Nutrition and Swallowing

Policy and Procedures

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Ageing, Disability and Home Care
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Document approval

The document ***Nutrition and swallowing policy and procedures*** has been endorsed and approved by:

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Chief Executive, ADHC	Deputy Director-General, ADHC

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1 Target group

The *Nutrition and Swallowing Policy* applies to Family and Community Services NSW, Ageing, Disability and Home Care (ADHC) operated and funded accommodation support services and centre based respite services.

The procedures are mandatory for ADHC operated services. Funded services may have their own procedures however they must ensure that all procedures comply with the principles and requirements set out in this *Policy.*

2 Background

Nutritional health is a basic human right for all people. Eating nutritious food is very important to maintaining our health. Food keeps us functioning, alert and active so that we can fully participate in family and community life. Poor nutrition can have severe adverse consequences for a person's health.

People with a disability are often dependant on others for access to nourishing, enjoyable and culturally appropriate food. Therefore the people supporting people with a disability need to ensure this access.

All disability services have responsibility to ensure good nutrition especially supported accommodation and respite services.

People with a disability have a spectrum of nutritional support needs that include:

1. Assistance in making wise food choices;
2. Assistance in food purchasing, preparation and other aspects of daily living related to food;
3. Managing medical problems where diet is an important part of treatment, eg obesity, diabetes;
4. Special attention to physical or visual difficulties with eating, drinking and swallowing, special seating/ positioning, special utensils, and supervision while eating;
5. Someone else assisting them while they eat or drink;
6. Specifically prepared food to meet their individual needs; and
7. Tube feeding as an alternative or supplementary method of receiving food and liquid.

3 Policy vision

1. People with a disability will achieve and maintain nutritional health and experience the benefits that are associated with it. These benefits are a sense of well being, improved physical health, prevention of illness, capacity to participate more in home, family and community life and prevention from harm.
2. People with a disability will be supported by a trained and skilled workforce of direct support staff who:
   - value and promote the individual's right to a safe and healthy diet;

- monitor, manage risk and review nutritional needs;
- balance the ideals of individual choice and self determination with duty of care and;
- take into due consideration the person's cultural and religious background.

3. People with a disability will have services from all kinds of health care professionals as needed.

4 Policy scope

Nutrition and swallowing is an overarching policy for ADHC funded supported accommodation and centre based respite care services, both Government and non-Government. The policy will be integral to ADHC's quality improvement and monitoring strategies for these services.

The policy including the appendices, Nutrition in Practice Manual, Food Services Manual, Nutrition Information Kit, which includes the Informed Decision Making Protocol, and Standards in Action, all provide a guide to services in their duty of care and best practice in the management of nutrition for people with a disability.

It is expected that this policy will also inform other types of disability services about nutritional health, for instance community support, leisure services, day programs Home and Community Care (HACC) services. The policy is a guide in best practice and standards for these services. It expected that where a supported accommodation service develops a nutrition plan, this plan will be communicated and coordinated with other services involved with the individual for instance, vocational, educational and recreational services.

4.1 Access to health services

The *Nutrition and Swallowing Policy* recognises the importance of ready access to health services through a collaborative approach between health professionals and those who support people with a disability.

Disability service providers are obliged to actively seek appropriate professional advice regarding the action they need to take when nutritional risks have been identified.

5 Policy statement and principles

This policy establishes the principles of good nutritional support for people with a disability. It is ADHC's statement of service provider obligation and as such sets expectations against which services and agencies will be measured.

In the context of ADHC's commitment to good health for people with a disability this Policy has been prepared to provide direction for all agencies including those providing supported accommodation and respite services.

For people with a disability to achieve and maintain nutritional health service providers need to implement the following principles:

- The service provider has a responsibility to ensure good nutritional health and this responsibility is at all levels of a service - direct support staff, supervisors and service

executives. This responsibility includes meeting various legal and statutory requirements that exist in state or federal legislation.

- The provision of appropriate and nutritious food is an essential feature of supported accommodation and centre based respite care.
- Religion and culture should be recognised in food preparation and meal selection.
- People with a disability must be involved as far as possible in decisions concerning their nutritional health.
- Families have a vital role to play in the nutrition and health of many people with a disability. Their involvement should be promoted, respected and encouraged.
- People with a disability may have a range of food related support needs that need to be met.
- A prevention and risk management approach to individual nutritional health is required. Annual assessment and review of individual support needs and identification of nutrition and health risks is critical to good nutritional health. People with a disability should be assisted to access appropriate health care professionals. Service providers will ensure that recommendations made by health care professionals are implemented in a timely fashion.
- Service planning, management and review systems should involve nutritional health policy, procedures and outcome review.
- Decisions about complex health and nutrition needs should be based on a process that balances duty of care with individuals' self determination.

6 Policy outcomes

- Services funded/provided by ADHC will strive to achieve and maintain nutritional health in the people they support.
- Services funded/provided by ADHC will have in place a system to assess, manage and review individual nutritional and eating support needs for the people they support.
- Services will ensure that each individual's nutritional support needs are assessed at least annually or more often if required, and that nutrition planning is part of individual service plans. The purpose of nutrition plans will be to ensure the provision of appropriate food and nutrition, and access to professional health advice if needed.

7 Policy in operation

Appendix 1 – Guidelines for Disability Service Providers provides an audit tool to assist services to assess their compliance with the principles of the Policy and the achievement of required outcomes.

Other resources that provide guidance include:

Nutrition in Practice Manual and the Food Services Manual

The *Nutrition and Swallowing Policy* is closely linked to the ADHC Nutrition in Practice Manual and the Food Services Manual. They include *The Nutrition and Swallowing*

Checklist (Attachment 1 of the Policy), which assists direct support staff to identify individual needs. This resource is for use in annual individual assessment and review. These resources will be provided to all services.

ADHC Nutrition Information Kit

The *Nutrition and Swallowing Policy* is accompanied by a Nutrition Information Kit, which includes the *Informed Decision Making Protocol* and provides information to all those involved in nutritional health care of people with a disability. The protocol includes a *Pathway for gathering information, comparing options and making decisions (*Attachment 2 of the Policy) to guide all parties to reach the best decision for and with the person with a disability. This includes situations where a conflict between individual choice and duty of care may exist.

8 Accountabilities and responsibilities

8.1 Family and Community Services NSW, Ageing, Disability and Home Care responsibilities

Family and Community Services NSW, Ageing, Disability and Home Care (ADHC) will:

- Lead policy development in nutritional health for disability services;
- Negotiate the implementation of the policy with all providers;
- Incorporate the policy into a nutritional health quality improvement and monitoring strategy for ADHC funded services; and
- Seek partnership with NSW Health in the implementation of this policy.

8.2 Funded NGO services responsibilities

ADHC funded NGO supported accommodation and centre based respite services will:

- Develop, implement and review operational policy that will achieve the objectives of the nutrition and swallowing policy;
- Work towards continuous quality improvement; and
- In the context of the nutritional health quality improvement and monitoring strategy, provide ADHC with evidence of how their services are achieving the objectives of the nutrition and swallowing policy.

Appendix 1: Guidelines for disability service providers

The *Nutrition and Swallowing Policy and Procedures* is underpinned by a number of principles that need to be reflected within your organisational policy and procedures.

The checklist below sets out minimum requirements that need to be covered in your policy and procedures and indicator reporting. You may need to expand on these requirements according to your service's context and the needs of the people who use your service. The Nutrition in Practice Manual and the Food Services Manual provide further guidance.

Operational policy areas	Responsibilities of the service
1. Nutritionally adequate food Food provision is planned so that individual people obtain a nutritionally adequate and healthy diet. Organisations therefore must address individual needs according to: ■ Age ■ Gender ■ Culture and religion ■ Level of activity ■ Health issues ■ Therapeutic requirements	**The service will ensure that:** ■ There is a policy indicating the organisation's commitment to nutritionally adequate food consistent with "the Australian guide to healthy eating". ■ Food preparation conforms to any applicable regulations and preserves nutritional value. ■ Food is varied, appealing and tasty.
2. Cultural and religious diversity Acknowledgement of cultural and religious diversity is applicable to many people receiving support. (N.B. even Anglo Australians have a food culture!) The organisation must therefore check each person's requirements and customs with the person and appropriate family and, or community cultural groupings.	**The service will ensure that:** ■ An individual's religion and culture are incorporated into and demonstrated within menu planning, meal preparation and meal time practices. ■ An environment is created that allows, enables and values an individual's cultural and religious expression through the choice of food and presentation of meals.
3. Risk identification and action Identification of nutrition risks and actions to address obvious and potential risk must be documented and actioned in a systematic and planned way.	**The service will:** ■ Identify and address individual risks related to food intake, nutrition and nutrition support needs by using an appropriate checklist. ■ Develop individualised health and nutrition plans which incorporate: 1. Supporting and encouraging the involvement of the person with a disability, family members and guardians in decision making. 2. Supporting people who have special needs. Eg: physical or sensory problems. 3. Ensuring that people who are tube fed

Operational policy areas	Responsibilities of the service
	have their nutritional care plans reviewed at least six monthly (good practice calls for the involvement of a dietitian in the review). 4. Ensuring that people who have difficulty swallowing have their nutritional care plans reviewed at least six monthly (good practice calls for the involvement of a speech pathologist in the review). 5. The use of the "Informed decision making protocol" if tube feeding is being considered. 6. Referral to Dietitian assessment when a person's 'healthy weight range' can't be determined, because their height can't be measured. ■ The service will monitor indications of unhealthy weight through periodical weighing, as often as individual need requires. ■ An organisation must seek assistance from health professionals when people are on medication, which may interfere with the absorption of food or nutrients. ■ Services will facilitate the involvement of a dietitian or an appropriate health care professional as needed.
4. Individual choice It is expected that wherever possible, individuals will be able to express their likes and dislikes about particular foods/drinks (crisp and crunchy, smooth, cold or hot etc) and have these recognised within the daily food selections, menu planning and food purchases. Whilst all people from time to time will choose foods which may not be optimal for them, generally organisations have a responsibility to safeguard the health of the people they support through education and information about the consequences of their choices.	**The service will ensure and appropriately record that:** ■ Individuals are encouraged to experience different foods. ■ Individuals receive appropriate information about the relationship between their health and their food choices. ■ Individuals are involved in menu planning and decision making about mealtime arrangements. ■ Families are involved in identifying individuals' food likes and dislikes. ■ Where individuals are involved in food preparation, they receive education about hygiene, food storage and appropriate preparation.
5. Balancing the tensions between individual choice and duty of care There is sometimes a tension between the reality of individual choice and an	**The service will undertake to, and appropriately record that they:** ■ Proactively seek to balance their duty of

Operational policy areas	Responsibilities of the service
organisation's duty of care. Balancing a person's right to choose and consume the food they might like and their health needs is an obvious one. A further tension is between a person's physical issues (positioning, swallowing or need for equipment) and their preferences.	care with the individual's freedom to choose as they wish; and Assist with individual choice based on health promotion and a nutritionally balanced diet. Where an individual's nutrition support needs are complex, the service will ensure that: ■ Food choices are based on all the information required. ■ Risks to nutritional health and general health are assessed and understood. ■ Individual, family and guardians are involved. ■ All decision making processes are documented. See Nutrition Kit for further information and suggested Informed Decision Making Protocol.

Appendix 2: Tell me about – aspiration and swallowing difficulty in people with developmental disability

1. I need to know more about 'aspiration'

Aspiration means that some food or fluid or saliva is entering the airway and going into the lungs. The food, fluid and saliva is not meant to enter the airway.

2. Why can it make the person with developmental disability sick?

When a person aspirates food or drink into their airway, sometimes their body mechanisms work to clear some or all of the material. At other times the food fluid or saliva remains in the lungs and contributes to development of respiratory illness, such as a chest infection or what is called 'aspiration pneumonia'. Some people who are known to aspirate are more likely to get sick, depending upon many factors. These include:

- Being dependent in being fed
- Having poor oral hygiene
- Being dependent in daily activities
- Being dependent in mobility
- Having other illnesses
- Having a history of respiratory illness
- Having a swallowing difficulty

3. About coughing and choking

Coughing is a response of the body to food fluid or saliva going down 'the wrong way'. The tube for receiving air (the trachea) is very close to the opening of the tube for receiving food (the oesophagus). Choking occurs when the food fluid or saliva has blocked the airway. It is important that people know what to do if a person is coughing or choking. It is also important that they follow instructions about ways to reduce the risk of illness or death related to coughing or choking.

4. Reducing the risk of developing illness related to aspiration

Many things can be done to reduce the risk of developing respiratory illness related to aspiration of saliva, food and fluid. The person's individual needs would indicate which strategies would be most helpful. The following are examples of a wide range of strategies that may be considered for the individual:

4.1 Focusing on the person:

- Make sure that the person has excellent daily oral hygiene.

- Monitor general health and responding immediately to any illness.

4.2 Focusing on the food:

- Change the texture of food or fluids, to make them easier to swallow.
- Make sure the food is not too solid, and also not too sloppy, but is tailored to suit the individual's needs.
- Aim for improved levels of nutrition.

4.3 Focusing on seating and equipment:

- Improve positioning and seating supports to enable an easier swallow.
- Provide a specific head support to use during mealtimes.
- Use particular types of spoons and cups to improve how the person manages what they eat and drink.

4.4 Focusing on the swallow:

- Give a smaller amount per spoonful.
- Encourage the person to have a chin down position during the swallow.
- Encourage mouth movements by particular methods of spoon entry and exit.
- Provide gentle support to jaw or lip when taking food off the spoon.
- Encourage the person to swallow twice for each mouthful.
- Encourage the person to have a break between mouthfuls, to give time for the food to be cleared from the neck area.

4.5 Focusing on the person assisting in the meal:

- Listen for signs of 'continuing to swallow' or signs of difficulty in the swallow.
- Feed more slowly, to give the person more time to swallow.
- Encouraging the person to cough.
- Supervise and monitor oral intake to ensure appropriate response to situations where the person is coughing and choking.
- Be aware of fatigue and tailor meal size to suit the individual.
- Give smaller meals more often, to avoid fatigue associated with larger meals.

You can get more information relating to aspiration and illness arising from aspiration of food or fluid from your General Practitioner, a Respiratory Physician, Paediatrician or Physician in Developmental Disability. A speech pathologist can also advise on ways to reduce the risk of aspiration when swallowing food, fluid or saliva.

Appendix 3: Tell me about - spoons and facilitation

1. Why is a special spoon needed?

Did you ever wonder why a particular spoon was recommended?

It may be because the spoon is made of a durable plastic material that some types of durable plastic spoons are recommended for some people, who have a 'bite' reflex or who bite down hard on cutlery. This is to protect their teeth from biting hard on metal, and to prevent them biting and breaking a more brittle plastic spoon, which may then be swallowed or be difficult to remove from the mouth.

A particular spoon may be recommended because of the shape of the spoon with a shallow 'bowl' can help to ease removal of food from the

A Speech Pathologist can advise you if a particular type of spoon is needed for a person who has difficulty eating, and where the spoon can be purchased.

2. Is there a better way to use the spoon?

In general, a spoon should not be overfilled with food.

In general, when a person clears food off a spoon, they do so with their top lip. The way the spoon is angled on leaving the mouth is also important. If they are unable to move their lip down, it can help to angle the spoon up to encourage lip contact with the spoon as it is removed. This can have the effect of promoting lip movement down on to the spoon, which can help clear the spoon, and can also help in 'starting off' the swallow.

3. There may be a better way to provide support to the chin, jaw and lips:

Some people benefit from having a gentle support under the chin when taking the food from the spoon or a fork. The support is aiming to promote movement in the direction of 'lips closing' or 'jaw closed' position; it is not necessarily done to 'hold still' these postures. It all depends on the individual's oral skills.

It is important not to force or push the jaw upwards, as there may well be an equal tension created in the person's 'jaw opening' as a result of spastic reflex patterns. A speech pathologist can advise on the need for jaw or lip support or facilitation for the individual that promotes natural progression to the movement pattern rather than forceful or rigid holding patterns.

Appendix 4: Tell me about – seating and positioning during meals for people with developmental disability

1. A general guideline: Sitting upright for meals and for 30 minutes after

In general, it is better to have an upright sitting position for eating and drinking. A good upright sitting position includes placing the feet on the floor or if in a wheelchair, on the footplates of the wheelchair; the hips are well back in the chair; the back is upright; arms are bent at the elbows, and the head is facing the front with the chin down. Some people with developmental disability can achieve this posture, and others have difficulty in sitting upright. There are many seating system options available that are designed to meet individual needs.

2. From Reclining to Upright

A person who sits in a wheelchair may have a number of positions to use at different times of the day. In general it is recommended that the position of the wheelchair be moved from reclining to upright during mealtimes, to promote the 'upright sitting' position.

3. An added neck support

Some people who have a headrest on their wheelchair need two positions for the headrest - one for general use and one for use during mealtimes. An alternative to this is to have an insert cushion that is designed for the individual, to be used during mealtimes.

4. If you think seating could be improved

If you think improvements in posture or seating systems are needed for mealtimes, please ask for assistance from an occupational therapist or seating consultant. A speech pathologist will often suggest ideas for improving positioning for mealtimes that enables the person better control of their mouth and swallow, and a safer swallow.

Appendix 5: Tell me about – tube feeding in people with developmental disability

1. About tube feeding

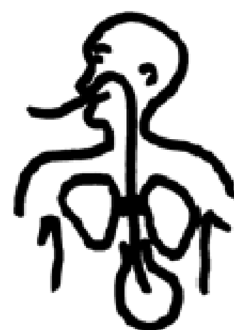
Gastrostomy tube (G-tube) feeding is a method of feeding that involves insertion of tubing through the abdomen and into the stomach. A special type of food mixture is put through the tube, and this goes directly into the stomach. The food provides all the vitamin, minerals, proteins, fats and so on, that a person needs to survive. Fluids can also be put through the tube into the stomach, and so can medications that have been made into a liquid form, or carefully crushed and delivered with a liquid through the tube.

2. About peg feeding

Percutaneous Endoscopic Gastrostomy (PEG) is the name given to a particular method of inserting the tube into the stomach. You do not necessarily need to have an anaesthetic to have a PEG. It is a considered a safe, simple procedure, but can be associated with some risks. Your gastroenterologist can advise you further on the risks and on the procedure in more detail. Once the PEG is inserted, food and fluids can be delivered to the person, directly into the stomach.

3. About NG tube feeding

Nasogastric (NG) tube feeding is where a tube is passed through the nose, down to the stomach. The tube is kept in place by taping the tube sometimes to the side of the face or the edge of the nose. Nasogastric tube feeding is normally considered a short-term option, however some people who are not able to have a PEG may have NG tube feeds for longer periods.



4. About Jejunostomy or Ileostomy tube feeding

A Jejunostomy tube (j-tube) is a tube that is inserted through the abdominal wall and into the top of the small intestine. Some people who have severe physical disability and deformity of the spine may need to have a tube inserted further down from the stomach, into the ‘jejunum’ (jejunostomy), or the ‘ileum’ at the bottom of the small intestine (ileostomy).

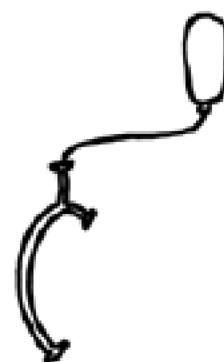
5. About the benefits of tube feeding

Having a tube can increase the person’s level of nutrition, if they are not able to take in enough food by the mouth. Having a tube may reduce the risk of developing illness related to breathing in food or fluid, as sometimes occurs in swallowing difficulties. The benefits of increased nutrition include improved wellness, having more energy, being more alert, having reduced rates of infection,

which all may contribute to an increased quality of life. Having a tube does not necessarily mean that the person will not be able to eat or drink by mouth. Very often the person can continue to eat and drink foods that are recommended, or sometimes food they would like to eat or drink, depending on their needs.

6. About risks and costs of tube feeding

Although tube feeding is considered a safe alternative, it carries with it some risks that need to be considered. Some of these risks, such as tube blockage and infection at the tube site, are easy to prevent and to treat. Others, such as aspiration of stomach contents because of reflux, tube malfunctioning, hemorrhage or abdominal wall cellulites; require more careful attention and active intervention.



In general, people will need to monitor the tube feeding to ensure that it is clean, safe and working properly, on a daily basis. Your gastroenterologist and enteral nurse or stomal nurse can give you more information about the risks associated with tube feeding, and how to manage and maintain tube feeding safely to minimise complications.

7. Who can I speak to for more information?

You can get more specific information relating to tube feeding as an option for an individual by speaking with that person's Paediatrician, Gastroenterologist, General Practitioner, or a Physician in Developmental Disability.

A Dietitian will advise on balancing nutrition with a tube feed, whether it is tube feed alone or tube feed with an oral intake as well. Please ask if you require further information before a decision is made. It is very likely that oral feeding can continue in some form after tube feeding is started. A Speech Pathologist can advise on this and the type of food or fluid that may be suitable to be taken orally.

For further information and support contact the Gastrostomy Information Support Society
www.giss.org.au
Postal Address:
GISS
PO Box 608
Box Hill 3128
Phone: 61 3 9843 2000
Fax: 61 3 9843 2033
Email: giss.crc@scopevic.org.au
GISS NSW: Karen Robertson
Phone: (02) 9975 8219
Email: krobertson@tscnsw.org.au

Appendix 6: Tell me about – modifying foods and fluids to suit people with developmental disability and swallowing difficulty

1. Modifying Foods and Fluids

If you have difficulty swallowing, you may have been advised to have a particular food or fluid texture, such as soft, mashed, or pureed food, or thickened fluid. This is done in order to make the food easier and safer for you to swallow.

2. Making a food texture change and still enjoying your meal

It can sometimes be difficult to change your diet, particularly if you really enjoyed your food before the change in texture. With a change in diet, some people stop eating the foods they used to eat. Some people need some new ideas to get those foods to the correct consistency to continue to enjoy eating them.

If you are told that you need to ‘modify’ your diet, it may mean that only the texture of the food or fluids has to change. You should still be able to enjoy most of the tastes and food items that you did before. This can be achieved by using a different cooking method; or by doing something to the food after it is cooked (such as cutting it up small, adding sauce or gravy; mashing it with butter; or putting it in the blender). The important thing is what the food tastes like and what the food looks like after it has been ‘modified’.

3. Some foods are easier to modify than others

Some foods are naturally softer than other foods. Try to find foods that you already eat that are naturally soft, mashed or pureed. You may need to think creatively in order to find new foods that suit you, so that you have a wide variety to choose from. There are many resources available to help you think of these foods. The Nutrition in Practice Manual contains a list of these resources and many food ideas for modified diets.

4. Cooking methods and kitchen equipment

The way a particular food is cooked can influence how much you have to ‘do’ to the food after it is cooked. Slow cooking and cooking with moisture (such as sweet or savoury sauces or gravies) can make the food softer and easier to modify if necessary. A fork can be used to mash; a hand-held blender can be used to puree small amounts; a food processor can be used to mix from a coarse to a smooth mashed consistency or a lumpy to a smooth puree.

It takes practice to perfect the art of creating tasty, appealing food to suit a person on a soft, mashed, minced or pureed diet. Getting involved in the shopping, the food preparation, and most importantly, trying out new foods for taste, is a good way to ease into a new diet.

5. Using your imagination

It is helpful to have a 'brainstorm' early on when given a 'new diet'. Try to think of a wide variety of food ideas, and have some taste tests in order to see which of the 'new foods' you might like to bring into your regular meals. Think about different mealtime situations - such as breakfast, lunch, dinner, snacks, eating out, having take-away, and so on. All of these mealtime situations can have creative ways to suit diets of all textures - whether soft, mashed, or pureed.

It may take a little more planning, and sometimes there needs to be a variety of replacement foods for lunchtime, particularly if bread is too difficult and sandwiches are not recommended. With advance warning, some restaurants will modify foods that are on the menu to suit the individual, particularly for a regular customer. Some will give permission for special foods to be brought into the premises, but it is worth checking on this first.

6. Let's talk about food

Spend some time thinking about your 'old' diet and your 'new' diet.
"These are foods that I am used to!"
What foods are in your current diet that are soft enough for the new diet?
"Trying some new foods that are the right texture"
What are some new foods that you haven't tried before, that are in the new diet?
Use the food ideas in the Nutrition in Practice Manual and other resources.
Brainstorm with the cooks in your family, with your friends, and your staff in order to collate lots of ideas.
"These are foods that I have been told to avoid eating"
What are the foods that you will not be able to eat any longer? Are there any that you will really miss?
"These are foods that need to be changed to keep eating them"
Is there any way you can modify the foods that you used to enjoy, in order to keep them in your diet?

7. In summary

- Make some food lists
- Get involved in the shopping
- Try lots of tastes and flavours in dips and sauces
- Vary the sauces - tomato, cheese, cream
- Keep a note of the ideas that work … and the ideas that don't!
- Make a new 'favourites' list as time goes by

Talk to your Speech Pathologist and Dietitian for more food ideas. Refer to the Nutrition in Practice Manual and other resources listed in the Nutrition in Practice Manual for more information.