

A stylized, dark blue graphic of a human figure in a dynamic, athletic pose, possibly representing a person with a physical disability. The figure is composed of thick, rounded shapes. The head is a solid dark blue oval. The torso is a curved shape that flows into a long, sweeping arm extending downwards and to the right. The leg is a thick, curved shape that extends downwards and to the left, ending in a foot-like shape.

Nutrition with ALS

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This brochure is a result of the collaboration between dieticians and speech therapists of the Dutch Neuromuscular reference center (NMRC's) and Nema Association.

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1 INTRODUCTION

This brochure gives insight into food and nutrition problems in ALS and to this end provides several advices and possible solutions. Also people in your surroundings, caregivers (family, friends) and assistants, physician, nurses, etc. can use them.

When the intake of food becomes a problem, the tendency occurs to reduce the food intake altogether. But it's now that the food and liquid intake becomes crucial to maintain quality of life for everyone and not the least those suffering from muscle weakness.

Therefore an individual, personal guidance in the knowledge of nutrition will for sure not be redundant. The symptoms, complains and remedies can vary greatly from one person to another. Advice and treatment accustomed to your personal needs are required. You can find this in a neuromuscular center near you, where a team of experts is ready to support you on all grounds of influence on your condition.

Knowing what is going on in your body, and understanding what the therapist or physician is expecting of you, will make you less confused and anxious and will help to successfully apply a therapy.

In treatment of persons with a chronic illness, the emphasis is clearly placed on dialogue and openness between caregiver and you, the patient who needs to be well informed.



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2 WHAT IS ALS?

Amyotrophic lateral sclerosis (ALS) is a disorder of the motor neurons in the spinal cord and brainstem who control voluntary muscles in the body. When these neurons get affected with ALS, the muscles, under their control, weaken and eventually will shrivel. The affected muscle groups and the order in which they get affected vary from person to person.

One speaks of the 'bulbar' form of ALS when the muscles from the throat, face, neck and tongue weaken. Chewing, swallowing and the control of slime and saliva may cause problems.

These symptoms may also occur in the other form of ALS, the spinal form, in which the disease begins in the extremities like arms and legs.

ALS only occurs in adulthood, usually in middle and old age.

The exact cause of ALS is unknown. It only occurs for 5 to 10% in the family (familial-ALS; fALS) and in 20% of the cases an abnormality can be determined in the gene.

Curative therapies don't exist (yet), but certain medications can somewhat slow down the process.

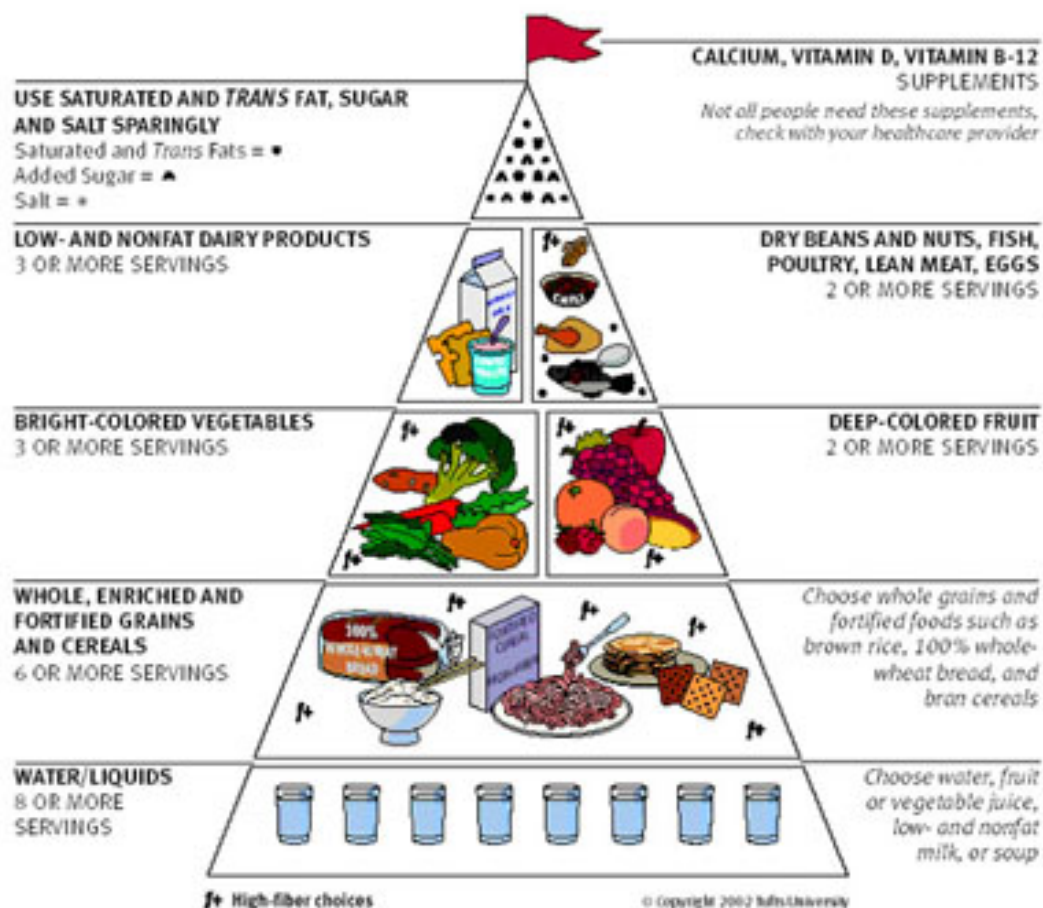
Regardless, an early diagnosis is very important to get started with the guidance and support on all area.

3 HEALTHY DIET

A healthy diet contains all the nutrients necessary for a normal functioning of the body. The nutrients pyramid is suggested as practical guide to a healthy diet.

The seven nutrient groups listed in the pyramid each accounting for a healthy, varied en balanced diet. Therefore choose daily from products listed in each group of the pyramid.

The size of the different groups gives you an idea of the amount you need on a daily base. The amounts listed per group are averages to be adjusted to your personal needs.



Food Pyramid

A Daily and varied diet intake based on the food pyramid provides sufficient nutrients: water, energy, proteins, fats, fibers, vitamins and minerals.

4 THE IMPORTANCE OF THE DIFFERENT NUTRIENTS

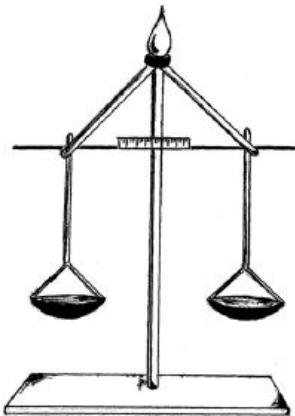
WATER is an essential part of the human body as well as of the daily diet. All the body functions depend on water. Because of the daily water loss of 1 to 2 l (breathing, transpiration, urination and defecation) it is necessary to compensate this loss daily by means of equal amounts of water and liquids.

ENERGY is the fuel measured in calories. The largest suppliers of calories are fats and carbohydrates. Energy is necessary to maintain and defend our body, to regulate our body temperature and to work the muscles.

PROTEINS are the nutrients for the muscles. A daily diet must have adequate proteins for growth and maintenance of the muscles. This will only be, if simultaneously the diet offers sufficient energy- otherwise the proteins will be consumed as fuel and not used for muscle maintenance and growth.

VITAMINS AND MINERALS have several important functions in the body. They are the adjuvants for the formation of muscles, enzymes, resistance, etc. A varied diet can accommodate these needs. But a too high intake of vitamins and minerals can be harmful.

DIETARY FIBERS are the indigestible parts of for instance vegetables, fruits, whole grain cereal (including oatmeal), legumes, nuts, etc. They maintain the human intestinal tract and are rich in vitamins and minerals. For a healthy bowel movement one needs sufficient fibers in the diet next to adequate fluid intake and exercise.



5 NUTRITION WITH ALS

When you are able to eat a sufficient amount of healthy, normal food, there are no specific dietary measures necessary. In case of insufficient energy intake, the body will start to consume its reserves resulting in weight loss. A Deficient in proteins in the diet will inhibits the repair and the structure of the muscles en will weaken the body furthermore. Continue a sufficient intake of all the nutrients is the message. It is possible that the relation between food intake and dietary needs will get out of balance.

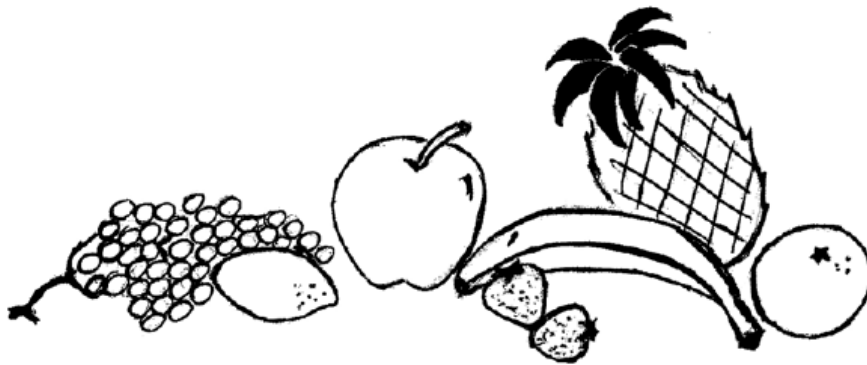
One may experience difficulties in chewing and swallowing. When the diet intake gets too low, the body weight may drop. This may lead to malnutrition, which in turn can cause further complications like dehydration.

With ALS the body weight may also drop due to degradation of the muscle mass. This amplifies the need for energy and proteins. The use of fats, concentrated carbohydrates (e.g. sugars) and proteins must be greatly increased (to even more than advised in the diet pyramid).

Constipation is a common issue with ALS. This is partly due to a lower dietary intake and partly by reduced exercise. An increase of dietary fibers is therefore necessary.

When one can't eat or drink enough due to chewing and swallowing problems, there are several possibilities to still ensure a sufficient dietary intake. These options will be discussed later in the brochure.

When your weight alters greatly, you better consult with an expert. For a personal nutritional advice you can definitely go see a multidisciplinary team, including a dietician and a speech therapist, at a neuromuscular center near you.

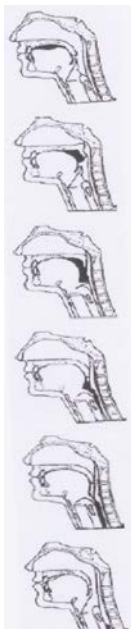


6 SWALLOWING

NORMAL SWALLOW PROCESS

The normal swallow process is a complex procedure, in which some thirty different muscles and nerves cooperate to bring the food or liquid from the mouth through the throat and esophagus into the stomach.

The schematic representation below can clarify the swallow movement.



In the first phase the food placed in the mouth will be guided by the tongue towards the molars for chewing. It gets mixed with saliva to become a chunk of food (bolus). This bolus, or an amount of liquid, is controlled by the tongue then pushed in to a rearward sweep movement to the pharynx, resulting in a sequence of swallow movements.

The vocal cords will be sealed off first, so no food can find its way into the windpipe. The nasal valve gets pulled up, to avoid food from getting in there.

By means of contraction from the throat muscles, the food gets pushed further down the throat into the esophagus.

The esophagus opens up when the larynx moves upwards and the food or liquid disappears completely in the opened esophagus.

This whole process takes, in normal circumstances, no more than 2 seconds.

7 DEVIATING SWALLOW PROCESS

Just because the swallowing is such a complex procedure, the coherence between different muscles, nerves and structures can sometimes go wrong.

Muscles disorders, where mouth and throat muscles are affected, can cause major swallow and /or eating problems. For some patients these swallow issues may be their first problem, with others they occur at a later stage of the disease.

All the same, it is important to recognize and identify the swallowing problems in time!

Below, you find a list of the possible symptoms you may experience and their causes.

Swallowing problems may cause many complications. Food may ebb into the mouth (regurgitation). Food or liquid may get into the windpipe (aspiration), which may cause choking or lung infection (pneumonia). Perhaps you don't dare to eat much because you are afraid of choking, which can lead to nutritional deficiency and weight loss.

8 EVALUATING THE SWALLOWDISORDERS

If during or separate from meals you develop difficulties to swallow, it is very important that you notify your medical team. Even when eating becomes tiring or when you start losing weight, it is recommended to contact an expert.

You will often be seen by a dietician and speech therapist. The dietician will check whether the swallow movement is efficient enough and whether you can have adequate and varied food intakes. The speech therapist evaluates the safety of swallowing and examines whether changes to posture, food thickness or the way you eat can be helpful.

Sometimes an additional radiological exam is needed to further investigate the swallowing detail. During those exams, you are given an contrast agent to swallow. As you do so, one can accurately assess the radiological course of the whole swallow movement.

Aberrant swallow course: possible causes and symptoms

Liquid or food passes from the mouth while drinking or eating.	The force of the lips is insufficient to powerfully keep the lips around a glass or a cup, or to keep them closed during swallowing.
Liquid runs up the nose when swallowing.	A soft palate contracts incomplete or insufficiently powerful, making the nasal passage remaining open during the swallowing.
Food remains in front of the mouth.	The tongue mobility has reduced, whereby the food can't be collected.
Food keeps sticking onto the tongue or the palate.	The tongue strength as well as the mobility are reduced so there is no strong backwards sweeping movement possible.

Chewing is impossible.	The tongue mobility is insufficient to bring the food sidewise to the molars.
Food gets stuck in the throat. Frequent and forceful swallowing is needed.	The throat muscles are weakened so they can't get the food down as fluently. If the tongue strength remains, a powerful sweeping movement can be compensating.
	The tongue is incapable to control liquids in the mouth, till all involved is ready to swallow, causing liquid running down the throat without any precaution to the trachea.
Coughing during or after eating solid food.	There may be some food scraps hanging in the throat, which after swallowing may end up in the trachea.

9 IF SWALLOWING BECOMES A PROBLEM: SPEECH THERAPY ADVICE

As a result of a loss of sensory and motor function in the upper neck region, the majority of patients with bulbar ALS encounter swallowing problems. These may increase during the course of the disease process. It's the task of the speech therapist to help you eat in a safe and comfortably way possible. At the early stage it often is enough to establish some compensation measures to facilitate the swallowing. When the swallowing problems increase, therapy is advised and the knowledge about what you and your surroundings can do when choking occurs.

COMPENSATING MEASURES

Beneath you can find some useful compensation strategies. But for a personalized assistance it is recommended to contact a speech therapist.

➤ **Posture**

It is important that you maintain a straight up position with your head slightly bent forward. This goes at the table as well as in bed. A slump with the head tilted backwards posture only increases the risks of choking. Therefore also use wide cups or glasses instead of the tumble cups.

➤ **Consistency (thickness) of the food**

When the sensitivity and strength in the mouth area reduce, you can get problems with consuming certain foods.

➤ **What if you choke in liquids?**

Hot or cold beverages, liquid foods, soups and desserts can be made less fluid by using a powdered thickening agent. Another possibility is the use of gelatinized (thickened) water. Both are available at the pharmacist.

➤ **• What if you choke on solid food?**

Solid food of uneven thickness (e.g. soup with chunks or meatballs) is liable for choking. Even dry, crumbled (e.g. cookies) and hard food (e.g. unpeeled fruits, legumes ...) can cause problems.

When these problems occur, you better stick with semi-solid food like crust less bread, soft en peeled fruit, mashed potatoes, rice, pudding, yoghurt, ice crème, etc. You can also crush your food with a good mixer and extra added cream, milk, fat etc.

There are also ready-made powder products which offer a worthy alternative for bread and /or hot meals e.g. instant oatmeal, instant mashed meals etc.

For specific product information, it's best to contact your dietician.

➤ **Temperature of the food.**

Both cold and warm food stimulates the swallow reflexes. To avoid your food from cooling off too fast, you can use a preheated plate or a hot water reservoir plate.

10 METHODE OF PRESENTMENT

Use manageable portions. Too small quantities will complicate the swallow reflex, as in contrast, too large portions may lead to choking.

Put the food centrally in the mouth. That way you can easier swallow it away. In order to generate the swallowing reflex, you can use a spoon to exert slight pressure on the tongue. Try to use ordinary tools as long as possible, instead of a tumble or thermal cup.

➤ **Pace**

Eat slow. Only take a new bite, after you completely swallowed the previous one. Don't think that a next bite will maneuver the previous one away. It is better to swallow again.

➤ **Surroundings**

It is recommended to have a meal in a quiet area, so you can concentrate better on the eating itself. Try not to communicate while eating.

➤ **Oral hygiene**

Make sure that your mouth and teeth (denture) are clean at the start of a meal. Check your mouth after eating on possible food scraps left behind. Brush your teeth regularly or rinse your mouth after eating.

SPEECH THERAPY

The swallowing rehabilitation is, next to the compensation techniques, very meaningful. Depending on your symptoms and the stage of the disease, they focus on the strength and sensibility of the oral area. In addition (preventive) swallow maneuvers may be taught to obtain a better safeguard of the pharynx.

You can contact a private speech therapist for this or go to one of the acknowledged revalidation center near you. In both cases the therapy is limited to a certain amount of sessions and will be reimbursed to a large extent by the Belgian Medical Association.

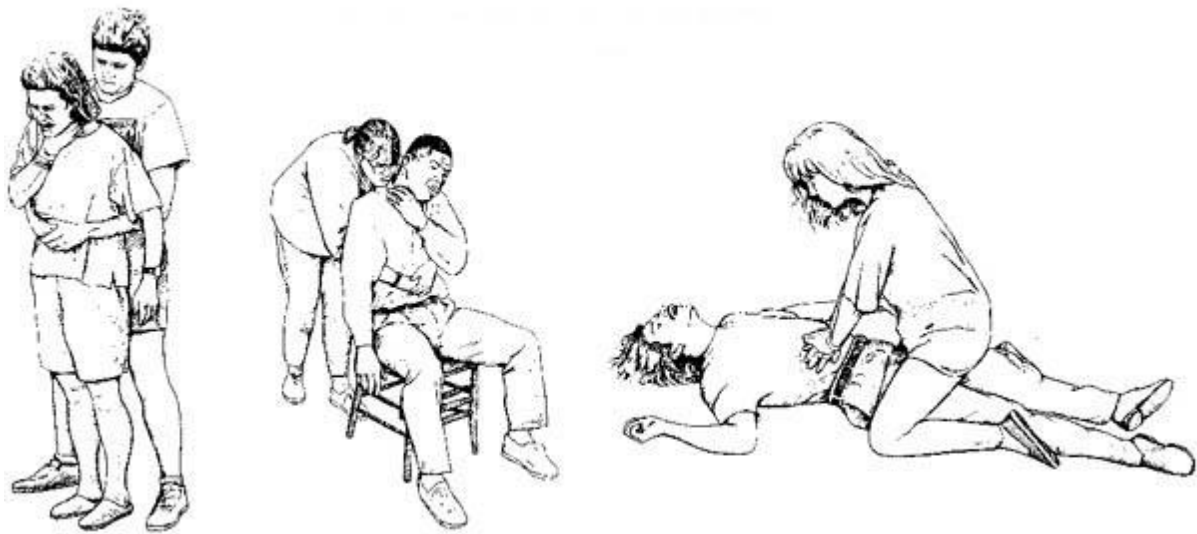
HOW TO RESPOND TO CHOKE

When you choke, you can clear your airway just by coughing. Suppressing the cough reflex might be dangerous.

In case of a piece of food been stuck between your vocal cords or in your windpipe, and you are not abler to release it, the Heimlich maneuver can be performed. Somebody performs firm pressure onto your diaphragm, causing the air in your lungs to be powerfully pushed outward. Thus the food chunk will be coughed up more easily (see picture below)

In case of frequent choking or in case of unexplainable, sudden fever it is advisable to contact a physician and if possible having a radiological examination of the swallow movement done.

The Heimlich Maneuver



The Heimlich Maneuver step by step instructions for the caregiver:

A *The person who is choking, is seated.*

- 1) Stand behind the person.
- 2) Place your arms around his waist
- 3) Make a fist with one hand
- 4) Place your fist with the thumbside just below the diaphragm
- 5) Put your other hand on your fist.
- 6) Make a strong upward movement
- 7) Repeat this maneuver until the food chunk is removed.

B *The person, who is choking, is lying down.*

- 1) Ensure that the person is lying flat, preferable on the floor
- 2) Put the palm of your hand under his diaphragm.

- 3) Place your other hand on top of it. The fingers are pointing up toward the head.
- 4) Make 6 to 10 short powerful upward movements.
- 5) Open the person's mouth and grasp the tongue and lower jaw in one hand.
- 6) Press the lower jaw and tongue down.
- 7) Remove the food chunk from the throat with the other hand's index finger.
- 8) Repeat if necessary.

11 WHEN EATING BECOMES A CHALLENGE

When all the previous advices aren't sufficiently helpful to you to take up the necessary nutrients, it is sometimes required to use dietary preparations. In general, these compositions provide in a small amount a lot of energy, vitamins and minerals. The range of these products is so extensive, that it's advisable to consult an expert first. He will be able to better help you making the right choice. We can distinguish between dietary preparations in liquid form (liquid nutrition) and dietary modules.

Als de voorgaande adviezen u onvoldoende helpen om de nodige voedingsstoffen op te nemen, is het soms nodig om dieetpreparaten te gebruiken. Algemeen geven deze preparaten in een klein volume een bom aan energie, vitaminen en mineralen. Het gamma van deze producten is zo uitgebreid dat u zeker eens te rade moet gaan bij een deskundige. Hij/zij zal u beter kunnen helpen bij de juiste keuze. We kunnen een onderscheid maken tussen dieetpreparaten in vloeibare vorm (drinkvoeding) en dieetmodules.

➤ **Liquid Diet**

Depending on your nutritional needs and what you yourself can, may and want to eat and drink, you can choose a specific liquid nutrition. Available are complete or additional liquid nutrition.

➤ **Complete Liquid Diet**

A complete liquid nutrition provides all the nutrients needed for your body to function normally: proteins, fats, sugars, vitamins and minerals. So you can use them as a full replacement or as a supplement to the normal diet.

In case of a general and greatly reduced appetite or if you can't eat solid food, a complete replacement nutritional drink is the best choice.

Additionally 1 to 3 portions a day will be sufficient, resulting in 300 to 900kcal.

As replacement 6 to 7 portions a day are necessary or 2 portions per meal, which delivers 1800 to 2100 kcal. This diet is available based on milk or yoghurt, and with or without fibers.

➤ **Supplementary Liquid Diet**

An additional nutritional drink contains certain nutrients in higher concentrations, e.g. proteins, or is without specific nutrients, e.g. fats.

That's way these liquid diets can't completely replace a normal diet, but only supplement them.

When you get selective on your diet, when protein sources in your diet are lacking (no or little meat, little cheese or dairy products), or when extra supply on proteins is required, you can use protein enriched food drinks, usually based on milk. 1 to 3 portions a day is sufficient.

With a rather general reduced appetite, one can use some extra energy by means of juice drinks. These are mainly fat free en therefore easy digestible, which benefits the appetite, but contain less energy compare to those based on milk. These are also helpful when you suffer easily from mucus. You cannot consider these drinks as a complete diet, since there is none or very little fat in them. Usually 1 to 3 portions a day are recommended.

In case of swallowing difficulties, a liquid diet can cause problems, because we are dealing with a thin liquid. Therefore, liquid diets are marketed in pudding phase, as an energy-riche dessert. You can only take them as a supplement to your diet, and not as a diet substitute. It is milk based and specially enriched with vitamins and minerals.

This dessert contains a small volume of 125 g. of calories compare to a regular pudding
Due to its consistency the chance on choking is much smaller because it doesn't turn liquid in interaction with saliva, which is the case with regular pudding.

➤ **A few useful tips when using liquid diets**

- Spread the supplementary liquid diets well over the day, preferable in between meals. Otherwise it might be that your appetite gets compromised during the general meals.
- Sealed liquid diets can be stored at room temperature. Once opened, they stay stable for 24 hours in the refrigerator and for about 2 hours if not refrigerated.
- Make sure you have enough flavor varieties. There are many kinds available most of them are sweet fruit flavors. Some manufactures even offer original flavors like citrus-cola, coffee or pink grapefruit and soups.
- A liquid diet is best served chilled. There are of course kinds that are better served warm, like the coffee and soup diets.
- If you have mucus problems, we recommend the fresh-sour flavors based on yoghurt or juice. Liquid diets based on milk can evoke the mucus.

12 DIET PRODUCTS OR MODULES

A module is a concentrated preparation that contributes **one nutrient** which you can mix into your diet. These modules are mainly available as a powder, but can be offered in liquid form. Their purpose is to enrich the daily diet. But due to the introduction of the liquid diets, these modules are used less.

There are modules based on e.g. sugars or proteins or on fats. That way you can enrich your daily soup with a fat-module, to make it creamier. Or you can add some extra proteins to your pudding dessert.

Modules are best consumed under supervision, because an overdose can happen easily, as these products are highly concentrated.

13 SALIVA AND MUCUS FROMATION

➤ Saliva

Everyone produces saliva en swallows it away all the time without thinking. During meals the saliva glands get activated in order to secrete their thin saliva. Saliva is important for the digestion of food as well as the oral hygiene. People with ALS develop an excess of saliva mainly because they swallow less frequently.

➤ Suggestions

One can succeed in controlling the abundant saliva just by being aware of the problem and to learn to consciously swallow the saliva. One can avoid products that stimulate the production of saliva, namely acidic drinks and diets like grapefruit juice and mashed fruits. In addition there are drugs available that inherent the saliva production and thereby keep the mouth dry. Your physician can inform you further on these matters.

➤ Dry Mouth Suggestions

In case of dry mouth, you can sip on ice water (if you can easily swallow it). Another way is to use cotton sticks dipped in water or mouthwash.

Some people use a vaporizer or mouth humidifier.

Maybe the cause is within the drugs you take. So ask your physician whether your medicines can evoke dry mouth.

Make sure that your house and especially your bedroom, maintain a suitable humidity. You can use a humidifier for that.

➤ Mucus

Especially milk products as milk, chocolate milk, chocolate, instant porridge and custard can evoke mucus formation. The mucus-forming effect is different for each person.

➤ Suggestions

The products that are less mucus enhancing are the acid milk products like yoghurt, soy milk, and buttermilk.

Just by exchanging the sweet by sour products one can reduce the symptoms.

If you suffer from mucus after eating or drinking, it's recommended you rinse your mouth thoroughly after a meal. Products that have a mucus resolving effect are pineapple juice, (dark) beer, red wine and Camilla tea. You can drink these during or after a meal, or you can just rinse your mouth with it.

14 TUBE FEEDING

Tube feeding can be a solution when you cannot, may not or even don't want to eat and drink in a sufficient extent, e.g. due to severe swallowing problems.

Therefore you better consult with your physician and /or team of nutritionists about when and how you can switch to tube feeding.

WHAT IS TUBE FEEDING?

It is a liquid, complete, and balanced diet that is administered, by means of a thin tube, directly into the stomach or intestine.

It is a proper diet composition which provides the needed energy, nutrients and moisture. It is a safe way of feeding, without changes on choking. Tube feeding can perfectly be administered at home. In case tube feeding is additional, you can still enjoy the general meals or just eat what you like. It can even be a temporary solution, in case of dealing with a tough period, as well as a permit decision. The pressure of having to eat disappears when tube feeding has started.

Because not everyone can handle the same type of tube, there are different options available. A team of nutritionists can assist you in making the right choice for your probe.

HOW WILL THE TUBE FEEDING BE ADMINISTERED?

The bottle – or bag containing the food is placed on a tripod. On this tripod, a pump system can be added which guarantees for a certain pace of feeding. This way, the flow rate (this is the amount of ml per hour) can be tuned exactly. Tube feeding is also possible without a pump, by means of the force of gravity. In this case, the administration is less accurate to set.

The food, from the bottle or bag, will go into the probe through a thin tube. This procedure is called 'trousse'. It is the connection between the food and your probe. When using a pump, a different type of 'trousse' will be needed compare to the use of gravity for the feeding. It is very well possible to also administer medicine by means of the 'trousse'. Of course it goes without saying that you must take extreme hygiene measures. The 'trousse' must be rinsed thoroughly after each feeding and be regularly replaced by a new one.

There are two types of probes: one through the nose and one through an opening in the abdominal area.

A **nasal probe** (or nasogastric probe) is a very fine tube that goes via the nose into the stomach. This type of probe is inserted in case of temporary tube feeding, since this tube can be very annoying. It irritates the nose, often doesn't fit right, isn't ideal esthetically, and gets quickly clogged.

An **abdominal probe** gets inserted via a hole in the abdominal wall. This type is also called a PEG-probe (percutaneous-endoscopic Gastrostomy). It sounds worse than it actually is. A small incision is made, under local anesthesia, in the abdominal wall at stomach height. Subsequently the probe is inserted with an 'guide wire' via the mouth and esophagus into the stomach and then attached by a button along the opening in the abdominal wall. The surgery goes quickly, and is virtually painless. It doesn't require a long stay at the hospital to have the gastrostomy placed and the tube feeding started. Mostly it doesn't take longer than three days. After surgery the trousse gets connected to the probe. SO this doesn't go through your nose, but is neatly hidden under your clothes. The risks of clogging and irritations are much smaller than with a nasal probe. Here too, hygiene is of the highest importance. A daily disinfection of the probe is not a luxury. You do have to turn the button slightly every day to avoid it from permanent growing together, this doesn't hurt at all. This probe needs to be replaced only after 6-12 months of use.

There are various **treatment schedules**.

One can **continuously** drop wise administer. In this case, the feeding is usually for 20 hours a day, so that there is 4 hours left for disconnection of the probe.

Tube feeding can also be administered drop wise during a part of the day. This is mainly overnight, and mostly involves additional feeding. About two to three hours before breakfast, the additional feeding is stopped, to ensure a good appetite for breakfast. The system stays disconnected for the remainder of the day. This way it will of course provides better movement during the day.

In case of feeding **per serving** (in bolus) a certain amount of food will be given at once, mainly about 200 to 250ml. This can be done by syringe. This way of feeding means a greater burden on the stomach.

PRACTICAL GUIDELINES PRAKTISCHE RICHTLIJNEN

- Wash your hands thoroughly.
- Make sure your food is at room temperature, certainly not from the fridge or reheated.
- Shake the food well, so that all the nutrients are dissolved.
- Disinfect the opening of the bag or bottle.
- Open the trousse and connect it with the bag or bottle.
- Then connect the other end of the trousse with the nasal probe or the gastric probe.
- When using a pump, adjust the flow rate and turn on the pump. When you are not using a pump, you have to set the roller clamp of the trousse to the right amount of drops.
- First have the food dropped to the end of the trousse, to avoid air into the trousse, which would be very unpleasant for your stomach. It will give you a bloated feeling.
- Place yourself in a 30° position, so not completely horizontal.
- It is of greatest importance that the trousse gets thoroughly rinsed with water after the feeding, to insure it's clean. Otherwise it will become a breeding for all kinds of bacteria.
- Replace the trousse regularly.
- Even your probe has to be rinsed with water after each meal, to ensure no food remains are left. When it's not completely clean, you can try rinse it with some regular coke. This will dissolve last remains.
- Do not forget to disinfect the surrounding of your probe and keep it dry, so the skin around doesn't get irritated.

15 TUBE FEEDING: QUESTIONS AND ANSWERS

WHAT TO DO WHEN THE PROBE IS CLOGGED?

- First check whether the probe is creased, this causes a blockage.
- Use a 50ml syringe (not a smaller one, the pressure gets too great otherwise) and try to extract as may food out of the probe as you can.

- Afterwards, spray the probe thoroughly with water.
- If unclogging with water doesn't work, spray some coke (not coke light) into the probe and leave it for a few minutes and try again with water.

HOW DO I TAKE MY MEDICATION WITH THE PROBE?

- You can take liquid and finely crushed medicines through the probe.
- Always ask permission from your physician, because not all medicines can be crushed.
- Never mix the medicines with the food.
- Dilute finely crushed medicines in a large volume of water.
- Rinse the probe with about 20 ml water before and after administering the drugs.

CAN I SHOWER OR HAVE A BATH WITH THE PROBE?

- Of course, but make sure that the button is waterproof sealed.

WHAT TO DO WHEN THE GASTRIC PROBE IS DETACHED?

- Consult with a physician as soon as possible. When not too many hours have passed, the probe can be re inserted without a problem, but never try to reposition a probe yourself.
- The probe may loosen by coughing or vomiting. Avoid this by keeping a half-seated posture.

WHAT TO DO WHEN THE SYSTEM LEAKS ?

- Check all the connections:
 - ✓ Connection 1: between nutrition and trousse (pipe)
 - ✓ Connection 2 between trousse and probe opening (entrance of gastrointestinal tract)
 - ✓ Make sure you use a universal connector.
- If necessary you can always contact a homecare nurse or the main company of tube feeding.

I AM GETTING STOMACH ACHES/DIARRHEA. WHAT ABOUT THAT AND WHAT CAN I DO ABOUT IT?

- Possible causes are:
 - ✓ An infection,
 - ✓ certain medications (e.g. Antibiotics),
 - ✓ too quickly start of the tube feeding,
 - ✓ too high administration rate (flow rate: number of ml/hour administered)

- What you can do:

- ✓ Try to administer the nutrition drop wise, whether or not regulated by pump.
- ✓ Replace the dosing system daily to avoid contamination.
- ✓ Take the diet at room temperature. Also store it at room temperature as well and out of direct sunlight. A too cold or too hot tube feeding is highly irritating to the intestines.
- ✓ Never use a tube feeding diet over 24 hours.
- ✓ Lower the administration speed. High speeds often cause diarrhea.

- When, despite these measures, the diarrhea still persists, notify a physician!

I HAVE NAUSEA AND ACTUALLY HAVE TO VOMITE. WHAT ABOUT THAT AND WHAT CAN I DO ABOUT IT?

- Possible causes are:

- ✓ An infection,
- ✓ Certain medication,
- ✓ A bad posture when administered (too flat),
- ✓ Too large servings in a short period of time,
- ✓ A flow rate of over 200ml/hour,
- ✓ Too cold tube feeding,
- ✓ A too thick nasal probe.

- What you can do:

- ✓ Try switching to a more continuous.
- ✓ A thick probe often causes nausea, because the sphincter of the stomach is more open. Ask your physician whether a smaller probe is an option (charriere 8).
- ✓ Check the headboard of the bed. When tube feeding is administered one has to make sure one is sitting in a 35° angle. (= half seated position).
- ✓ Make sure the tube feeding is given at room temperature.
- ✓ Ensure that the flow rate isn't below 200 ml/hour. A greater speed often triggers to vomiting.

I AM CONSTIPATED. WHAT ABOUT THAT AND WHAT CAN I DO ABOUT IT?

- Possible causes are:

- ✓ too little fluid administration,
- ✓ insufficient exercise,

✓ certain medications like analgesics (narcotic drugs) antacids (for heartburn), anticonvulsants, diuretics (urinary bladder drugs), anti-depressants and prolonged use of laxatives.

✓ too low fiber diet,

✓ complication of the disease itself.

- What you can do:

✓ Try anyhow to get about 2 liters of fluid in 24 hours timeframe (inclusive the nutrition). Don't forget that in case of fever, diarrhea, wounds, or nausea one needs more fluid

✓ Ask the physician to possibly switch to a high fiber tube feeding

✓ More exercise (if possible).

CAN I GET REIMBURSEMENT FOR THE TUBE FEEDING?

- Yes. The conditions are that you will be treated in your surroundings, i.e. at home, a nursing home, or an elderly home and that your disorder is listed among the diseases that are eligible for a financial intervention. Your physician is aware of this.

WHERE DO I APPLY FOR THE REIMBURSEMENT?

-The form 'request for reimbursement', must be completed by the treating physician. Usually this is done in the hospital, where the tube feeding is started.

- When finished you have to provide the form with your label of health insurance. Consequently you fill this form to your health insurance. Note: It is wise to make a copy for your records

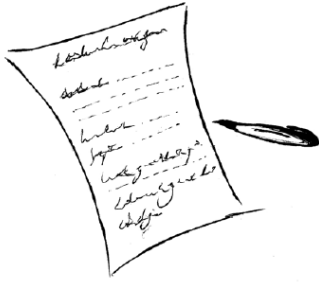
- After about 2-4 weeks you will receive an approval to reimbursement by the national health insurance

- This approval only stands for a year, and therefore has to be renewed annually. .Note: also in case of adjustments (e.g. type of tube feeding, pump use, etc.) one has to file a new request.

- All the invoices of purchase have to be filled monthly, copied for your records, and the originals send to the health insurance service.

- When tube feeding is purchased at the pharmacist, he will have to complete a 704F form, which defines the purchase of tube feeding, trousse, probes, rental pumps material etc. and provides with a stamp and signature of the pharmacist.

- If the tube feeding is purchased from a homedelivery company, the invoice is seen as a valid intervention.



WHAT ARE THE COSTS OF TUBE FEEDING AND ADMINISTRATION SYSTEMS?

The cost of tube feeding with all its accessories is strongly depending from the brand and the product you need. Furthermore the prices change quickly, therefore the information is quickly outdated as well. That's why we cannot mention concrete costs. It's best to get well informed when the time comes. Despite the intervention from the insurance, you will still have to pay your share.

WHERE CAN I BUY TUBE FEEDING?

You can purchase tube feeding at your local pharmacy. Some pharmacists also provide accessories. Pump rental is usually not done. Ask for information and prices at different drugstores. Don't forget to always ask to complete a 74 F form.

You can also get your food and equipment from a homecare company. Each company that sells probe products has its own homecare department. Check which company provides your food, and contact their homecare department. Not only the prices vary between companies but also their rental conditions and after sale services (e.g. startup of tube feeding, monitoring, supplies, problem solving, availability, etc.

WHERE TO TURN TO WITH QUESTIONS AND PROBLEMS?

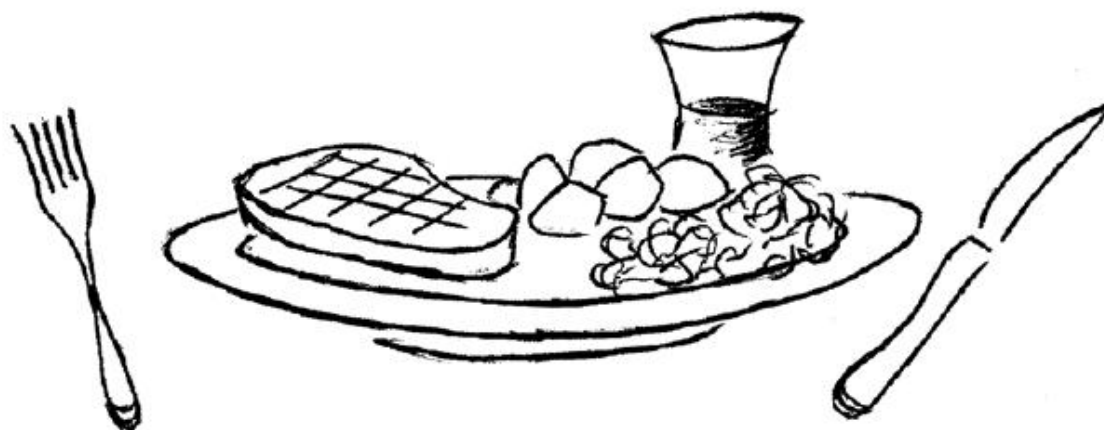
- When you deal with a home care company, you better contact their service department. Depending on the company, they might have dieticians who can be of assistance.
- When you do your purchases at the pharmacy, you can turn to them for assistance or even to your physician
- Otherwise you can call the dietary department of the hospital, where the tube feeding has started.

16 CONCLUSION

This brochure can be helpful when, due to your conditions, you need to adapt your eating habits.

Eating is not just a technical matter. Dining is also a social event, making it even harder if eating and drinking are a burden. This nourishes the feeling of being a big burden to others. But don't forget that also for those struggling with eating and drinking, a quality and meaningful live is just as possible as for others.

If you have difficulties with this, you can always turn to the psychological counseling offered at your local NMR center. A good relationship and contact with other patients can also be very helpful.



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