



Living with dysphagia

A guide to manage swallowing
difficulties in your day-to-day life

Amanda's dysphagia journey

Amanda has spent her entire life tending to her local florist shop. She is a true artist, that carefully selects the perfect combination of flowers to craft breath-taking bouquets for each and every customer.

But Amanda's life extends far beyond her work. At home, she is surrounded by her beloved family, and takes great care in preparing meals that bring joy to her children and grandchildren.

Just a few months ago, she had a stroke and was hospitalized. As a result of this, and along with other consequences, she began to have swallowing difficulties, and after undergoing some tests, she was diagnosed with dysphagia.

Though it has been a difficult journey , Amanda and her family have persevered. **With the help of her family and the guidance of from healthcare professionals, Amanda has adapted to her new reality, and learned how to live with dysphagia.**

At first, it was not easy, but as a family, they have developed a routine that works for them. They have learned how to cook and eat in ways that are safe for Amanda, and she has even started to prepare her favourite recipes once again, adapting them to the consistency level she needs.

This booklet has been developed to guide you through this new journey, the same way it did for Amanda. Whether you live with dysphagia or you are supporting a loved one who does, the aim of what follows is to help you to feel confident as you attempt to manage food and drink safely.

What is dysphagia?

Dysphagia is the medical term for swallowing difficulties.

Dysphagia can be caused by a wide range of diseases, such as stroke, head & neck cancer, Alzheimer's disease and Parkinson's disease. Although it is more common in the elderly, it can affect people of all ages.

Swallowing becomes difficult because the muscles used for chewing and swallowing (lips, jaw, tongue, palate and throat muscles) **become weak or uncoordinated**. As a result, food and drink can enter the lungs instead of the stomach, — what it is commonly known as “going down the wrong way”.

The severity of dysphagia can vary — some people struggle to swallow certain foods, liquids or saliva, while others cannot swallow anything at all.

There are two types of dysphagia, depending on which part of the swallowing process is affected: oropharyngeal or esophageal dysphagia.

Oralopharyngeal dysphagia can be divided in dysphagia to solid (if the person has difficulty to swallow solid food) and dysphagia to liquid (if the person has difficulty to swallow liquids).

It is possible to have dysphagia to liquid, to solid, or both.



THE MAIN COMPLICATIONS OF DYSPHAGIA

Dysphagia can cause serious health complications, especially if it is not treated or managed carefully, so it's important to know what they entail and how to minimise their likelihood.



Aspiration pneumonia:

Besides the risk of choking, experiencing aspiration, where liquid or food particles enter the airway, may have severe consequences. Aspiration pneumonia may result from it. Although not everyone who “aspirates” food or liquid into their airway will develop aspiration pneumonia, however, there is a 50% risk of developing it, depending upon the health of the individual. Please seek medical attention in case of food or drink aspiration.



Malnutrition:

Recurrent swallowing problems and/or the fear of choking may lead to eating aversion.

In turn, the loss of appetite may prevent you from reaching the recommended intake levels of daily nutrients.

Malnutrition complications (eg. weight loss, weakness, fatigue or mobility problems) may arise. It is recommended that a dietitian provides advice to ensure a balanced and nutritionally adequate diet.



Risk of choking:

Choking occurs when liquids or food accidentally go down the wrong way, blocking your airway. Not being able to cough up may lead to prolonged airway obstruction and even to asphyxiation. A few simple precautions such as the change of one's body posture or the adjustment of the consistency of drinks and foods, can help to minimise risk of choking.



Dehydration:

For some patients with dysphagia, liquids can be difficult to swallow. **Not reaching the recommended daily intake may cause dehydration.** To drink safely, **we recommend using** thickening agents that increase the viscosity of fluids. Follow the advice of healthcare professionals on how to thicken liquids.



Consult with a healthcare professional to receive personalized advice on swallowing-related matters.

HOW TO SWALLOW SAFELY?

An adequate body posture during mealtimes is one of the simplest yet most effective solution to help eat and drink safely and prevent food from going the wrong way.

Here are some general principles:

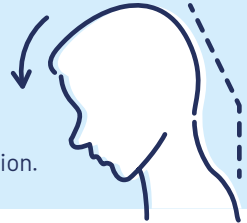
- **SIT IN AN UPRIGHT POSITION:**

Be as comfortable and upright as possible, even if you need to eat from bed. If necessary, use pillows to prop up and to stop slipping down or to the side.



- **KEEP THE HEAD TILTED FORWARD:**

When swallowing, keep the neck stretched out and the chin bent towards the chest. This **may help prevent food or liquids from entering the airway**. If necessary, use neck cushions to maintain a steady position.



- If it ever feels as if food is **getting stuck on your throat or chest area, even for a short time, sit up and stretch so as to help the food to slip down** into the stomach.

DURING MEALTIME

- **Do not rush.** Take the necessary time to chew and swallow.
- Set up a **peaceful and quiet environment**.
- **Reduce distractions** while eating or drinking. Turn off the TV.
- **Sit upright** (as close to 90° as possible). If necessary, use pillows.
- In case of wearing **dentures**, make sure they **fit properly**.
- **Take regular sips** of fluids, thickened if recommended by your dysphagia clinician.
- **Empty the mouth completely** between bites or sips.
- If the mouth has a weak side, **use the stronger side** to introduce the spoon.
- **Avoid talking** when eating or drinking.

AFTER EATING

- **Sit upright** for at least **30-60 minutes after** the meal.
- Get the last main meal **two to three hours before going to bed** to minimise the risk of reflux.
- **If you are assisting someone** with their meal, **confirm regularly that their mouth is empty** between bites or sips.

How to drink safely?

HOW TO CHANGE THE CONSISTENCY OF LIQUIDS

Adding thickeners to drinks and liquid meals can help slow down the swallowing process, making it less likely for liquids to go into the airway by mistake.

When mixed with liquids, the xanthan-based thickening powder thickens within minutes, turning it into a safe drink to swallow. Rest assured that it does not modify the taste, smell or appearance of the drink, so you can continue to enjoy them!

It can be mixed with hot, cold, fizzy and still drinks such as water, juices, milk-based liquids, carbonated drinks, beer, wine, cocktails and spirits.

How to use a xanthan-based thickening powder?

Always follow the instructions on the tin and prepare the beverage at the viscosity level recommended by your healthcare professional.



1.

Powder first: Check the xanthan-based thickening powder dosage chart. Use the dosage scoop included in the tin or the sachets. For best results, add the powder to a clean dry glass or beaker.

2.



Add liquid: Add the liquid to the powder.

3.



Stir: Stir immediately and until the powder is completely dissolved.

4.



Serve: Leave to stand at least for one minute. Milk based beverages may take up to 20 minutes to reach the desired consistency.



Before drinking, you may test the viscosity of your beverages following the **IDDSI** (International Dysphagia Diet Standardisation Initiative) framework. Find out more here: <https://iddsi.org>

How to drink safely?

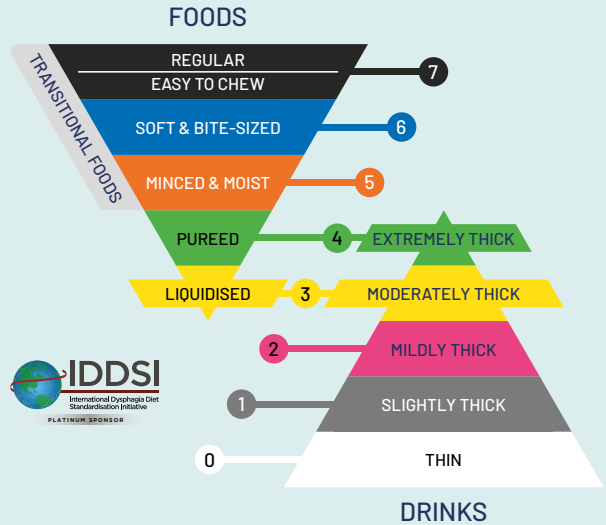
HOW TO CHANGE THE
CONSISTENCY OF LIQUIDS

IDDSI Framework

The International Dysphagia Diet Standardisation Initiative (IDDSI) framework is an evidence-based framework that provides a common terminology for describing food textures and drink thicknesses.

After being diagnosed with dysphagia, the healthcare professional will indicate the IDDSI level and type of diet to follow. For further information, please consult a healthcare professional or dysphagia expert and visit: www.iddsi.org.

THE IDDSI FRAMEWORK



IDDSI FLOW TEST

You may use **the IDDSI funnel** to test the viscosity of your drinks.



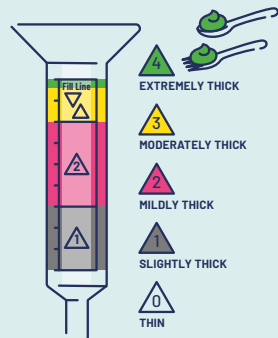
Cover nozzle with
finger and fill 10ml.



Release nozzle
and start timer



Stop at 10 seconds



You need a 10 ml syringe.

Where the liquid stops after the 10 seconds indicates the viscosity level of the drink. IDDSI funnel is not suitable for evaluate level 4.

For more information, visit: www.iddsi.org

DRINK RECIPES

Café Frappé



Pour the milk, the soluble coffee, the sugar and ice into a container.



Blend or mix all ingredients well thoroughly.



Adjust the consistency of the frappe to your recommended the IDDSI level you need by adding a xanthan-based thickening powder.



Wait until it reaches the desired consistency and serve chilled.



INGREDIENTS:

- 120ml of any milk of your choice
- 10g soluble coffee
- 10g sugar
- 2 scoops of vanilla ice cream
- Xanthan-based thickening powder according with the viscosity level you need to reach

Mango milkshake



Defrost the mango pieces, if frozen.



Add the mango to the yoghurt, the milk and the cardamom.



Puree with a blender and sieve.



Add sugar to taste.



If necessary, use a **xanthan gum powdered thickener**.



INGREDIENTS:

- 125g of of mango or frozen mango
- 100ml of Greek yoghurt
- 100ml of any milk of your choice
- 1 tablespoon of cardamom
- Xanthan-based thickening powder according with the viscosity you need to reach

DRINK RECIPES

Chilled Soda



Place the required amount of the xanthan-based thickening powder into a clean, dry glass.



Open the soda bottle and wait until flat. Pour just enough soda down the side of the glass to cover the powder (~50mL).



Stir for 10-20 seconds or until the mixture starts to thicken.



Gradually add the remaining soda, stirring well between additions. Wait 5 minutes, then stir and serve immediately.



INGREDIENTS:

- 150ml of soda
- Xanthan-based thickening powder according with the viscosity level you need to reach

Please note: Carbonated drinks produce a head of bubbles. Add small amounts of carbonated drink gradually to prevent the thickened carbonated drink from overflowing.

Red Wine

Please Drink Responsibly



Place the required amount of xanthan-based thickening powder into a clean, dry glass.



Add just enough wine to cover powder (~50ml.)



Stir for 10-20 seconds or until the mixture starts to thicken.



Gradually add the remaining wine, stirring well between additions. Wait 5 minutes then stir, serve and best consume immediately.



INGREDIENTS:

- 150ml of Red Wine (room temperature)
- Xanthan-based thickening powder according with the viscosity level you need to reach

Please note: For all recipes check the consistency before serving

How to eat safely?

HOW TO CHANGE THE CONSISTENCY OF FOODS



Blend the solids to give them a smoother, more uniform texture in accordance with the recommendations of healthcare professionals.

TIP!

Temperature and time change the viscosity of liquids/solids. Try to blend the food just before eating it.



Use a xanthan-based thickening powder to increase the consistency of foods and liquids.

To soften and moisturise dishes, add oil or butter.



Remove any hard-to-blend bits or parts that may prevent smoothness, such as seeds, peels, spices pieces or skin.



Cook or steam certain foods (e.g. meat) if necessary, until they're very tender.



Chop the food into small pieces before filling the blender.



Blend the food in small quantities at a time to avoid lumps.



Once blended, sieve the puree to remove the remaining lumps or pieces.



With solid or drier food, add extra liquids, such as milk, cream, non-dairy alternatives, gravy or any other sauces.



How to eat safely?

HOW TO CHANGE THE CONSISTENCY OF FOODS

3.

Adapt the consistency of the food following the recommendations of healthcare professionals and guidance based on the IDDSI framework.

4.

Make sure the food has a smooth and uniform texture and no lumps, which will allow a safe swallowing.

Make sure each bite is compact and easy to swallow.

Take small mouthfuls. 1/2 or 1 dessert spoon at a time. Avoid using a straw.

It is recommended to test the texture of your food before serving. You can do this following IDDSI Framework guideline.

Find our more here: <https://iddsi.org>

You can test the texture of your food using an usual fork and spoon.

PUREED

4



Falls off spoon in a single spoonful when tilted and continues to hold shape on a plate. Leaves little food on spoon.



A small amount may flow through and form a short tail below the fork. It should not dollop, flow or drip continuously through the fork prongs.

MINCED & MOIST

5



ADULT
4mm

When pressed with a fork, food comes through the tines of the fork, indicating the size of particles is less than 4 mm.

SOFT & BITE-SIZED

6



Thumb nail blanches white.

Can be mashed/broken down with pressure from fork, spoon or chopsticks.

REGULAR EASY TO CHEW

7



Thumbnail blanches white.

Normal, everyday foods of soft/tender textures.



For further information, please consult a healthcare professional and visit: <https://www.iddssi.org/Testing-Methods>

HOW TO MAKE MEALS MORE NUTRITIOUS

Many patients diagnosed with dysphagia find it difficult to stay well nourished and have a balanced and nutritious diet.

A nutritionist may provide personalised dietary recommendations.

A proper diet must include ingredients from all food groups as well as all the necessary nutrients. **Eat little and often**, spread out meals throughout the day and snack in-between.



PROTEINS:

- **Add eggs** (high in protein) to your menu.
- **Use dairy products** like milk, cream, yoghurt and ice cream or fortified non-dairy alternatives.
- **Mix smooth cream cheese**, cottage cheese or grated cheese into dishes when cooking.
- **Purée high-protein plant-based foods** like lentils, peas, mushrooms...
- **Eat fish** — try smooth, pureed versions or mousses of oily fish, like salmon and mackerel.



FIBRES:

Include in puree fruits, vegetables, whole grains and legumes.

Steamed cooked allows food to keep their fibres content.



FATS AND SUGARS:

- **Enrich your dishes** with olive oil, butter, condiments and sauces.
- **Add high-fat dairy products** like milk or cream to dishes.
- **Add honey and fruit juices** to purees or desserts.



HOW TO MAKE MEALS MORE APPEALING

TIP!

Avoid overcooking

vegetables to keep their nutritional value.

TIP!

Oral Nutritional Supplements exist to support your daily nutrition intake. Ask for advice to your healthcare professional.



A healthcare professional can recommend oral nutritional supplements.



Go for enjoyable and tasty dishes,

add any spices that you desire while adjusting to the recommended consistency.



Mind the presentation.

Use a variety of colored vegetables to enhance taste and appearance.



Use shape moulds

with pureed/ blended foods.



Serve meals at the right temperature to maximise their taste.



Serve meat and vegetables separately

to appreciate the best of each.



Meals suggestions

Breakfast and Snacks

CHOOSE ONE OF THE FOLLOWING OPTIONS ACCORDING TO YOUR TASTE.

Vegan banana shake

- ½ glass of non-dairy milk like soy milk or oat milk or coconut milk
- 1 banana
- Cinnamon

Yummy white bean egg puree

- 1 egg (scramble, poach, or boil)
- 1 tablespoon white beans flour
- 2-3 tablespoon milk (add more milk to attain desired consistency)

Mango smoothie puree

- ½ cup Greek yogurt
- ½ mango
- Fresh lemon juice
- Milk (if needed to attain desired consistency)

Pineapple puree with cookies and milk

- 2 pineapple slices in syrup
- 3 cookies
- ¾ cup of milk



Place the ingredients into a blender and blend until completely smooth.

TIPS:

- **Do not forget your drink** to accompany your meal.
- Prepare your meal **right before eating**.
- **You can add xanthan-based thickening powder** to prevent excess water or to obtain the texture prescribed by your healthcare professional. **To be used under medical supervision.**
- You can change the fruit to your preference. **Avoid fruits seeds** such as strawberry, kiwis, blackberry, etc.
- **Do not add ice cubes** on the thickened prepared recipes.

Meals suggestions

Lunch and Dinner

Prepare your balanced lunch and dinner and include ingredients from at least 3 food groups. For dessert, you may have a piece of fruit or milk based puree.

1 VEGETABLES

Use a variety of vegetables to enrich your diet with vitamins and minerals.



2 POTATO / RICE / PASTA / BEANS

Carbohydrates like potatoes, rice, beans, pasta are easy to cook in a puree format and provide energy to your body.



CHICKEN / BEEF PORK / FISH / EGGS

Include animal and vegetable-based **proteins** in your diet to maintain muscle mass strength.



Cook with hot liquid until smooth in texture.



Transfer to a blender.



Add olive oil or melted butter/margarine, and **puree** until you reach your desired consistency.

We are pleased to support you in the journey of living with dysphagia.

This booklet has been assembled to help you and your loved ones. It contains detailed information about dysphagia, comprehensive and practical advice easy to apply on a daily basis.

With compliments



Endorsed by



**European Society for
Swallowing Disorders
ESSD**