

LIVING WITH DYSPHAGIA AFTER AN ICTUS

A GUIDE FOR PEOPLE WITH SWALLOWING
DIFFICULTIES AND THEIR CAREGIVERS



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Introduction

Having an ictus can leave you feeling weakness on one side of your face, having difficulties to control your tongue or throat and finding that chewing and swallowing is harder than before. This can get in the way of following a proper diet and staying hydrated.

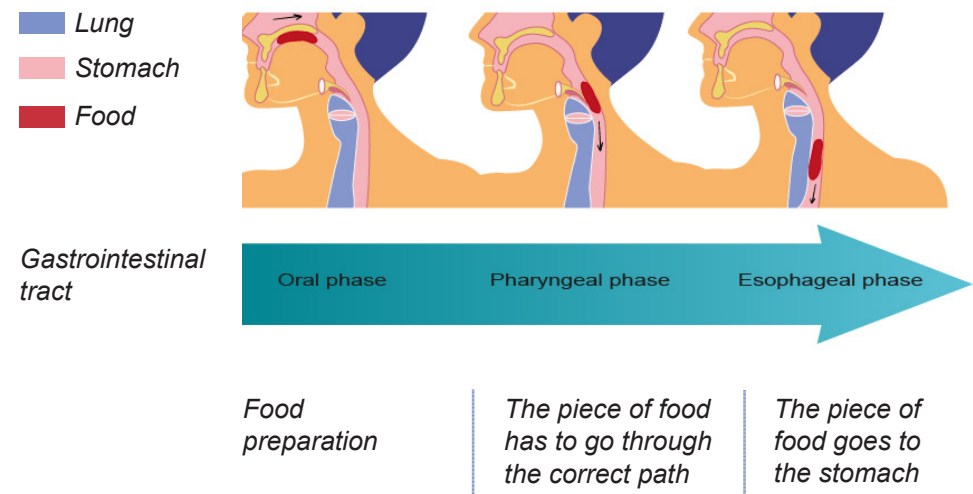
Sometimes, if the issue is not detected and is left untreated, you are at risk of choking or getting acute respiratory infections.

The goal of this guide is to serve as a summarized collection of all the helpful information for people with dysphagia after an ictus and their caregivers.

It is also meant to give visibility to the condition and to rise awareness about the importance of communicating these issues to one's primary care providers (nurse and family physician) by facilitating self-care and providing information about how to prevent potential complications.

Swallowing

Deglutition or swallowing is the passage of food, saliva and fluids from the mouth to the stomach. You can see the swallowing stages in the following picture:



What is dysphagia?

A person with dysphagia has trouble swallowing food. There are several different types of dysphagia. Your physician and nurse will help you understand which one you have.

Types of dysphagia

- **Depending on its cause:**

- **Organic or mechanical dysphagia:**

There is an obstruction in the digestive tract that makes it difficult for food to pass through, due to tumors, infections or other causes.

- **Functional or motor dysphagia:**

In this case, swallowing mechanisms are altered (weakness of the facial or throat muscles, transmission failure in the swallowing command of the brain, lack of coordination in the sequence...), as it happens in neurological diseases, cerebrovascular accidents, dementia or in the elderly, among others.

- **Depending on the affected swallowing phase:**

- **Oropharyngeal dysphagia:**

The difficulty can come up anytime from the moment the food or drink enters the mouth until it reaches the entrance to the oesophagus.

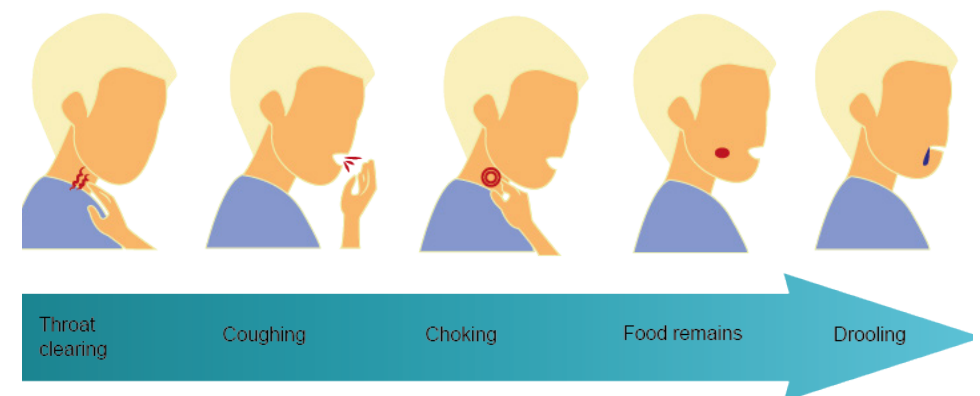
- **Esophageal dysphagia:**

The difficulty can appear from the moment the food or fluid goes into the oesophagus until it reaches the stomach. Oropharyngeal functional dysphagia is the most common after an ictus.

Main signs of dysphagia

People who suffer from dysphagia may have:

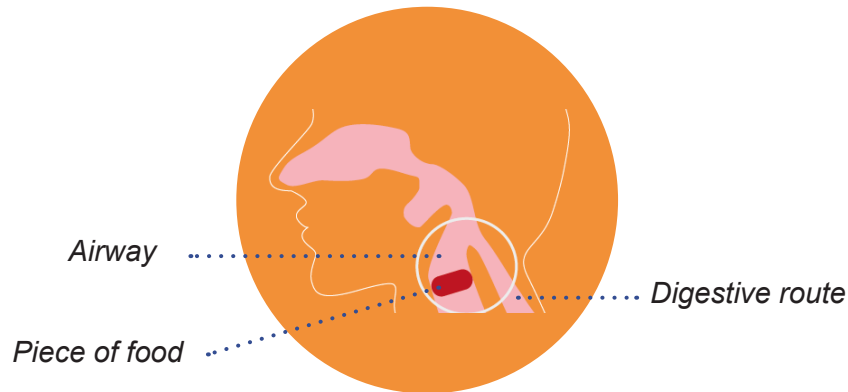
- Persistent cough and throat clearing during or after meals, which is more common when drinking fluids.
- Frequent choking.
- Voice changes (aphonia or loss of voice, wet-sounding voice), usually during meals.
- The need to swallow several times in order to have one tablespoon.
- Frequent drooling.
- Food held in the cheeks.
- A much slower pace for eating.
- Fear of eating, because it has become difficult and takes a huge effort.
- Changes in nutritional habits — rejecting to eat certain foods or fluids that were eaten often before and now are avoided because of fear of choking.



If you notice some of these signs or symptoms, please inform your physician or nurse as soon as possible. They will initiate the community health center's protocol for screening, detecting, making a diagnosis and establishing a treatment for dysphagia.

Which are the most frequent complications?

A person who suffers from dysphagia may not ingest enough food or fluid and it can result in dehydration or malnutrition. Choking and food getting into the lungs may occur as well, which may result in breathing difficulties and acute respiratory infections.



How to deal with choking

Only air should enter the airways.

When other elements such as pieces of food pass through, the result can be a life-threatening obstruction.

In the case of a partial obstruction (some oxygen can pass through), the person will be able to speak and breathe.

The key is to cough or encourage the person to do so. That will clear the airway.

In the case of complete obstruction, it will be impossible for the person to breathe, speak or cough. It is important for the people close to them to know what to do and be able to perform the Heimlich maneuver.

Assessing whether there is a complete or partial obstruction

- **Partial obstruction:**

The person can breathe.

- Do not tap their back.
- Encourage them to cough.
- Check if they remove food scraps by the mouth.

- **Complete obstruction:**

The person cannot cough or speak, they have their hands on the neck and show agitation.

If the person is unconscious:

Call 112

CPR



If the person is conscious:

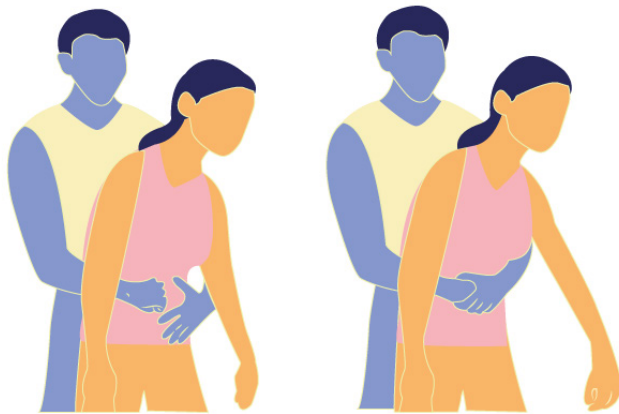
5 hits between the shoulder blades

5 abdominal compressions (Heimlich manoeuvre)



How to perform the Heimlich maneuver

The person should place themselves behind the patient and enclose their arms at the level of the patient's abdomen. A fist should be placed in between the patient's chest and their abdomen, while the other hand should be placed on the fist to push upwards.



Nutritional and hydration status assessment

Your physician and nurse will assess your nutritional and hydration status by using your clinical and nutritional history, a physical examination, your BMI (body mass index), blood tests and the assessment of the interactions of the medications you take.

Good practices for eating with dysphagia

- Keep a varied and balanced diet.
- Take into account the presentation of the food.
- Have several small meals a day.
- Eat only one full, nourishing dish in order to avoid tiredness derived from eating.
- Keep a smooth and uniform consistency of the food.



*The three keys for eating with dysphagia are:
VOLUME ADJUSTMENT, VISCOSITY AND TEXTURE.*

You may need to adapt the consistency of your food, both solids and fluids.

Solid foods consistency varies depending on its specific problem. It can range from a diet with mashed solid food, more or less thick, with a smooth texture and without chunks, to a diet consisting of soft food that can be bitten and swallowed easily.

How to approach diet progression

Homogeneous, grinded diet

This will be a suitable diet when:

1. It is not possible to chew well.
2. It is not possible to completely close your lips.
3. There is low mobility and weakness of mouth and face.
4. Difficulty to control, maintain and make an alimentary bolus inside the mouth.
5. Alteration of the pharyngeal phase.

It is recommended to start with purées of smooth, uniform consistency (do not mix different types of consistency).

It is possible to use thickeners, depending on the needs of the person.

Here are some examples:

- Cremes or purées of all types of solid and well sifted foods, custard, fruit shakes, fruit, purées, etc.

Soft texture diet

This is the next step of the grinded diet, but there is not a mix of consistencies.

Foods that split into firm, dry pieces should be avoided.

It is possible to have this food with spoon or fork and mould it.

Here are some examples:

- Pudding, fish or cheese cake, mousse, soufflé, flan, etc.

You can try this diet when you feel able to chew softly and handle the piece of food in your mouth, but there can be the following difficulties:

1. Alteration of the pharyngeal phase.
2. Your tongue does not move properly or does not have enough strength to push the food backwards.

Easy-to-chew diet

This diet has the following characteristics:

Soft but wet foods, not grinded.

It requires soft chewing.

It is accompanied by thick sauces.

It admits texture modifications.

It can be easily grinded with a fork.

Here are some examples: full foods that are soft, such as an omelette, boiled fish, boiled potato and ripe, boiled, roasted or stewed fruit.

This kind of diet is indicated as a transition to a normal type of nourishment.

Fluids should have the viscosity recommended by the patient's health providers and will be adapted to every person.

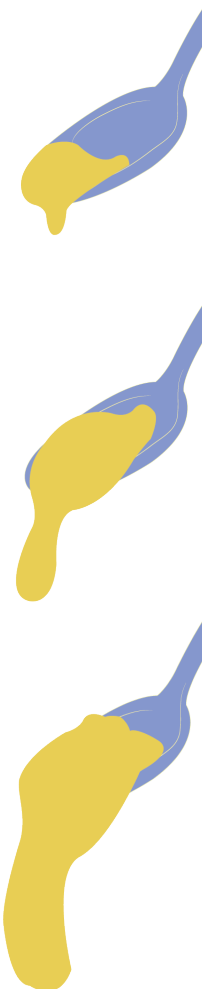
Viscosity of fluids can be:

- **Thin fluids:** water, coffee, milk, infusions, etc.
- **Nectar** or mildly thick, which has to be drunk in a cup: peach juice, liquid yogurt, etc.
- **Pudding** thick, which has to be had with a spoon: flan, gelatine, etc.

It is recommended to adapt the volume of the spoon to the person, to choose the one that has the lowest risk for the health.

For that, we will use different sizes of spoons: coffee spoon, dessert spoon or tablespoon.

When it comes to modifying fluids viscosity, the general approach is to buy commercial thickeners, but it is possible to use natural ingredients to increase the consistency of fluids.



Food and fluids to thicken

» MILK, YOGURT, HOMEMADE JUICES, SUPPLEMENTS

Powder porridge cereals.
Biscuits or cupcakes: add the ingredients and mash them to get a purée texture.
Corn flour: add cold and heat later.

» JUICE

Powder porridge cereals.

» WATER

Use gelatine or a commercial thickener. Put the powder first and add water later.

» SOUP, BROTH, CREME, PURÉE

Flours (corn, legumes, tapioca, etc.).
Semolina, rice, pasta or boiled potato.
Mashed potato flakes.

Add the thickener gradually in all the recipes. After that, dissolve or mash until getting the proper texture.

Risky food for people with dysphagia

Pay special attention to these types of food, you may need to modify them before having them.

Slippery food:

peas, clams, beans...

Mixed consistency food:

milk with full biscuits, rice soup, pasta...

Liquid that leaks from solid food:

watermelon, orange, tangerine, pear...

Melting food:

ice-cream, gelatine...

Food that doesn't make an alimentary bolus:

rice, uncut legumes, peas...

Food that gets shred in the mouth:

minced meat, puff pastry, toasts...

Sticky foods:

condensed milk, honey, bakery, sweets...



Environmental conditions

It is important to pay attention to the environment while eating, whether the person with dysphagia can eat on their own or they need another person's help. It is important to have in mind the following recommendations:

A quiet, distraction-free, noise-free environment (avoid hectic places, television, radio and other distracting elements).

A lit up, clear, pleasant environment.

Avoid eating on the bed. If you have to, use pillows and a cervical cushion to keep your back straight and your neck slightly forward-leaning.

Use ménage that is adapted to your needs.

If you are helping someone else, try to encourage their independence by letting them do everything they can on their own, but with your supervision.

Establish fixed schedules for daily meals, avoiding drowsing hours and checking first that the person is woken up and responds to simple orders.

If the person is sleepy or anxious, please wait for them to wake up or relax before feeding them.



Posture

Keeping a proper position during meals is crucial to avoid complications in people with dysphagia.

- Try to keep your head line-up with your trunk. Keep your back touching the chair back.
- Use a short-back chair — that will help your head lean forward and your chin downward the chest (which will help you swallow).
- Your feet should be on the floor and your arms on the table or on the chair armrest.
- If the person is bedridden, the back of the bed should always be raised higher than 45 degrees and as close as possible to 90 degrees.



After the meal, the person must be sitting up at least 40 degrees for 30 or 40 minutes without laying down in order to avoid gastric reflux and the possibility of some stomach content getting into the airways.

Some advice to avoid choking

- Show calm and assurance. Sit down in front of the person at their level to let them know and see what you are feeding them.
- It is very important to offer the spoon from below to above in order to avoid hyperextension of the neck.



- Respect the person's pace to eat, having in mind that the recommended duration of meals is 30 or 40 minutes and its should not take longer.
- If the person has facial paralysis, feed them on the healthy side of the face.
- Do not ever offer sweets.
- Do not speak while eating — the airways open for that and choking is more likely.
- Use a small spoon or do not fill a tablespoon completely. Do not introduce more food into your mouth until you are sure you have swallowed everything.
- Do not use straws to drink fluids nor drink directly from a bottle. It is better to use small spoons and adapted cups.
- Dental prostheses should be properly fitted before eating. If that is not the case, it is better to not use them and adapt the food texture.

Face and mouth stimulation

Specific massages to the face, cheeks, lips, mouth and tongue are an option to stimulate these areas and facilitate swallowing.

When your face is flaccid or soft → apply cold to massage in circles, putting pressure on cheeks and lips.

When your face is tense or hard → apply heat for softer and longer massages on cheeks and lips.

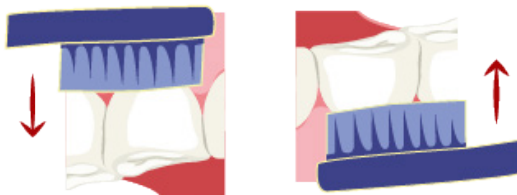
Oral hygiene

How to wash your teeth

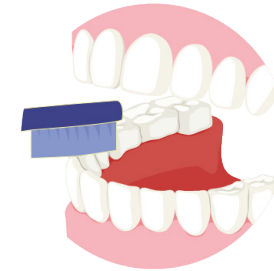
Washing your teeth at least twice a day (after breakfast and dinner) will prevent you from mouth and respiratory diseases.

Follow these steps:

- From red (gums) to white (teeth).
- From above to below in the upper dental arch.
- From below to above in the lower dental arch.
- Wash the external part first and the internal part afterwards.



Continue horizontally on the chewing surface from front to back.



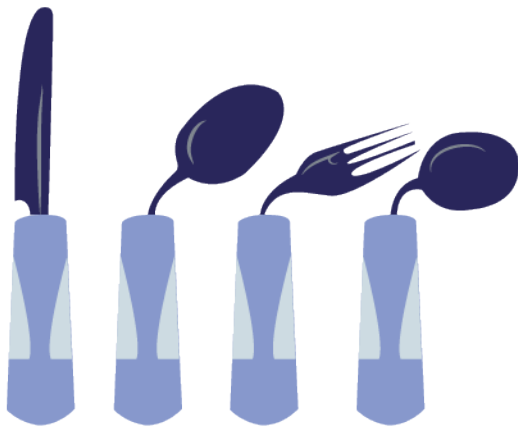
- 1 Remove your dental prostheses before going to bed.
- 2 Use cleansing pills for dental prostheses at least once a week.
- 3 If you cannot wash your teeth, it is not recommended to use toothpaste or mouthwash. Use a chlorhexidine gauze at 0.12% or rinse your mouth.
- 4 If you feel your mouth dry, make sure you drink at least four cups of water a day. You can use artificial saliva solutions.
- 5 Visit your dentist at least once a year.

Support products for eating with dysphagia

There are products that can be helpful for eating, for using and grabbing cutlery more easily and precisely and avoiding incidents such as spilled food.

Cutlery

1. Cutlery with a standard wide handle: they make grabbing easier for people in pain or with a lack of strength.
2. Cutlery handles with the inferior part wide and the superior part malleable: they help redirect the spoon to the mouth.
3. Cutlery with a heavy handle, for distal tremor: very useful for Parkinson's disease, for example.
4. Cutlery with foam handle, easy to grab with weak hands.
5. Cutlery with a mitten handle (adjustable hand strap): useful when it is not possible to grab the piece of cutlery with one's fingers.
6. Special cutlery for specific needs (i.e. there are pieces that can be both a fork and a knife at the same time).



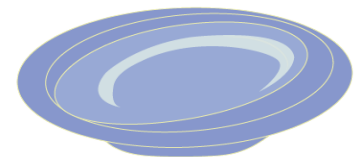
Cups

1. Nosey cup. They help the thicken fluids descend without raising one's head.
2. Double handle cup: with or without a nipple. Easy to grab, recommended for people with tremors.
3. Weighted cups for managing with tremors: it avoids spilling.
4. Lightweight cups, for muscle weakness.



Plates

1. Scooper bowl or plate, to pick up the food more easily.
2. Plate with adjustable edge, to facilitate the pickup of the food at the edge of the plate.
3. Thermal plates.
4. Anti-slip plates.
5. 360-degree-turning plates.



Other helpful objects

1. Anti-slip tablecloth.
2. Manual puree machine.
3. Blender.
4. Whisk.
5. Kitchen robot.



Avoid using straws or syringes unless a professional has recommended it.



Oropharyngeal dysphagia treatment

The aim is to prevent respiratory infections, to improve nutritional status and normalise oral diet of a person with dysphagia. The guidance of a speech therapist would be ideal. Here you have some guidelines that will be helpful. Your treatment is divided in:

Compensatory strategies

In order to facilitate swallowing.

Adapting the diet

Modification of food consistency and volume adjustment.



SOLIDS:

Grind, soft or easy to chew foods in small pieces or a small tablespoon.



FLUIDS:

Use commercial thickeners depending on your needs. Enhance with caloric intake: powdered milk, fresh cheese, cereal flour...

Eat more times a day in small quantities.

Sensory increasing techniques

The nervous system is notified before swallowing by sensory input. For example, the smells and the visual image of the food stimulate saliva secretion.

- **Tactile stimulation:** pressing the tongue with the spoon.
- **Taste stimulation:** chilly flavours, spices, acids... they all help.
- **Thermal stimulation:** cold in the mouth stimulates pharyngeal reflexes.

Postural maneuvers

Chin-down



Objective

Sealing the back of your tongue with your palate to close the airway. To increase the speed of the food passing from the mouth to the pharynx with the effect of gravity.

Procedure

Introduce the food in your mouth and swallow with your chin directed to the chest.

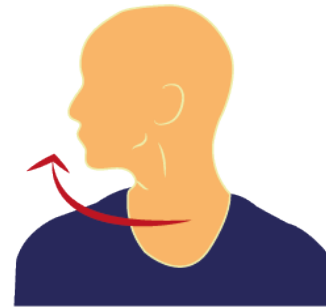
Head rotation to the damaged side

Objective

Rotating your head to the damaged side for the food to move to the healthy side.

Procedure

Introduce the food in your mouth. Turn your head towards the damaged side and swallow in that position.



Head tilted toward the stronger side

Objective

Helping the food move toward the stronger side.

Procedure

Introduce the food in the mouth and swallow while your head is tilted toward the stronger side.



Therapeutical strategies

They are rehabilitating because they modify and improve swallowing functioning.

Effortful swallow maneuver

They demand the capacity to follow instructions in order and making muscle effort.



Objective

Increasing tongue and pharynx movement. Avoiding accumulation of food remains at the back of the tongue.

Procedure

Swallow strongly, while being focused. You can make it easier for yourself with verbal support (We are going to swallow strongly or Now you have to make a huge effort to swallow).

Super supraglottic swallowing method

Objective

Improving laryngeal closure by holding one's breath to facilitate the food's passing through.

Procedure

Introduce the food in your mouth, breath in, hold your breath and swallow strongly. Cough once you have swallowed.

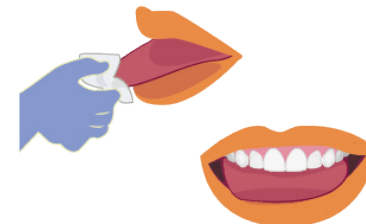
Mendelsohn maneuver

Improving the airway's closure and opening digestive track longer protects the airway and reduces the food remains in the pharynx. Find your Adam's apple. Swallow as usual. When you notice your Adam's apple is going up, hold it by tightening your throat muscles for three seconds. After that, let it go down.



Masako maneuver

The purpose is to increase the pharynx movement forward during swallowing with the tongue held. Stick your tongue out, hold it with your teeth and swallow in that position.



Motor control exercises

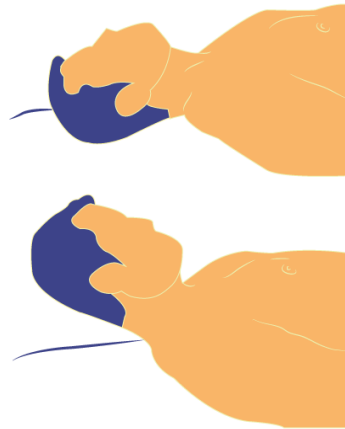
They improve lips strength and mobility, mouth muscles, tongue, soft palate, larynx and glottal closure.

Shaker exercise:

Lie down on your back over a firm surface and rise your head until you can see your toes. **YOU SHOULD NOT HAVE FOOD IN YOUR MOUTH.**

Stay in this position for a minute and rest another minute.

Repeat these steps: rise you head, look at your toes and put your head down consecutively 30 times.



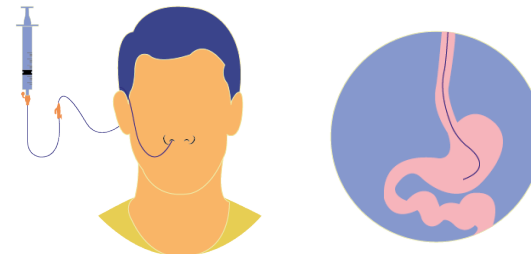
There are other treatments a specialist can tell you about:

- Neuromuscular electrical stimulation
- Botulinum toxin

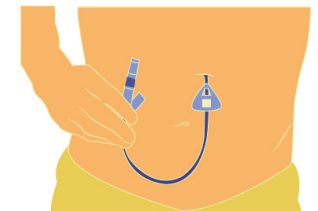
Alternative feeding methods: Artificial nutrition

If you do not consume enough nutrients or water, there are other alternatives until the situation gets better:

- Nutritional supplements (like milkshakes): they complement the daily diet.
- Dobhoff feeding tube: a small calibre plastic tube that is introduced up the nose and gets to the stomach. The nutrients you need can get to your body through this tube. It is a temporary measure.



- Percutaneous Endoscopic Gastrostomy (PEG): the feeding tube is placed directly in the stomach through an orifice in the abdomen. It is used in long treatments (over 6 weeks).



- Parenteral feeding: the nutrients are provided through a venous catheter directly into the bloodstream. It is used when the gastrointestinal tract cannot be used.

Recommended exercises

Exercises to develop lip-movement

Exercise 1

Say “oo-oo-oo” (like a ghost or the wind) and “ee-ee-ee” (forcing a smile) and exaggerate the movement of the lips.

Exercise 2

Pretend you are kissing someone. Start with a smile and change the position of your lips for a kiss. You can paint your lips and leave a mark on the mirror or on paper.

Exercise 3

Simulate you are inhaling through a straw, blowing a whistle or lighting off candles.

Exercise 4

Hold a pencil with your lips without touching it with your teeth for 10 seconds approximately.

Exercise 5

Extend your lips showing your teeth.

Exercises for tongue and jaw mobility

Exercise 1

Put pressure on your tongue to get it down (with a spoon, for example) and try to get it up in spite of the pressure.

Exercise 2

Move your tongue up, down, right and left.

Exercise 3

With the tip of your tongue:

Touch the center of your upper and lower lip, up and down.

Lick the lower lip from right to left.

Lick the upper lip from right to left.

Exercise 4

Open your mouth and pass the tip of your tongue through the edge of your lips in circles in both directions.

Exercise 5

Touch your hard palate with the tip of your tongue.

Exercise 6

Blow your cheeks and close your lips tightly to block the air. Hit your cheek with a finger for the air to come out in bursts.



Menu and recipes

Each menu must be individual and adapted to every person's needs regarding viscosity and volume, according to their nurse and physician recommendations.

This is an example of a weekly menu for a person who tolerates pudding textures.

	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
BREAKFAST	Milk (plain, cocoa or instant coffee) with cereal powder. Pineapple juice and apple purée.	Milk (plain, cocoa or instant coffee) and cookies purée and fruit.	Milk (plain, cocoa or instant coffee) and toast purée. Apple compote.	Milk (plain, cocoa or instant coffee) with cereal powder. Pineapple juice and apple purée.	Milk (plain, cocoa or instant coffee) and cookies purée and fruit.	Milk (plain, cocoa or instant coffee) and toast purée. Plain yogurt and strawberries.	Milk (plain, cocoa or instant coffee) + Cupcake to grind. Pineapple juice and apple purée.
MAIN MEAL	Cream of vegetables + chicken. Flavored yogurt.	Lamb stew purée. Fruit purée.	Fish and vegetables purée. Cocoa custard and fruit.	Lentils and a hard-boiled egg purée. Orange juice and banana.	Chicken rice and vegetables purée. Apple compote.	Chickpea and spinach stew + cod purée. Homemade custard.	Caprese cream + chicken and potato cream. Fruit purée.
AFTERNOON STACK	Fruit purée + cookies purée.	Peach purée and fresh cheese.	Plain yogurt and strawberries purée.	Cold, not frozen pineapple cake.	Fruits and cookies purée.	Apple compote.	Fresh cheese and strawberries purée.
DINNER	Pumpkin + Cheese + Bread + turkey purée.	Aubergine + chicken + potato + purée Flavored Yogurt.	Pasta soup, Egg and Spinach Purée. Peach in syrup purée.	Gilt-head bream, carrot and potatoes purée. Apple compote.	Grilled vegetables with anchovies and hake purée. Fruit purée.	Spanish omelette and zucchini purée. Banana and cinnamon purée.	Beans + Potato + Sole purée. Cocoa custard and fruit.

Lamb stew

Ingredients (4 portions):

- 500 grams of lamb, preferable beef shank, but any other type can be used.
- 1 onion medium size.
- Half head of garlic.
- 1 bay leaf.
- 200 grams of crushed tomatoes.
- 3 potatoes medium size to boil.
- 2 carrots.
- 150 grams of peas.
- 1 red pepper.
- Extra virgin olive oil.
- White pepper and ground cumin.
- Salt.



Preparation

1. Wash and chop all the ingredients, both the meat and the vegetables, and reserve.
2. Add oil into a pot, covering the bottom, and heat it up. Once it is hot, add the bay leaf and stir the meat until it is seared for 3 minutes.
3. Add the diced onion, the pepper, half a garlic head without peeling and leave it for 5 minutes.
4. Add the tomato and two cloves of garlic diced. Leave it boil for a couple of minutes and cover everything with water.
5. Add salt and cover the pot. Once it starts boiling, let it bake for 30 more minutes, until it is tender.
6. While it bakes, peel and cut the potatoes and carrots. Add to the pot with the peas, cover it with water and let it boil for 20 more minutes.
7. After that, add salt and pepper and put it out of the fire. Then, mince it until it is a lumpless mash.

Grilled vegetables with anchovies

Ingredients (4 portions):

- 130 grams of red peppers.
- 70 grams of aubergines.
- 30 grams of potatoes.
- 10 cubic centimeters of extra virgin olive oil.
- 60 mililiter of boiled potato broth.
- 30 mililiter of low-fat milk.
- A commercial thickener.



Elaboración

1. Ember-bake the aubergine and the peppers in the oven. Once it is baked, peel, remove the seeds and season it.
2. Bake the potato (and remove and keep the cooking water).
3. Chop all the prepared food with the potato cooking water and add low-fat milk.
4. Grind everything until getting a mash.

Cocoa custard with fruit

Ingredients (2 custards approx.):

- 1 ripe persimmon.
- 1 plain yogurt (125 grams).
- 1 pure cocoa teaspoonful.

Preparation

1. Peel the persimmon and put it in a bowl.
2. Add the yogurt and pure cocoa to taste (a teaspoonful is enough, adding more could make it bitter).
3. Grind everything and enjoy it.

This document is meant to be a reference guide that serves as a complement for the information provided by the patient's care providers.

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