mean for your nursing practice?

Practice Points: MEALTIME MANAGEMENT

- Nurses must have a comprehensive understanding of risk factors and adverse outcomes related to poor nutrition.
- Nurses perform an essential role in the screening and monitoring of nutritional status, along with risk factors for poor nutrition.
- Good nutrition underpins health and wellbeing.
- Malnutrition, resulting in underweight, obesity and lack of essential nutrients, is prevalent in people with an intellectual disability.
- Good nutrition is related to sensual and social experiences and socioeconomic factors.
- Nutritional problems may exist even when healthy food is available.
- Nutritional problems can be complex and are associated with pathology that interferes with intake, digestion and absorption of nutrients.
- Appetite problems are a signal for assessment of physical and psychological health issues.
- Undernutrition and overnutrition must be assessed for causes. Referral to members of multidisciplinary is necessary for full assessment.
- Impaired communication, along with dependence on others, are major contributors to inadequate nutrition and hydration for people with an intellectual disability.
- Inadequate nutrition and hydration are identified as causing death in vulnerable people. Education of support staff and regular monitoring of people with disability are essential to address such preventable deaths.
- High rates of dysphagia in people with an intellectual disability result in aspiration, pulmonary infection and death.
- Effective management of dysphagia enhances health and prevents death.
- Pulmonary aspiration of saliva, food, drink, or gastric contents may be apparent or 'silent'.
- Regular screening for dysphagia is essential, along with referral to members of multidisciplinary team for specialised assessment when indicated.
- Appropriate positioning and posture are essential in dysphagia, and eating and drinking management.
- People with dysphagia are at high risk of dehydration.
- Nurses educate families and support staff about implementation of eating and drinking plans.
- Some medications affect swallowing.
- Poor oral health contributes to aspiration pneumonia.
- Enteral nutrition may be necessary for swallowing safety and adequate nutrition and hydration.
- Decisions regarding permanent enteral feeding are very difficult for individuals, families and carers. Nurses must be aware of this and ensure adequate information and support.
- Nurses are responsible for ensuring Dietitians' plans for feed and fluid requirements are implemented correctly. Fluid calculations must include water flushes. Nurses may plan the fluids across a 24 hour period
- Social and sensual aspect of eating must not be neglected for people with

gastrostomies.

• Nurses are responsible for ensuring they are up to date with best practice in enteral feeding practice.

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