
Culinary Care in ALS
-A Nutritional Toolkit-
SLA ALS
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sla-quebec.ca

INTRODUCTION & ACKNOWLEDGMENTS

This nutritional toolkit has been revised by the ALS Society of Quebec with the collaboration and expertise of multidisciplinary professionals specialized in caring for the ALS community across the province of Quebec. It is intended to be a reference resource for people diagnosed with ALS, their caregivers, family members and friends, as well as, health care professionals who may be caring for families with this illness. The information, safety tips, recommendations and links provided are a guide to better equip the ALS community and are meant to compliment the information and advice provided by your qualified team of healthcare professionals. The toolkit is available in both English and French in digital format.

The ALS Society of Quebec would like to acknowledge and sincerely thank all content contributors for their collaboration, as well as, L'Appui National pour les proches aidants d'ainés and the Friends of The Neuro for their instrumental financial support that has made this virtual learning resource possible.

IMPORTANT: PLEASE READ

We hope that the information you will find in this Culinary Care in ALS Toolkit will help you better understand your nutritional needs, improve the quality of your daily life and assist you effectively during your journey with ALS. The content will help you prepare for the discussions you will have with the different members of your medical care team.

Please take note that the information and advice presented in this Nutritional toolkit are general in nature and are not intended to replace medical advice, discussions or evaluations with your qualified healthcare providers. Please consult your treating physician and allied healthcare team with any questions or concerns regarding your particular medical needs.

About the Culinary Care in ALS Toolkit

This nutritional toolkit is intended to inform, equip and empower individuals diagnosed with ALS, their caregiver(s), families and support network. The aim is to provide useful information, tips, practical advice, tools and resources that can help to manage daily life and a variety of decisions related to nutrition during your journey with ALS. As a result, the toolkit content assists in a better understanding swallowing problems and related treatment options.

Because swallowing is vital to nutrition and health it often becomes a focus in quality of life issues. It is important to be aware of changes in your ability to swallow so that your healthcare team can identify strategies to keep swallowing safe and maximize your nutrition over the course of your illness. A high proportion of people living with ALS are estimated to experience swallowing impairment or dysphagia at some point during their illness. The prevalence of dysphagia ranges from 35 to 73% for those with a spinal onset of ALS, and 95 to 98% for those with a bulbar onset of ALS (Britton et al, 2018).

Complications associated with swallowing problems in ALS include: dehydration, malnutrition, the possibility of choking, and aspirating liquids, food and/or saliva which can in turn cause a risk of pneumonia. These can become daily concerns.

To learn more about swallowing changes, dysphagia and nutrition in ALS, which is also know as Motor Neuron Disease(MND), please consult the following resource guides and links: (*some available uniquely in English)*

- ALS Society of Quebec A Guide For People Living with ALS –Section 04-D Living with ALS-Swallowing Nutrition and Oral Health
- ALS Society of Quebec- *Taking Care* - Online, On demand virtual learning environment
- ALS Association Living with ALS Resource Guide 8: Adjusting to Swallowing Changes and Nutritional Management in ALS
- Motor Neuron Disease Association(MNDA)-Living With MND-Swallowing, Eating and Drinking
- Association professionnelle des nutritionnistes experts en dysphagie (APNED)
- Nestle Health Science Canada- Dysphagia Care

Current evidence-based research about ALS suggests that it is essential to prevent weight loss. Key elements for people living with ALS to help achieve this goal are:

- to seek care by specialized multidisciplinary holistic ALS Clinics along with your primary care provider, which allow access to allied healthcare professionals that can provide close attention to nutritional support and respiratory care, as well as, drug therapies and clinical trials that can help to manage challenging symptoms over the course of your journey with the illness;
- to maintaining and/or gain weight which has been proven to help increase the length and quality of your life;
- to eat a well-balanced high calorie diet is essential to maintaining your body composition (preserving muscle mass and body fat stores) – this is the goal.

The ALS Society of Quebec is a collaborative partner in your care, with our team being committed to supporting you, your caregivers/family in your efforts to thrive and live well with ALS. We hope that this resource will help to make mealtimes safer, more enjoyable and nourishing. Bon Appetit!

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Tips to Help Make Every Spoonful Count

If swallowing has become more difficult and meal times have become more tiring, making every spoonful count is important to help maintain a healthy weight and to make sure you get all your nutritional needs. Here are some tips to help you achieve this. Review these with your dietitian-nutritionist so that they can help you personalize your diet.

- √ Eat 6 or more smaller meals or snacks per day
- √ Have beverages after from meals
- √ Take short breaks during meals
- √ Enjoy regular fat, thick and creamy yogurt as a snack
    - Try Greek yogurt for extra protein
- √ Add 1-2 scoops of protein powder (Beneprotein ®) to purees or beverages
- √ Add 1-2 tablespoons of butter, margarine, mayonnaise, gravy or cream sauce to purees vegetables or meats
- √ Stir 1-2 tablespoons of flaxseed oil or fish oil to smoothies or cooked vegetable purees for added good fat
- √ Add ground nut or seeds to desserts or smoothies
- √ Mix plain soft tofu into purees, desserts, soups or smoothies
- √ Add 1-2 tablespoons of nut butter into smoothies or desserts
- √ Mix 2-3 tablespoons skim powder, soy powder, cream, or sweetened condensed milk to milk, milk beverages, mashed potatoes, cream soups and sauces, cereals, pureed fruits, milk-based desserts, puddings, hot cereals, milk shakes
- √ Use whole milk (3.25%) instead of skim milk, 1% or 2% milk
- √ Use milk instead of water when making soups, sauces, hot cereals, or hot cocoa
- √ Add liquid pasteurized egg to milk shakes or smoothies – do not use raw eggs
- √ Blend beans or lentils and add to meat purees
- √ Add ripened, mashed avocado to vegetable soups and purees
- √ Add a spoonful of fibre supplement(e.g.: psyllium) to purees or beverages for extra fibre
- √ Have ½ to a whole bottle of nutritional supplement between meals

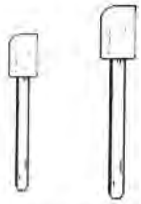
Culinary Care – Equipping your Kitchen and Practical Tools

The following kitchen utensils and equipment will help you to prepare your meals or beverages with an adapted texture or consistency. Some of these items can be found in discount stores, as well as specialty stores that sell kitchen appliances and accessories.

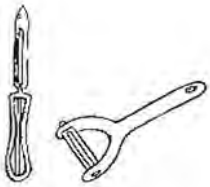
Measuring Cups

Measuring Spoons

Whisks (Large and Small)



Silicone Spatulas (Large and Small)



Peelers (Y and Straight)

Knives (Sharpened)

Juicer

Glass Containers

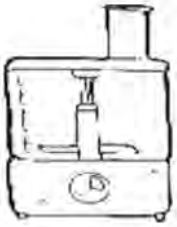
Sieves (Fine and Medium Mesh)

Cheese Cloth

Food Mill

Hand Blender

Blender



Food Processor

When choosing equipment/ items it is a good idea to do some homework and look at online reviews on the manufacturer or retailer's website. Once you know which models seem the best for you, go to the store and to look at the physical product on display and ask yourself the following questions:

- Does the size will fit your kitchen space?
- Is it large enough for the intended use?
- Is the item lightweight?
- Is it easy to clean?
- Is it easy to manipulate?

These factors are especially important to consider for blenders and food processors, as you will be using this equipment several times per day.

Whisks, large and small, are used to help combine thickening products used for transforming liquids into nectar, honey and pudding consistencies. Glass storage containers are helpful to have as thickened beverages and foods that are frozen or stored in plastic containers have a tendency to stick to plastic but not to glass.

Mesh sieves are used for straining particles of fruit, seeds, skins and any lumps out of purée. The use of a silicone spatula helps push the food through the sieve. For seeds such as those with strawberries, or other small food clumps, a layer of cheesecloth within the strainer will help catch small seeds and finer particles.

A food mill is essentially a sieve with muscle. No other tool can mash and strain soft chunks of food more neatly and less strenuously, all at one time. Food mills produce very smooth and consistent purées. A food mill purées soft food while it strains fiber, seeds, and skin. It may not be as versatile as a blender or a food processor, but for certain jobs, a food mill works more efficiently than pulsing in a food processor and then forcing through a strainer. Some models have different sieve disks that allow for varied levels of texture.

Blenders (hand or countertop models) are often used and one of the most important tools for creating a purée texture. Choose a machine that is simple to use and easy to clean. If you intend to blend hot liquids, such as soups, look for a model that has a vented lid. This feature will help reduce steam splatters and burns when opening the lid. There are many brands to choose from, and most are about the same price. Focus on choosing a brand and a model with a reliable motor, at least two speeds and an easy set up/clean up.

Food processors are very helpful for modifying food textures. A capacity of 2.5 to 3.5 cup size is generally large enough for preparing most meals. The size of the bowl is related to the quantity of food or liquid being prepared; and so, it should not be too full, or too empty for the blades to work efficiently.

Lastly, there are also several varieties of foods molds available to make your own reshaped pureed foods at home:

- http://www.hubert.ca/73153/Baby-Carrot-Food-Molds-for-Pureed-Foods.html
- https://www.dysphagia-diet.com/c-488-puree-molds.aspx

These kitchen items will not only serve a function, but will save time, effort and energy. When cooking try to prepare larger batches of meals and then freeze individual portions in glass containers. When you or your loved one are ready to eat, take one of the containers out of the freezer and microwave or place in an oven-safe dish and heat through. Stocking your freezer with pre-made meals means you will have more nutritious meals that are ready to go and are less expensive than store-bought versions.

- Read the article "Freezing 101" for food storage tips
- Watch a short video (2:21) about freezing tips to make frozen food last longer

For people living with ALS, there may be a variety of daily challenges for which an increased effort is required during food preparation and eating. They may experience trouble preparing meals due to fatigue, reduced dexterity or breathing changes. Everyday tasks such as, shopping for groceries, accessing cupboards, walking to the refrigerator, lifting cookware, opening containers, standing for prolonged periods to prepare food, or physical challenges related to getting food and beverages to their mouth during mealtime can all present as overwhelming tasks. Some of these tasks may need to be done by a caregiver or other family members. There are a number of strategies and modifications that can increase safety within the kitchen and assistive devices that can maximize independence during food preparation and mealtimes.

Ask the occupational therapist and speech language pathologist caring for you about assistive devices and strategies for troubleshooting safety and autonomy during mealtimes.

- To learn more about home safety modifications and adaptations for ALS in the Kitchen, watch this 5 minute video where occupational therapist, Ann-Marie Léporé, highlights strategies that help guide caregivers and families living with ALS to improve safety and conserve energy within the kitchen.

Practical tools & assistive devices that help with independence at mealtimes

Adapted plates and scooper bowls:

Designed to make dining easier by reducing the amount of effort it takes to gather and consume food. Scooper bowls have partial lips around the rim to prevent food from sliding off. There are also a variety of bumpers and guards that are available to slip or clip onto nearly any type of plate to perform a similar function to scooper plates.

Non-skid plates and bowls:

These items include suction bases, mats and gripper feet that help to keep plates and bowls from moving under the force of eating utensils. In some cases, all that is needed is a plate guard that can be clipped onto your own dishware.

Weighted utensils/cutlery holders & cuffs for a better grip:

Weighted utensils can be suggested if hand tremors are present, as the weight helps to steady hands while eating. Special adapted rocker knives **(A)** *and adapted cutting boards* **(B)** *can help with cutting food autonomously. The use of weighted holders, foam tubing* **(E)** *and universal cuffs* **(D)** *can be used to insert cutlery/utensils and other items (such a comb, razor, toothbrush and pencil/pen) for individuals who have difficulty gripping/holding* **(C)** *for any period of time. To help with energy conservation, these holders and cuffs are so efficient that no finger strength is needed; the hand and holder alone do the work. Foam handles and universal cuffs are also ergonomically shaped, portable and easy to manage even when travelling or using cutlery /utensils outside the home or at restaurants.*

A B C D E

Cups that can help with drinking and staying hydrated:

Cups and glasses have also been re-designed and adapted to make drinking liquids easier and safer. The Nosey and Dual™ cups **(A)** *have cut outs on the non-drinking side of the glass providing room for the nose, and allows a person to drink without having to tilt their head back lowering the chances of liquids slipping to the back of the mouth. The Provale™cup* **(C)** *is designed to hold very small amounts of liquid, preventing large gulps of liquid, some cups* **(B)** *are designed to support hand weakness by providing a*

two-hand steady grip with covers that only allow for sipping. A wedge cup **(D)** *allows people with dysphagia to safely drink thickened liquids and is designed for people with limited muscle control or decreased strength, and those with weak or limited range of arm or upper body motion. Lastly, if straws have been recommended by your occupational therapist or speech language pathologist, Sip and Tip type glasses* **(E)** *have valves incorporated in their straws which allows the straw to stay filled with liquid, reducing the effort required to drink from a straw and limits air ingestion. The valve placement can be adapted by occupational therapists and speech language pathologists to suit individual needs.*

A B C D E

Specialized and automated feeding devices:

Recent developments in assistive technologies and devices have given rise to specialized and automated feeding devices, like the Obi Robotic feeder. These robotic feeding aids help individuals with complex needs and/or those with reduced or limited arm functions to become independent eaters. These devices remain expensive and are not always suitable for people living with progressive neurological illnesses, like ALS, where swallowing difficulties and choking risks may also be present.

If you are interested in learning more about assistive devices, please consult the following internet links:

- https://www.parsonsadl.com/products.php
- https://www.performancehealth.com/what-we-sell

Culinary Care for Caregivers

If you're reading this section of the toolkit, it's probably because someone you care about deeply has ALS. Caring for a loved one can be both a rewarding and a challenging experience. One of the important steps in caring for someone with ALS is making decisions about which care tasks and responsibilities you can take on through the progression of their illness and over the course of your journey as a caregiver. Whether you are a main caregiver or a friend looking to offer some help, cooking healthy meals is a great way to support someone who is living with ALS. Keeping the person you care for well-nourished can help improve their strength and well-being, as well as, help them to stay hydrated and prevent malnutrition.

Being a caregiver for a person with ALS is emotionally and physically strenuous, but also deeply rewarding in highly personal ways. It is also really hard work. It involves learning about new tasks and equipment, while going through the emotions that arise when a loved one has a progressive, debilitating illness. In many cases you may have additional outside responsibilities, like working a full-time or part-time job, taking care of your own children, or others within your family. Often, caregivers are so busy supporting their loved ones that their own physical or mental health takes second priority. This can lead situations where you may find yourself skipping meals, grabbing fast food on the run, or forgetting to buy healthy foods because you are too worn out. An overwhelming situation where you can not successfully take care of anyone else because you are not taking care of yourself. It is important that you get the support and assistance you need so you can care for your loved one to the best of your abilities. This involves knowing your limits, accepting help and equipping yourself with the information and resources that can help you fulfil the caregiver responsibilities you have chosen to undertake. A valuable book written for ALS Caregivers on the subject of dysphagia is entitled, *Swallow Safely*. It is one of many online, on demand resources on the *Taking Care* platform on the ALS Society of Quebec's website. Resourceful caregivers have come up with ingenious solutions to address their challenges. Not every suggestion works for every caregiver; and sometimes you'll find a better idea than those mentioned here. If you do, please share them with us!

Tips for maintaining your own nutritional needs as a caregiver

- Set realistic goals. Break large tasks into smaller steps you can do one at a time, and then prioritize them. This can help you keep up your energy level during a busy day, without getting too overwhelmed.
- Don't be afraid to ask for help. List the things you think you may need help with, and let the helper choose what he or she would like to do. For instance, you may need someone to pick up the groceries or cook for you occasionally to give yourself a break. Or look into your local community support services (meals on wheels), having your groceries delivered, consider wholesome ready-to-eat foods or meal kits and food box subscriptions. Please refer to the **Community Resources** (Section 3) of this toolkit for more information about options that exist in your area.
- Cook by the batch. Having nutritious leftovers in the fridge or freezer rather than cooking from scratch is a great time-saver. This is a great way to have family favorites ready to enjoy on days when time is limited.

- Consider a nutritional liquid supplement or smoothie. It's a great way to help you and your loved ones get the nutrition you need. In fact, consider keeping some on hand on hectic days when you are on the go.

Tips to keep in mind when cooking for someone with dysphagia:

- **Find out their favorite recipes:** Talk to the person diagnosed with ALS and determine what their food preferences are so you can create a dysphagia-friendly version. If it is a favorite food, the person with ALS will be more likely to eat more of it;
- **Focus on variety:** Mix it up by including different ingredients and balancing tastes;
- **Make it a family affair:** If you are worried that someone will be embarrassed or feel left out because they are eating "different" foods unlike the rest of the family or group, try recipes that everyone can enjoy to make the meal experience more inclusive;
- **Get creative:** Need more inspiration for new recipes? Consider doing recipe "swaps" with other friends or other families you have met that are living with ALS, or experiment on your own;
- **Have a candid conversation:** Do not be afraid to talk openly about dysphagia; showing your support and how understanding you are of this condition is critical. There can be challenges with eating out at restaurants and/or at social gatherings as meal time may last longer than expected and food choices may be limited. It can also be hard for caregivers to see loved ones struggling with their eating. If you are in need of support, consider attending a support group or contact a psychosocial counsellor at the ALS Society of Quebec for some personalized support.

It is important to remember that food should not only nourish the body, but also the soul. No one should ever assume they have to resort to simple, "mushy" food just because it is easily consumed. There are many ways to create delicious recipes that can be enjoyed. Try to be inventive with the food you prepare, in families affected by ALS, it is one of the things that you and your family can control. Take a look at the **Cookbooks and Recipes** (Section 4) of this toolkit for examples and ideas that might be right for your family.

If you are concerned about changes in swallowing ability, weight loss, or fatigue in the person living with ALS that you are caring for, or need to learn more about modified liquids and adapted textured foods, speak with the specialized ALS multidisciplinary healthcare team that cares for your loved one. There are several professionals, such as: the treating neurologist; nurse clinician; speech language pathologists; occupational therapists; nutritionists; and respiratory therapists that are equipped to help discuss your concerns in detail.

How to Optimize and Maintain Oral Health

A healthy, balanced diet provides the nutrients needed for general health, including oral health. Without the proper nutrients, the structures of the mouth (which include the tongue, teeth/dentures, gums, cheeks, and palate) are more susceptible to cavities, gum disease and infections. Saliva is complex even though it is 99% water! Saliva plays several essential roles such as: being the mouth's immunologic defense, starting the digestion process with enzymes, it assists with eating via lubrication, contains proteins that help with taste, cleanses, hydrates, buffers and protects. The mouth provides a rich environment for germs and bacteria which can travel to the blood stream causing infections of various organ systems and which can be inhaled and aspirated to cause life threatening pneumonia. It is the gateway to our body.

ALS can bring about several changes that challenge maintaining nutrition and oral health:

- Weakening and fatigue of the muscles in the face, cheeks, jaw, tongue, mouth, lips, throat and neck;
    - Changes the ability to chew effectively or manage different textures within the mouth (food particles staying trapped or left behind)
    - Impairs the ability to swallow food, liquids and saliva effectively and safely
    - Alters the ability to hold the mouth open or closed for long periods of time, or hold the head upright if the neck muscles are weakened
    - Increases the difficulty in safely managing and holding toothpaste, excess water or mouthwash/rinses in the mouth with a changing ability to coordinate muscles to rinse, spit, or swish
    - Reduces the control of the tongue, lips and swallowing or results in the inability to seal the lips of the mouth can result in drooling (even when there is a normal production of saliva)
    - Changes in cough reflex and ability to cough spontaneously
    - Can also cause a malfunction of the gag reflex to occur
- Changes in weight (dramatic gain and/or loss) can cause issues for people that have dentures (full or partial artificial teeth);
    - Poorly fitting dentures can injure underlying gum tissue and increase the possibility of a local infection
    - Tightly fitting dentures can trap bacteria
    - Painful dentures can interfere with adequate chewing
- Changes in the amount of saliva being produced;
    - Excessive salivation (called sialorrhea)
    - Dry mouth (called xerostomia) This symptom can also be a result of medication side effects and treatments provided for excessive salivation in ALS
- Changes in breathing ability;
    - Makes it more difficult to coordinate breathing while eating or performing oral care
    - Mouth breathing, or use of breathing equipment, such as BiPap devices or when a tracheostomy is present, can result in reduced moisture inside the mouth causing risks for dental decay and bad breath (called halitosis).
- Muscle weakness and fatigue in hands/arms resulting in difficulties with reaching up to the mouth for eating, have the dexterity to manage enteral feedings or for performing oral hygiene tasks independently.

These changes and challenges often dramatically change daily routines for people with ALS and their caregivers. Oral care that was once automatic can become a task that requires extra time, effort and comes to increasingly rely upon the physical help of a caregiver or family member.

Good dental hygiene practices are essential for people living with ALS. In addition to maintaining an oral care routine everyday at home, it is also essential to maintain regularly scheduled dental checkups and professional cleanings (every 6 months) by oral healthcare teams.

Oral hygiene requires particular consideration in people with ALS that are receiving all their nutrition and fluids via a feeding tube, as well as those requiring assisted ventilation. The mouth remains a fertile site for growth of bacteria. Care is aimed at maintaining oral health, reducing harmful oral bacteria, reducing the risk of pneumonia from aspiration of food, fluids or bacteria that are found in the mouth.

Daily oral care should include taking time to look at the following:

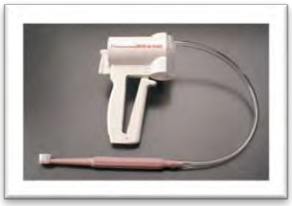
- Lips, tongue, tissues inside the cheek and floor/roof of the mouth
- Gums between the teeth and/or under dentures for any signs of redness, irritation or bleeding
- General condition and fit of natural and/or artificial teeth
- Teeth pairs at the back of the mouth
- General oral appearance, cleanliness and any areas which may be sore
- Taking notice of excessive saliva, dry mouth, and/or bad breath

What to do and how often?

- Brush natural teeth with a soft bristled toothbrush and fluoride containing toothpaste for 1 to 2 minutes upon waking, following meals and before bedtime.
- Change toothbrush or electric toothbrush heads about every 3 months, following a dental cleaning, when the bristles are bent, misshapen or when a whitish layer accumulates at the bottom of the bristles.
- Floss in between the teeth at least once a day with dental floss, or flossers (Y and F shaped).
- Clean the tongue by brushing the surface gently with your toothbrush or by using a tongue scraper.
- Dentures (full or partial) should be removed and soaked overnight with denture cleansers/soaps, be cleaned following meals, and the gums should be brushed and massaged, either with a soft toothbrush or with a warm, damp cloth.
- Hydrate the lips using water-based lip balms (avoiding petrolatum-based lip balms as these do not penetrate or moisturize the tissues). Consider one with lanolin, beeswax and UVA/UVB sunscreen filters if you are outdoors.
- Use mouthwash/rinses (hydrating or without alcohol) or artificial saliva substitute sprays, hydrating sprays/gels or adhering pastilles/patches as advised by your dental care professional and medical health care team.

Tools that may help with oral care

There are a number of helpful adaptive aids and specialized equipment for maintaining oral health. It is recommended that you discuss your specific needs and questions with your occupational therapist, medical care and dental care teams. They are best suited to tell you about which adaptive equipment and strategies are best in your individual situation; they are also well-positioned to refer you to dentists that are specialized and equipped to care for people with ALS.



- Toothpaste dispensers (pumps and hands-free)
- A powered/electric toothbrush; the handles are larger and the oscillating and pulsating motion helps to clean the teeth for you with minimal effort
- Non-foaming fluoride toothpaste that easily dissolves can help if you are worried about choking. Toothpastes without the foaming ingredient sodium lauryl sulfate or SLS are available in several brands
- Oral irrigators/flossers (also called WaterPik®, Water Flosser, Interplak® Water Jet) can help clean between teeth when flossing is too difficult to manage
- Mouth rest prop, bite block or guard for oral care when fatigue in holding the mouth open or muscle spasms occur
- Disposable mouth/oral care swabs with foam tips (Toothette® type).
- A vaporizer or room humidifier can sometimes help keep the air humidified if mouth breathing is a common source of dry mouth.
- Suction toothbrushes (Plak-Vak®) can be an essential item to have when cleaning the mouth of a person with ALS who can not swallow safely, manage their saliva and who cannot brush his/her own teeth and tongue
- A portable suction device at home, this can be used during oral care or for removal of excessive saliva

Things to think about when it comes to dental visits:

- Is my dentist's office adapted for people with reduced mobility and/or wheelchair accessible?
- Can dental cleanings be performed while remaining tilted or reclined in a motorized wheelchair, or is a transfer to a dental chair necessary?
- Can they provide oral care without completely reclining the head of the chair (help adapt if there are swallowing difficulties, challenges with pooling saliva at the back of the throat or breathing impairments)?
- Can shorter appointments or frequent breaks during dental hygiene be accommodated?
- Are home visits offered?

Be sure to ask your healthcare team about recommendations and referrals to dental professionals. Specialized dental services can be provided in hospital centres, freestanding clinics and there are also mobile dental services which can be accessed.

Mobile Dental Services

- **Service dentaire mobile MDC Inc.**
  Areas served: Montreal, South Shore, Laval, and the Laurentians.
  Provide in-home appointments; long-term care facilities, and senior's residences for persons that are immobile or unable to travel to a dental office (in operation for the past 25 years).
  Telephone: 514- 984-3092
  No referral is needed to access their services
  There may be a waiting list (of up to 2-3 months) depending on the availability of the dentists (possibility of having an earlier appointment if/when there is a cancellation).
  Services are provided by a team of dentists who can perform treatments even if a person is in a chair, or lying in bed, and they also have a folding chair that can be brought with them to accommodate positioning.
  Costs: $85 for travel expenses + $98 for full examination + treatment plan fees (prices vary depending on the procedure/ dental services required or requested)
  Business hours: Monday to Thursday from 9 AM to 4 PM and Friday from 9 AM to 1 PM

- **Mobile Dentist Service: Dentisterie à domicile/House Call Dentist**
  Area served: Montreal
  Telephone: 514-867-3667
  https://dentisterieadomicile.com/home
  Provides home dental care services for those who are unable to physically visit a dental office.
  Dr. Alexandra Stasinopoulos, *Dental Surgeon since 1993*
  Member of L'Ordre des Dentistes du Québec, L'Association des Chirurgiens du Québec and Academy of Dental Sleep Medicine
  Business Hours: Monday to Thursday 9 AM to 4PM, Friday 9 AM to 5 PM, Closed on Saturday and Sunday
  Services: dental emergencies, complete dental examination and cleaning, manufacturing and repair of complete and partial dentures, oral cancer screening, oral care instruction for geriatric patients, teeth whitening.
  Costs: All fees are set by l'Ordre des Dentistes du Québec

- **Clinique Dentaire Mobile Inc.**
  Areas served: Greater Quebec City metropolitan area and the South Shore of Quebec City (travels within less than an hour's distance from Quebec City, in Portneuf, Lévis and Sainte-Anne-de-Beaupré)
  Telephone: 418-570-3793 or Email: info@dentistemobile.com
  https://dentistemobile.com/
  A dentist who travels to your home or senior's residence to provide quality dental care for the elderly or people with reduced mobility.
  Dr. Sarah Gagné, *Dental Surgeon since 2005*
  Business Hours: Monday to Thursday 9 AM to 3 PM with appointment bookings 7 days a week.
  Services: Complete examination, scaling and dental cleaning, detection and repair of prostheses or dentures, fillings, crowns and bridges, treatment of dental and gum abscesses, staff training (in senior's residences and long-term care facilities).

- **Clinique Dentaire Mobile Inc.** ***(continued…)***

  Recent news report about these dental services:
  https://www.cbc.ca/news/canada/montreal/dentist-seniors-quebec-city-1.5029549?__vfz=medium%3Dsharebar&fbclid=IwAR1y9KD1KImL5uu1Wj9bEO8FAEJqqaWfNt_uUlF8_gB5uahKqJZnne9p5S8

Recommended by one of our members living with ALS

- **Centre Dentaire Hélène Langevin**
  1436 Boulevard Curé- Labelle (corner Boul. Céleron), suite 205
  Blainville, Québec J7C 2P2
  Telephone: 450-951-7647 or Email: info@centredentairehl.com
  https://www.centredentairehl.com/
  Un centre dentaire, humain, personnalisé et souriant. Des soins professionnels de qualité en plus d'un service des plus personnalisés.
  Dre. Hélène Langevin *graduated from the University of Montreal in 2006 and practiced in various clinics before opening the Centre Dentaire Hélène Langevin in 2012***.**
  Horaire : Lundi au vendredi : L'horaire peut se varier selon les semaines.

Online resources and websites about oral care and products:

L'Ordre des dentistes du Québec is a reference in oral health care and general information:
https://www.maboucheensante.com/en/

The Canadian Dental Association: https://www.cda-adc.ca/en/index.asp

L'Ordre de hygiénistes dentaires du Québec (uniquely in French): https://masantemonsourire.com/conseils/

Dental Hygiene Canada (CDHA): https://www.dentalhygienecanada.ca/

- Daily Denture and Mouth Care
- Denture Care: Advice For Caregivers

University of Manitoba-Rady Faculty of Health Sciences

- Product list and suppliers in Canada:
- Mouthcare Resources for Caregivers: Fact Sheets & Video Clips
  http://umanitoba.ca/faculties/health_sciences/dentistry/ccoh/longterm-care-facts.html

The Challenges and Risks of Swallowing Difficulties

Dehydration

Dehydration is caused by too little water coming in, too much water going out, or both.

A dehydrated person will urinate less often, produce less saliva and be constipated often. He or she will have an increased risk of infection, such as a urinary tract infection or pneumonia. It's not just swallowing that suffers when you're dehydrated. Dehydration also means less blood to the brain and muscles. This can impair thinking, balance and overall strength, making a person confused, dizzy, weak and more vulnerable to falls. In addition, being dehydrated can make you feel just plain miserable, even depressed.

Beware of symptoms of dehydration, which can occur when you sweat excessively or don't drink enough:

- Dark yellow urine with a strong odor
- Small amounts of urine
- Feeling fatigued or tired
- Headache
- Thirst
- Dry mouth
- Cracked lips
- Dry skin
- Loss of skin tone - the skin on the back of the hand or forearm does not return to its original shape when pinched.
- Loss of appetite, or low or no appetite
- Restlessness, impatience or feeling agitated
- Dizziness or light-headedness
- Muscle weakness

Malnutrition

Maintaining good nutritional state can be difficult when living with ALS. Decreased appetite, stress, and difficulty chewing or swallowing may affect your food intake. However, your energy needs may be greater than ever.

Research shows that the calorie needs of people with ALS are as follows:

- Your energy needs are about 15 percent higher than those of a person not living with ALS;
- Inadequate nutritional intake accelerates the breakdown and weakening of muscles in the extremities and breathing;
- A large percentage of ALS patients consume fewer calories per day than they need;
- Weight loss and inadequate energy intake can accelerate disease progression.

Weight maintenance in ALS seems to have a beneficial and protective effect. The more weight you are able to keep on or maintain, the better your strength, energy and appetite.

Monitoring your body weight is one way to keep track of your nutritional status. It is generally recommended that you do not try to lose weight after being diagnosed with ALS. The goal is to maintain your weight. You may experience minor weight loss due to reduced muscle mass. However, dieting is not recommended, even if you feel you are overweight.

Make an effort to watch your weight:

- Keep a chart of your weight as of today!
- Weigh yourself once a week, preferably on the same day and at the same time each week;
- Compare any changes to your usual weight, rather than to standardized weight charts;
- Fluctuations of 1 to 2 pounds (0.5 to 1 kg) are common. However, if you notice a pattern of weight loss, be sure to tell your doctor and dietitian/nutritionist;
- **At a minimum, your weight should be evaluated every 3 months.**

Your ALS care team will assess and recommend the number of calories and water(hydration) you need to consume per day based on your weight and progress throughout your ALS journey.

Bitesnap Application

https://getbitesnap.com/

(*Available for free on Google Play and the App Store*)

Count calories and nutrients simply by taking a picture. Bitesnap recognizes the food contents of your meals, saving you time and making it easy to track what you eat. The app uses artificial intelligence to recognize the contents of a photo. Easily add portion size and extras like barbecue sauce to improve accuracy. Bitesnap calculates calories and nutrients almost automatically, without the usual research, scrolling, or tedious food entry. Food and calorie apps track what you eat and drink each day and provide other information about carbohydrates, fat and nutritional value. Most people use these apps to lose weight, but others use them to maintain weight, gain weight, or have a more nutritious diet.

Aspiration of foods

Aspiration occurs when liquid (including saliva), solid food or medicine enters the airway instead of the digestive tract. This can be dangerous and cause lung infections or pneumonia. Watch for signs of an aspiration; they may be a sign that you need to change the consistency or texture of your food or liquids. If you notice any changes in your swallowing, tell your doctor or other professionals of your multidisciplinary healthcare team as soon as possible.

Possible signs of aspiration:

- A change in voice (wet voice or gurgling)
- Coughing or choking during meals
- Wheezing
- Tearing of the eyes
- Increasing chest congestion, with more frequent coughing spells, more secretions and more difficulty breathing than usual
- The feeling or sensation that there is food stuck or caught in the throat

Factors that contribute to aspiration:

- Eating too quickly
- Taking too many big bites
- Getting too tired while eating
- Being distracted or talking while eating
- Not keeping an upright sitting position while eating
- Weakness of the tongue or lack of control of the tongue, which prevents food or drink from within the mouth from moving efficiently from the mouth to the throat
- Lack of saliva or weakness in the muscles involved in chewing
- Difficulty or lack of coordination between breathing and swallowing

Tips for Easier and Safer Swallowing

- Rest before each meal, if meal times have become more tiring.
- Eat in a peaceful environment with no distractions.
- Make sure to be sit upright when eating or drinking.
- Tuck your chin into your chest.
- Wear dentures and eye glasses.
- Avoid talking when eating.
- Moisten dry foods with gravy, sauce, cream, butter and broths.
- Cold drinks and foods may be easier to swallow.
- Choose softer foods.
- Eat slowly and try eating one food at a time.
- Try not to mix different foods in the same mouthful.
- Cut foods into smaller pieces and take small bites.
- Do not mix solids and liquids in the same mouthful.
- Completely swallow and empty mouth before taking another bite.
- If someone is feeding you, they should be sitting at the same level as you.
- After eating, remain in an upright position for 30-45 minutes.
- Practice good oral hygiene before & after each meal and before bed.
- Follow any additional instructions provided by your health care team

Modified textured diets change throughout the progression of ALS, so have your needs reassessed often!

- Remember to swallow frequently, but slowly and carefully.
- Very sweet or very acidic foods can stimulate salivation.
- Stay well hydrated, water is best, but juices, soups, stews and broths can also help prevent dehydration.
- If you find that dairy products (cow/goat) thicken your saliva, try soy milk, nut, oat or rice milk.
- You may tolerate cooked milk, such as pudding or custard, better.
- Eating foods with a high water content, such as canned fruit, well-cooked vegetables, yogurt, custard and pudding, will help you stay hydrated.

How to Manage Choking Episodes

Choking can cause a tremendous amount of anxiety for the person with ALS and their caregivers/family.

The best thing to do about choking is to try to keep it from happening. Choking is often scary, unnerving physically exhausting and frustrating for all involved. Unfortunately, it is not always going to be possible to prevent a choking episode. So, if you are living with ALS and have or suspect a swallowing impairment be sure to discuss your concerns with your healthcare team, avoid eating when you are alone, try to eat in the company of a friend or family member, and consider emergency alert devices (*Philips Lifeline, SOS Médic, Living Well Companion™ TELUS Health*) for times when you may be alone or experiencing an emergency. Whether you are assisting a loved one with ALS at home, dining with friends at a restaurant, or eating by yourself, it is important to be able to recognize a choking emergency and deal with it effectively.

Choking (not gagging and/or coughing) specifically refers to an airway obstruction (something blocking your airway either partially or completely):

- a blockage of airflow to a person's lungs (usually includes, the larynx(voice box) and the uppermost part of the trachea(windpipe or entrance to the airway);
- can be caused by food, liquid, medications, saliva, thick mucous/phlegm, or a foreign object;
- when something sometimes feels stuck in your throat or esophagus(food pipe) after trying to clear it by coughing, swallow repeatedly, if gagging or if it is vomited back up into the throat, it can be accidentally inhaled creating a choking emergency.

The Inability to breathe is a strange sensation that can quickly trigger a sense of panic. It is therefore important to know what to do when you or a loved one is choking. A person's signs of distress in response to an obstruction airway:

- partially blocked airway:
  - ✓ person may be able to breathe, but with difficulty and wheezing sound;
  - ✓ If the person can speak at all, voice may be high-pitched, strained, noisy or weak.

- completely blocked airway:
  - ✓ face changes colour and may become red to scarlet red;
  - ✓ eyes may be bulging in panic;
  - ✓ person may appear agitated;
  - ✓ might try to walk away in distress, panic or to avoid embarrassment;
  - ✓ might clutch throat with hands (universal choking signal), can have only one hand held at the throat like with two hands, it is also possible that people throw objects to attract attention or hit surfaces for the same reason;
  - ✓ might collapse and lose consciousness.

A complete blockage prevents breathing, talking, and cough, as well as, air from getting through the airway and into the lungs. Some people with ALS are no longer able to cough, or have a loss of their cough reflex.

If a person is choking in your presence, you need to observe them carefully, stay as calm as possible and be ready to start first aid without delay.

There are three levels of obstruction: mild, severe and complete.

- Always start by asking the person '***Are you choking?***'
  - If they nod their head 'no', are coughing, breathing and talking:

Mild

- ✓ do not leave them alone;
- ✓ observe them carefully and stay calm;
- ✓ coach them by encouraging them to keep coughing until the choking is resolved.

  - If they nod their head 'yes' or have difficulty speaking, tries to cough, makes a wheezing noise or they try to walk away, act immediately:

Severe

- ✓ Stay with them (and keep your mobile phone with you), act as calmly as possible, tell them you will help, and explain what you will do;
- ✓ Do not offer water or reach into their mouth or throat to remove the obstructing food or other item. This wastes time and can push the obstruction further down the airway;
- ✓ Alternate between any two of the following three methods (depending on the position and size of the person) until the obstruction comes out:

1. **Back blows** (when person is seated or standing)
   Stand behind, slightly to the side of the choking person. Place your arms across the person's chest. Bend the person forward and deliver up to 5 firm back blows between the shoulder blades.
   Back blows should be combined with abdominal thrusts or chest thrusts. The steps should be combined by alternating 5 back blows followed immediately by 5 abdominal thrusts or 5 chest thrusts until the airway is cleared.

- ✓ If Method 1 does not clear the obstruction, alternate between two of the following three methods (depending on the person's position and size) until the obstruction is dislodged.

2. **Abdominal thrusts (previously called Heimlich maneuver)**
   Stand behind the choking person and wrap your arms around their waist. Place the thumb side of your fist against their upper abdomen (just above the belly button), then wrap your fist with your other hand. Give quick, inward and upward thrusts, making a J-like motion. You may actually lift the person off the chair or floor. Continue to do thrusts until the obstruction is dislodged or if there is loss of consciousness.

   If the person who is choking is sitting on a chair, depending on the size and type of chair, you will normally be able to practice abdominal thrusts by kneeling behind the person. (Illustration by Anet James, 'Swallow Safely')

3. **Chest thrusts**

Stand behind the choking person, wrap your arms around the middle of the person's chest with your thumb facing inward and on the sternum, then wrap your other hand over your fist. Give thrusts by pulling straight back, so as to press in the sternum by 5 cm or 2 inches.

If the person is in a wheelchair, push the wheelchair against the wall, lock the brakes and kneel in front of the person who is choking. Draw an imaginary line from one armpit to the other (horizontally) and place the heel of one hand on the middle bone (sternum) or the imaginary junction of a cross then place the other hand on top of it and interlock your fingers. Forcefully press straight back so as to press in the sternum by 5 cm or 2 inches. (Illustration by Anet James, 'Swallow Safely')

- ✓ These three techniques create pressure in the airway, and mimic a strong and forceful cough which is often what is needed to dislodge the what is blocking the airway and allow the person to breathe normally again.

- If what is causing the choking is not dislodged, choose one single technique (abdominal or thoracic thrusts or back blows) and call EMS (Emergency Medical Services)/ 9-1-1, activate your emergency alert device or get someone else to do it.

Complete

You can also access a **TEXT with 9-1-1 (T9-1-1)** service if you are part of the deaf, deafened, hard of hearing or speech impaired (DHHSI) community in Quebec and other parts of Canada. During an emergency, T9-1-1 provides 9-1-1 call centres with the ability to converse with you using text messaging. Before using this service, you:

- ✓ Must register for T9-1-1 with your wireless service provider; **AND**
- ✓ Must have a compatible cell phone. Information on cell phones that meet T9-1-1 requirements is available on your wireless service provider's website;
- ✓ To learn more about this service visit: https://www.textwith911.ca/en/home/
- ✓ Text with 9-1-1 is available in most areas of Quebec, including major urban areas. For a complete list of municipalities that offer T9-1-1 click here.

- After you have performed these techniques to resolve an episode of choking, it is important to follow up with your treating health care team. Thrusts can cause internal injuries and the object that was causing the choking can sometimes partially go through to the lungs causing a risk for respiratory illness or infection. These risks can occur weeks and even months following the choking episode. It is also important to review what caused the choking episode and discuss the possible strategies for prevention of future choking episodes.

What to do if you are alone and find yourself choking?

- Try not to panic if you find yourself unable to cough, speak or breathe
- ***Time is of essence!*** *You must act quickly because you risk losing consciousness if the foreign body or obstruction is not dislodged*
- If you have an emergency device, trigger it immediately or call 9-1-1
- If you are in a public place, try to convey the universal choking sign to get someone's attention
- Try to cough, and keep coughing as forcefully as you can
- Carry out abdominal thrusts by standing against a sink, countertop, desk, sturdy chair:

✓ *Press your upper belly firmly against its upper edge, so that your belly button is below the chair back and let yourself fall onto the surface. It's your weight that will do the work from above, as if you were coughing vigorously.*
(Illustration by Anet James, 'Swallow Safely')

How and where do I learn first aid skills?

Signing up for a first aid course is a great way to learn how to respond effectively in the face of a choking emergency at home or elsewhere. These courses are designed to help you acquire the knowledge and skills you need to learn and provide a simulated environment to practice these techniques. To find programs and courses that offer the most up-to-date first aid techniques and CPR (cardiopulmonary resuscitation) standards, consult with the following organizations for a course located within your community or region of the province.

Courses should include the ILCOR standards and recommendations for CPR (International Liaison Committee on Resuscitation). To ensure quality training that meets international standards, make sure that the training is provided by one of these three pan-Canadian organizations and that the certificate of completion is issued to you by one of these three organizations as well.

Remember to indicate that you are a caregiver or family member of someone living with ALS as some instructors or courses are tailored specifically for persons that have a high frequency/risk of choking and have reduced mobility or autonomy. It is important that the course is tailored to your reality and needs.

https://cpr.heartandstroke.ca/s/?language=en_US

https://www.sja.ca/English/Courses-and-Training/Pages/default.aspx

https://myrc.redcross.ca/en/

First Aid Application*

The official Canadian Red Cross First Aid app puts lifesaving advice in your hands. Available for Apple and Android mobile devices, the app helps you maintain your first aid skills and respond to everyday emergencies.
By downloading the app on your smartphone or tablet, you get instant access to videos, interactive quizzes and simple step-by-step advice to help you maintain your life-saving skills and respond when needed. Download the app to keep lifesaving help in your hands.

***Although helpful, applications are not always updated. It is always better to follow a first aid course.**

NB: ***This content has been reviewed by Jacques Durand, Master Instructor of Heart+Stroke.***

Frequently Asked Questions (FAQ's) About Gastrostomy (Enteral) Feeding Tubes

Information regarding the potential benefits and risks of having a feeding tube placed is usually provided by your multidisciplinary ALS healthcare team early on in the course of your ALS journey. Most, but not all, people diagnosed with ALS decide to get a feeding tube. Making the decision to have a gastrostomy feeding tube placed is a very personal decision that involves not only your own perspective and abilities but also those of your caregiver(s) and family members. It is also possible to ask to connect and speak with someone living with ALS who is already using a feeding tube to help you during your decision-making process. It is important to be well-informed and have discussions based on accurate information about the advantages, disadvantages and your wishes related to nutrition. Simply because a procedure is possible and potentially beneficial, does not mean that it is the right choice for you or acceptable for everyone living with ALS. It is also important to realize that your perspective about a feeding tube may change over time. Below are a few commonly asked questions about enteral feeding.

Why a feeding tube?

There are times when a person living with ALS can no longer swallow effectively enough to maintain their weight, stay hydrated or take medications/supplements by mouth safely. Eating and swallowing food, liquids, saliva and medications can become exhausting and time-consuming. Ineffective swallowing and dysphagia also lead to malnourishment, dehydration, constipation and increases the risk of choking or aspiration (inhaling into the lungs, which can increase lung infections). Changes in hand and arm control can also make it difficult to get the necessary amount of food and water to the mouth in order to stay nourished and hydrated everyday. Maintaining weight and striving for optimal nutrition is of paramount importance and is very challenging for anyone diagnosed with ALS because there is an increased requirement for calories and the added challenge of muscle wasting that occurs with the illness. Research studies show that when timed properly, a feeding tube can greatly improve nutrition, hydration, energy conservation and the quality of life for people living with ALS. It does not however, change the progression of the disease.

When is the best time to get a gastrostomy tube?

A feeding tube is generally suggested well before it is absolutely needed. This is when it is becoming difficult to swallow safely, and/or eat and drink sufficient amounts to maintain weight and nourish the body, as well as, when respiratory muscles and breathing ability continue to be relatively strong. When to consider enteral nutrition:

- ✓ When ALS interferes with the ability to swallow food and fluids;
- ✓ When nutrition needs cannot be met by eating by mouth;
- ✓ Before significant weight loss occurs;
- ✓ Before breathing is severely impaired.

The multidisciplinary ALS team caring for you will likely recommend that a feeding tube should be considered when:*

- There is a ≥ 5-10% weight loss from usual (baseline) weight;
- A ≥ one-point reduction in usual BMI (*Body Mass Index: is a calculation using a person's weight (kilograms) divided by their height(meters) squared or (Kg ÷ m^2 =Kg/m^2*), a BMI that is less than 18.5 (*a healthy weight range BMI is 18.5 – 24.99*);
- When there is an increased risk of aspiration despite food texture and liquid consistency modifications;
- When a person's Total Daily Energy Expenditure (TDEE) exceeds their daily energy intake. TDEE is an estimation of the amount of energy in calories you burn per day and takes into account your activity level. TDEE is calculated by your ALS healthcare team;
- When there is a decrease in Forced Vital Capacity (FVC) approaching 50%. FVC is the total amount of air exhaled during the FEV test, and is a lung function test performed by a respiratory/inhalation therapist to assess your breathing ability.

***Canadian best practice recommendations for the management of amyotrophic lateral sclerosis**

What are there different types of gastrostomy feeding tubes that are used?

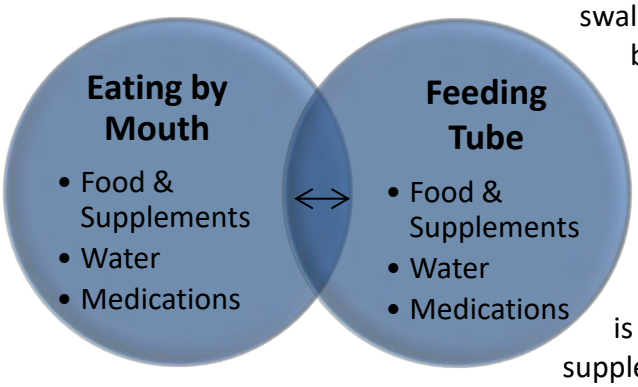
There are typically two types of enteral feeding tubes that are placed for people living with ALS:

1. Radiologically Inserted Gastrostomy (RIG)
2. Percutaneous Endoscopic Gastrostomy(PEG)

These gastrostomy tubes provide a way of bypassing the mouth and allow direct access to the stomach. A gastrostomy tube will not slow the course of the illness but it will enable a person living with ALS to receive food, fluids and medicine directly into the stomach when it is difficult or unsafe to swallow by mouth. The type of enteral feeding tube that is placed depends on several factors, including your respiratory/breathing capacity, as well as, how these surgical procedures are organized within the hospital that your multidisciplinary ALS team works in. A maximum delay of 4 weeks can be considered before placing a feeding tube once the criteria are met. Post-insertion follow-up to prevent complications is also a standard of practice in Canada. To know more about what happens during the feeding tube surgical insertion procedure please see the reference guides in Section 5 of this toolkit.

If I have a gastrostomy/feeding tube placed can I continue to eat and enjoy food by mouth?

The answer to this question lies in whether you can swallow safely. Your speech language pathologist, swallowing specialist and multidisciplinary ALS care team are best-suited to advise you about this. Some people decide to have the feeding tube placed in advance, while they are still able to swallow effectively. This strategy allows them to use the feeding tube as soon as they need to and increase its use gradually and supplement their intake of food by mouth. Most people have some degree of swallowing difficulty when their feeding tube is placed. They will often use the feeding tube to supplement some nutrition, hydration and or to deliver



medications to alleviate the pressure of having to swallow everything by mouth. Enteral feeding can relieve feelings of hunger and thirst, often conserves energy and reduces the fear of choking for both the person living with ALS and their caregiver/family.

For people with ALS who rely on the feeding tube for all of their nutrition and hydration; some will still taste foods and flavours in their mouth without swallowing or enjoy the aromas and smell of food without experiencing the risks that accompany trying to swallow. A dietician/nutritionist will discuss and help guide you regarding the method/frequency of feedings and amount/type of specially prepared enteral formula and the fluid requirements in order to meet your daily nutritional and hydration needs via the gastrostomy tube. Decisions about how often and the method for receiving your tube feedings (by bolus, gravity or by an electric infusion pump) will involve your personal needs, lifestyle and daily routine/activity. For example, some people will opt to have their enteral feedings at the same time that their family members also have their meals. The dietician/nutritionist will also choose an enteral feeding formula that is highly personalized to your needs whether it is: the number of calories; protein; carbohydrate; fats; minerals; vitamins; quantity of fiber and water, as well as, being mindful of any dietary restrictions, intolerances or allergies that you may have.

Can I take all my oral medications through the gastrostomy feeding tube?

Most medicines can be provided through the gastrostomy tube; however, it is important to consider the following:

- Some medications also come in a liquid form and can be more easily given through the tube;
- For medications that only exist in pill form, most can be crushed (time-released and enteric-coated medications should not be crushed), dissolved in water and then administered via the feeding tube;
- **Verify with your pharmacist** which medications can be crushed, dissolved, are available in a liquid form, and which medicines should not be given together. In addition to your pharmacist's advice, the Institute for Safe Medication Practices Canada has a section of their website dedicated to safer medication practices: https://safemedicationuse.ca/;
- To learn more about pill crushers visit this online link (uniquely in English): https://wiki.ezvid.com/best-pill-crushers;

Where can I find information about what daily life is like with a gastrostomy tube?

Listed below are some useful online links for information about living with a feeding tube and how it pertains to someone diagnosed with ALS. These resource links also include information for caregivers:

- ***My Tube Feeding***: Your Tube Feeding Resource Hub by Nestle Health Science
  - https://www.nestlehealthscience.ca/en/mytubefeedingadult
- ***My Tube***: MNDA(Motor Neurone Disease Association and University of Sheffield) (Uniquely available in English)
  - http://mytube.mymnd.org.uk/
- http://alscare.com/feeding_tube.asp

What is a blenderized tube feeding?

A blenderized tube feeding (BTF) is simply when whole foods are liquefied using a high-performance blender (similar to a Vitamix®or Blendtec™ type) and administered through a gastrostomy tube. Blenderized tube feeding is labor intensive and requires additional food storage space and equipment that is not always covered by medical or insurance plans. In view of these factors, BTF is not accessible to everyone because of the lack of time and energy required to prepare the feedings, as well as the financial resources that are needed. It has also been associated with risks of high bacterial load, uncertain nutrient composition, and the potential to clog feeding tubes. Commercial formulas have been mainly used for enteral feeding over the last few decades, and BTF has been reserved for people who have intolerances or allergies to commercial formula ingredients. Recently BTFs are becoming more popular and some people with feeding tubes use a combination of commercial formulas and homemade blended diets. There are several blenderized diet recipes that are available (please refer to Section 4 for details). Learning about proper hygiene and sanitary practices in preparing and administering these types of enteral feeds is crucial, a minimum gastrostomy tube size of 14Fr is required to minimize the chances of tube blockage, and only people who tolerate a large volume of fluid through their gastrostomy tube are candidates for this type of feeding. For people living with ALS, it is vitally important to consult with and be guided by a qualified dietitian/nutritionist that has expertise with ALS. This will ensure that you receive recommendations on how to optimize the required nutritional ingredients that are tailored to your personal needs.

- Visit these online links to read more about blenderized tube feeding:
  - https://oley.org/page/HomeTF_BlenderFoods/Home-Tube-Feeding-with-Blenderized-Foods-
  - https://www.nestlehealthscience.ca/en/brands/compleat/documents/4162w6%20nhs%20compleat%20adult%20recipe%20book%20web%20en%20lr_final%20sep.pdf
  - https://www.compleat.com/recipes

Can I travel and continue to enjoy a variety of activities if I have a feeding tube?

Yes, once the skin around the insertion site of the gastrostomy tube has fully healed and your multidisciplinary ALS care team have advised you to resume your usual level of activity/travel. Once adjusted to the feeling of having a feeding tube, many people living with ALS feel an increase in their energy level, are sometimes able to regain lost weight and have more time to focus on leisure activities that they find enjoyable. Travel is absolutely possible with a bit of advanced planning.

- To learn more about planning a trip that meets your needs, watch this webinar where Isabelle Ducharme, Chair of the Board at Kéroul, highlights strategies that help you, your caregiver and travel companions to avoid common inconveniences and prepare for a trip that you can fully enjoy.
- The Oley Foundation in the United States strives to enrich the lives of those living with home intravenous nutrition and tube feeding through education, advocacy, and networking. Their online information offers many practical suggestions including pre-formatted letters/documents when travelling abroad with an enteral feeding tube and related supplies. These materials are uniquely provided in English.

Does a gastrostomy feeding tube entirely eliminate the possibility of aspiration?

No it does not. Although you may no longer eat, drink or take medications by mouth, you do continue to produce saliva. Saliva and the related bacteria in the mouth can still be inhaled into the lungs and potentially increase your risk of lung infections and pneumonia. This is why optimizing and maintaining oral health remains an essential part of your daily care routine even though you are receiving most, if not all of your nutrition, hydration and medicine by way of a gastrostomy tube.

Once I have had a gastrostomy feeding tube placed, can I change my mind or opt to refuse food at some point?

Yes, you can always choose to have a feeding tube placed and then either not use it or have it removed. There are a number of factors that come into play when making the decision to continue or to stop enteral feeding. For some people, having an alternative to maintain their nutrition is eagerly welcome. For others it can be very difficult to accept that they need to rely on a feeding tube to sustain their nutrition. These complex feelings are often related to end of life issues and wishes. A feeding tube can prolong your life beyond your preferred quality-of-life threshold. As with any type of medical care or intervention, you have the right to determine what is acceptable for you. When planning advanced care directives, it is important to think about and include your views and wishes regarding any limitations and/or boundaries relating to enteral nutrition. Be sure to discuss and share these directives with your multidisciplinary ALS care team, caregiver(s)/family and support network so that your wishes can be honoured.

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Eating well when you have dysphagia - modified textures and adapting your diet

This section of the nutritional toolkit offers practical information related to the different therapeutic dietary regimens for people who are experiencing dysphagia.

The information that follows considers nutritional standards and guidelines, namely:

- A healthy menu based on the *2021 Canada's Food Guide*
  - Eat a variety of healthy foods every day:
    - ✓ Have plenty of vegetables and fruits
    - ✓ Eat protein foods
    - ✓ Choose whole grain foods
    - ✓ Make water your drink of choice;
- A menu rich in energy and calories has been recommended to improve nutritional indicators and possibly survival in people living with ALS.
  - Some research studies have shown evidence that high-calorie and high-carbohydrate diets may be better than high-calorie and high-fat diets.
- Modified texture meals that are energy and protein-dense, tailored the needs of people living with ALS and adhering to the standards of the Professional Association of Dysphagia Expert Nutritionists (APNED) and the Ordre professionnel des diététistes du Québec (OPDQ).

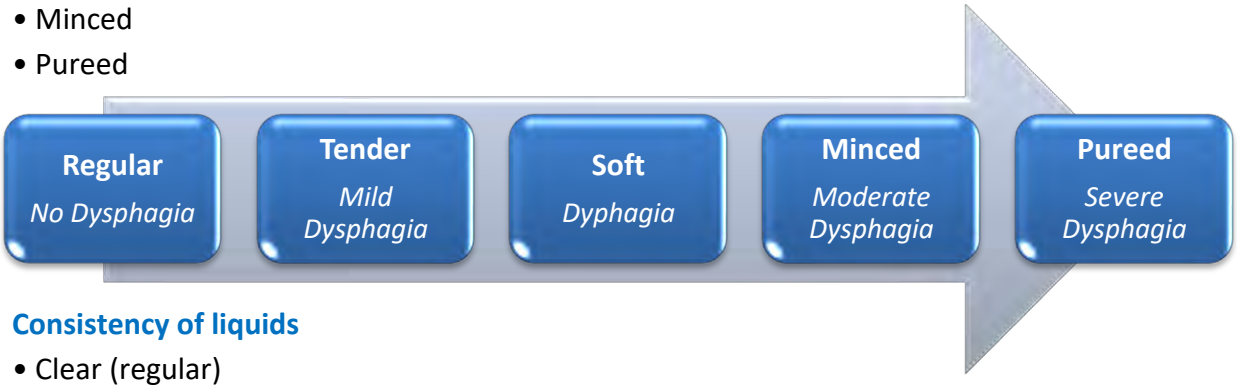
You will also find descriptions and features for each therapeutic food texture. The modifications to the existing diet textures were developed according to the most recent recommendations of the OPDQ and the APNED, as well as, the criteria and methods for preparing modified textures. Finally, certain sections of the *Clinical Nutrition Manual* of the Ordre professionnel des diététistes du Québec (OPDQ) have also been incorporated to supplement the information.

Recognized terminology of food textures and consistencies for people diagnosed with Dysphagia in Quebec

Since 2010, standardized provincial terminology has been defined by the Professional Order of Dietitians of Quebec (OPDQ) and published in the OPDQ Clinical Nutrition Manual. This terminology is also endorsed by (APNED) a Professional Association of Dysphagia Expert Nutritionists (APNED). Please find the official Quebec terminology for modified textures and consistencies below:

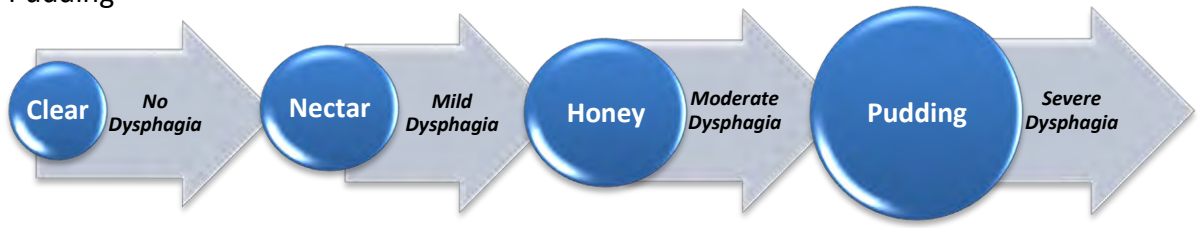
Adapted texture food plans:

- Regular
- Tender
- Soft
- Minced
- Pureed



Consistency of liquids

- Clear (regular)
- Nectar
- Honey
- Pudding



This classification of textures and consistencies supports the individualization of nutritional plans.

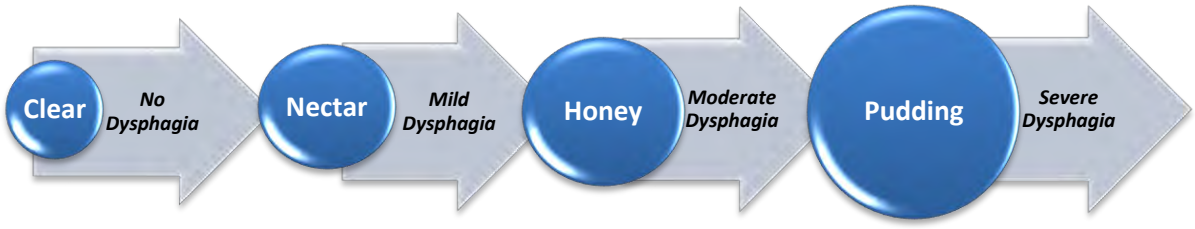
You may find products or information online about resources that use another framework called the International Dysphagia Diet Standardization Initiatives (IDDSI). This can potentially lead to some confusion about the texture or consistency that is appropriate to your situation. If you have any questions or for clarification, please consult your medical care team, nutritionist and / or speech language pathologist about which textures and food consistencies are the safest and most personalized for you.

How To Thicken Your Liquids

Your healthcare team may have advised you to thicken the beverages that you drink to make them easier to swallow. Thickening liquids slows down the flow of the liquids you drink. This makes swallowing safer because it improves your control when you drink and reduces the risk of the liquid flowing the wrong way, into your lungs. The official terminology for modified consistencies in Quebec is:

Consistency of liquids

- Clear (regular)
- Nectar (Bostwick 14-B14) – Reference beverage: Drinkable yogurt such as Yop
- Honey (Bostwick 8-B8) – Reference beverage(s): Condensed milk (sweetened) Eagle Brand or honey
- Pudding (Bostwick 4 -B4) – Reference beverage(s): Smooth yogurt such as Ïogo or commercial pudding



Clear liquids are those that have the consistency of water (like juice, broth, coffee and tea). Here are some tips to help you thicken the liquids you drink at home.

Ready-to-consume products with a honey or nectar consistency
(Sold in pharmacies, specialty stores and sometimes online)
ThickenUp®Resource®Beverage thickened juice, milk and water beverages
Lassonde Oasis NutriSolution Hydra+^{MC} Thickened juice, milk and water beverages
Thick-It®AquaCareH2O® (water, juice, coffee and tea)
Hormel Health Labs Thick & Easy® Beverages (lemon water, juice, tea, milk, and chocolate milk)
Lyon's Ready Care™ (lemon water, juice, tea, coffee, milk and hot chocolate)

Commercial thickening agents

(*The costs of commercial food thickeners are not covered by RAMQ plans, but receipts for expenses may be eligible for the tax credit. These products are sold in pharmacies, specialty stores and online)*

In Canada, the two most common types of thickening agents are starch-based and xanthan gum-based. Starch-based thickeners are less popular because they give clear beverages an opaque appearance and have a slightly grainy texture. Lumps can form if they are not mixed well and they can continue to thicken over time. They are also more difficult to use with fizzy drinks and hot liquids.

There are two types of thickening agents based with xanthan gum: those in powder form and those in liquid form. Both types of thickening agents can be used to change the consistency of beverages. Consider the following when choosing a thickener that is right for you:

- Xanthan gum thickeners in powder or liquid form require different mixing techniques. Therefore, you must be sure to follow the directions carefully when preparing them.
- Xanthan gum thickeners in powder or liquid form have a different effect on taste. Powdered xanthan gum thickeners are, in most cases, tasteless, while some liquid xanthan gum thickeners can add a slight sour taste to the food or beverage they are mixed with.

Powder Thickeners	**Ingredients and link(s) to online information**
Resource® ThickenUp® Clear[MC]	*Corn and potato maltodextrins, xanthan gum, potassium chloride, may contain milk (in pharmacies, online and in specialty stores)*
	https://www.nestlehealthscience.ca/en/brands/resource-thickenup/index
Resource®ThickenUp®,	*Modified food starch (corn)*
	https://www.nestlehealthscience.ca/en/brands/resource-thickenup/thickenup-original
Thick-It®Clear Advantage[MC]	*Xanthan gum, maltodextrin, ascorbic acid.*
	https://thickit.com/nutrition-product-category/thickeners/
Thick-It®	*Modified food starch and maltodextrin*
	http://thickit.com/
Consistaide by Berthelet®	*Modified corn starch*
	https://b2b.berthelet.com/catalogue/produits-complementaires/produits-complementaires-2/paississant-alimentaire-instantan-consistaide-325gr/
Hormel Health Labs Thick & Easy® Clear Thickener	*Maltodextrin, xanthan gum, carrageenan, erythritol*
	https://www.hormelhealthlabs.com/product/thick-easy-clear-food-beverage-thickeners/
Hormel Health Labs Thick & Easy® Starch Thickener	*Modified food starch*
	http://www.hormelhealthlabs.com/products/thickeners
Lyon's Ready Care[MC]	*Modified food starch (corn)*
	https://store.lyonsreadycare.com/collections/thickeners
Purathick[MC]	*Organic tapioca maltodextrin, organic tara gum and calcium carbonate.*
	https://www.healthierthickening.com/purathick/
	https://www.caringsolutions.ca/collections/thickeners-food-drink
Colourless Gel Thickeners	**Ingredients and link(s) to online information**
SimplyThick®	*Water, soluble fiber, xanthan gum, glucono delta lactone, gellan gum, potassium sorbate (preservative), calcium chloride, citric acid, sodium citrate, guar gum, pectin.*
	http://www.simplythick.com/
	http://www.ergogrip.ca/simplythick-gel-epaississant-alimentaire

Thickening agents for household use

- Cornstarch
- Xanthan gum
- Dehydrated potato flakes
- Instant pudding mix
- Unflavoured gelatin powder
- Infant cereal

Using thickeners

- Prepare liquids to the consistency recommended by your health care professional (nectar, honey or pudding consistency) and use a whisk to mix well.
- For commercial thickeners, follow package directions.
- Pour the measured amount of liquid (drink) into a container.
- Start with the recommended amount of thickener for the desired consistency.
- Gradually add the thickener to the liquid and whisk vigorously for 20-30 seconds until the thickener is completely dissolved and the desired consistency is achieved.
- Clear liquids take about 5 minutes to thicken.
- Some thickeners continue to work if left to stand (potato flakes).
- If you are using commercial thickeners, you can prepare large quantities of liquids using an electric blender.
- Some commercial food thickeners may react with and alter the action and absorption of certain medications. Instead, it is recommended that you take your medications with naturally thickened alternatives such as applesauce, Greek yogurt or pudding.

Tips and information for thickening liquids

- To thicken hot liquids (soups and sauces), use cornstarch, potato flakes, infant cereal or commercial products.
- Hot beverages with some thickeners (starch-based) added will continue to thicken as they cool.
- Clear liquids can take anywhere from 1 to 5 minutes to thicken. Nutritional supplements (Boost® or Ensure®) take much longer to thicken (about 20 minutes), so sometimes it is recommended to choose supplements in pudding form instead of thickening liquid supplements.
- It is also possible to thicken soft drinks, but they will lose their effervescence during stirring. Whisk liquids before adding the thickener.
- For dairy products, use pudding mix or infant cereal. Add a teaspoon (5 ml) of vanilla extract or maple syrup for extra flavour.
- When you have difficulty taking food and liquids by mouth, it can be especially difficult to get enough fluids. People with mobility impairments who have dysphagia are at high risk for dehydration because they often rely on others to meet their needs for thickened fluids to stay hydrated throughout the day. Ease of use is another important factor in ensuring that you can get enough hydration. Making thickened beverages in larger quantities and keeping them nearby in the refrigerator is a great strategy to set the stage for easy hydration. Commercially available pre-thickened drinks are also convenient, but they are more expensive than making your own thickened drinks.

Clear liquids that can be misleading and pose a risk to people with swallowing difficulties

Clear liquids also include foods and drinks that melt at room temperature. The following foods should not be consumed by people who have difficulty swallowing regular liquids and should not be included in their diet (see the recipe section for strategies to change the consistency of these types of clear liquids to make them safer to swallow):

- Ice cream
- Sorbet
- Popsicles
- Crushed ice
- Flavored gelatins (like Jell-O®)
- Lack of saliva or weakness in the muscles involved in chewing
- Difficulty or lack of coordination between breathing and swallowing

For thickener recipes please refer to the respective commercial thickener brand websites,

- **Resource®ThickenUp® Clear[MC] :**
  - https://www.nestlehealthscience.ca/fr/dysphagiacare/helpful-solutions#thickening-agents
  - Preparation video : https://www.youtube.com/watch?v=bXNitX5IrDU
  - Recipes: https://www.nestlehealthscience.ca/en/brands/resource-thickenup/index
- **Thick-It**
  - https://thickit.com/products/thickeners/
  - Recipes : https://www.thickenupclear.com/recipes
- **Hormel Health Labs Thick & Easy®**
  - Recipes : https://www.hormelhealthlabs.com/resources/category/recipes/
- **Lyon's Ready Care[MC]**
  - https://lyonsreadycare.com/collections/thickeners/home
  - Recipes and preparation instructions (mixing chart) : https://lyonsreadycare.com/pages/recipe-collection?_pos=1&_sid=b22cb5fe6&_ss=r
- **Purathick®**
  - Information and preparation video: https://www.healthierthickening.com/purathick/
- **SimplyThick®**
  - Preparation video : https://www.youtube.com/watch?v=mx7idnxwhHI
  - Preparation brochure and recipes: https://www.ergogrip.ca/img/category/description/brochures/simplythick-gel-food-thickener-brochure.pdf
  - Recipes(in English and Spanish) : https://www.simplythick.com/Online-Recipes

How to puree and modify your food

Your health professional may have suggested for you to begin modifying your foods into purees to make it easier swallow. Here are some tips to puree your foods:

- Using a blender or food processor will make it easier.
- Measure out desired portion of foods and cut into smaller pieces so that the food purees more evenly.
- Add the recommended amount of liquid to make blenderizing easier. See chart below.
- Use hot, cooked meats vegetables and casseroles and soups when pureeing as these are easier to blend compared to cold uncooked foods.
- Blend at a low speed.
- Stop processing and scrap down the sides of the bowl to make sure that all the ingredients are incorporated evenly.
- Strain any lumps or seeds.
- Once food is pureed, reheat or cool before serving.
- Blend one food item at a time.
- Wash and rinse bowl properly between foods.

Recommended amount of liquid to use

Food type	**Amount of food**	**Amount of liquid**
Fruit	125ml (1/2 cup) cooked or canned	15ml (1tbsp) of juice from can or fruit juice
Vegetables	125ml (1/2 cup) well cooked or canned vegetables	30-45ml (2-3tbsp) of cooking water, vegetable juice
Meat	125ml (1/2 cup) of tender meat, fish or poultry	45-60ml (3-4tbsp) vegetable juice, broth, gravy or sauce
Cereal	125ml (1/2 cup) of cooked cereal or 30g (3/4 cup) cold cereal (reduced to a powder)	60-120ml (1/4 – 1/2cup) of milk or milk beverage ***(Caution: this may become sticky if over-mixed)***

*Add additional liquid if necessary to get a uniform consistency

Foods which are harder to blend

- Coarse bread with nuts, seeds or dried fruit
- Granola or whole grain cereal
- Fried noodles or rice
- Fried meats
- Sausage, wieners, or meats with tough membranes
- Chicken skin
- Fish with bones, anchovies
- Fried eggs
- Nuts
- Fruits with seeds or tough skins (berries, oranges, cherries, grapes)
- Raw or fried vegetables
- Corn, lettuce, celery
- Hard cheese
- Ice cream or yogurt with nuts, candy pieces, fruit chunks or seeds
- Baked goods with nuts, seeds or coconut
- Popcorn, coconut, chips, relishes, chocolate chips
- Pasta

Modified Textures

Tender → Soft → Minced → Pureed

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Minced

Pureed

Criteria to consider when purchasing equipment

- The size of the bowl must be chosen according to the quantity of food that will be prepared. When in use, the bowl should neither be too full nor too empty, otherwise the blades will not work properly.
- It is recommended to choose a good quality appliance with a motor that will withstand repeated use over time.

Characteristics of a minced texture that is safe to eat

- Food particles are smaller than 5 mm
- Non sticky and not dry
- Requires little chewing

Characteristics of a puree that is safe to eat

- Smooth and homogeneous
- Food particles are smaller than 0.5 mm
- Non sticky
- No chewing is required

To Improve Food Textures

AT ALL TIMES, MEALS MUST BE:

- Good to taste
- Visually appetizing
- Nutritious

To remove lumps	It can be useful to use a sieve or a strainer lined with a cheese cloth.
To thin a food texture	Milk or yogurt ≥ 2% fat(M.F.), cream, chicken/beef/vegetable broth (it may be preferable to add a powdered base to a nutritious liquid than use a broth), cream soup, sauce (e.g. demi-glace, brown sauce, tomato sauce), drippings/gravy, milk, tomato juice, vegetable or fruit juice, soy beverage, silken tofu and pasteurized egg white
To thicken a food texture	Milk powder, infant rice cereals, potato flakes, mashed potatoes, bread crumbs, wheat bran and commercial thickeners.
To reduce adhesion (make it less sticky)	Yogurt ≥ 2% M.F., pasteurized egg white, silken tofu, fatty substances (canola oil, margarine, mayonnaise, cream: 15% M.F and 35% M.F), and various sauces.

This document has been translated into English for the Culinary Care in ALS- A Nutritional Toolkit (2019) - (Source: APNED Textures Modifiées-GuidePurée)

Minced Method

GENERAL INFORMATION

1. Dairy products such as cottage cheese, quark, ricotta, grated Parmesan, tapioca, and firm or stirred yogurt can be served with pieces of fruit less than 5 mm in size.
2. As for fruits, bananas are a good option when very ripe. Other ripe or canned fruits are usually served minced or pureed.
3. Whether processed into a mousse or a puree, vegetables must always be well cooked and minced. You can also use creamed corn.
4. Mashed potatoes should be slightly adhesive. Boiled potatoes are served mashed with a fork with a emollient substance (butter), cream or sauce added.
5. Muffins and white cakes without frosting/icing can be served mixed with milk, cream, yogurt, pudding or fruit puree.
6. Hot cereals such as oatmeal, baby/infant cereals and cream of wheat are allowed. Cold cereals should not include nuts or dried fruit. These can be softened by letting them soak in a bit of milk.
7. Fruit gelatin (Jello®) is another dessert that can be made with fruit puree or chopped fruit that is less than 5 mm in size.
8. Scrambled eggs and plain omelettes can be served as is, provided they are less than 5 mm in size. Souffles or quiches are served without a crust and with small pieces of vegetables of 5 mm in size or less.
9. Silken tofu and hummus are also served as is, and legumes are pureed or mashed with a fork.

MEATS

1. Always ensure the meat's tenderness (veal, beef, pork, lamb, game, poultry) in order to obtain a minced texture of optimal quality.
2. Cut the meat into 2.5 cm-pieces before adding to the food processor. Pulse until the meat has been reduced to pieces of 5 mm in size or less.
3. From time to time, scrape the sides of the inside of the bowl with a spatula and add it to the mixture in order to ensure a uniform texture. Glance at the mixture and look for and remove any over-sized pieces.
4. You can also use a mincer/grinder to chop the meat before cooking. Make sure that the meat pieces are not dry. Coat with enough sauce and ensure the mixture is well moistened.
5. Whenever the sauce is served separately, keep the meat in a bit of broth and cover. This will prevent it from drying out while waiting for the food to be served.
6. Meat can also be finely chopped with a knife, as long as the particle size limitations of 5 mm or less is respected.

NUTRITIONAL VALUE

Calculate 75-90 g (2 ½ - 3 oz) of **cooked meat** per person before altering the texture.

Tips

- Do not fill more than 2/3 of the capacity (volume) of the mixing/processing bowl as too much pulsing will turn the mixture into a puree.
- Taste before serving to make sure the texture and taste are as intended. Adjust the seasoning if necessary.
- Serve the different components of the plate in separately.

PASTA

1. Process the pasta and the sauce in a food processor.
2. You can simply use soup noodles, as long as they are less than 5 mm in size, while ensuring that the sauce also does not contain any food particles that are larger than 5 mm in size.
3. Larger pasta noodles can also be finely chopped with a knife, ensuring the size limitation of 5 mm or less.
4. Do not serve pasta au gratin(melted layers of oven-baked cheese), offer grated Parmesan sprinkled overtop instead.

FISH

1. Poached or baked white fish, as well as canned flaked tuna and salmon are served as is.
2. Chop the fish by pulsing, and once in a while, scrape the sides of the inside of the bowl with a spatula to ensure a uniform texture.
3. When chopping fish in a food processor, always add sauce as you are blending. While waiting for the food to be served, add a bit of cooking juice to prevent the mixture from drying.
4. Fish is very delicate and can quickly turn into a pureed texture. It is possible to cut fish with a knife, especially for small quantities.

In collaboration with: Regroupement provincial d'analyse sensorielle de textures et consistances, Mélina Lachance, Nutritionist, Access Desk ID-ASD-PD, Vincent Labbé, Head of Logistics, Centre intégré universitaire de santé et de services sociaux de la Capitale-Nationale, and Lucie Fillion, P.Dt. M.Sc., responsible for practical assignments and research. References: La purée dans tous ses états!, Daniel Lavoie, P.Dt., M.Sc., and Danielle Daunais, P.Dt., 2013, La dysphagie oropharyngée chez l'adulte, F. Cot et al., 1996, Manuel de nutrition clinique, Ordre professionnel des diététistes du Québec; Training: The puree texture for deglutition disorders - Practical solutions for food preparation challenges, Laval University; Site: http://pureequecestbon.fsaa.ulaval.ca.

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Pureed

Method

A pureed texture is smooth and has the shape of a ball that slightly spreads when served onto the plate.

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Pureed Vegetables

1. Follow the recommended cooking time in order to preserve the colour (avoid overcooking). Longer cooking time means more water being added to the mixture, thus making the puree more liquidy. Steaming is recommended for frozen and fresh vegetables. Canned vegetables can be used as is. Some frozen vegetables are harder than others to process into a smooth puree (e.g. green peas, asparagus and corn), but canned green peas provide a
2. Drain well to ensure that the final product is not too thin and to avoid the need to add a thickening agent. When drained properly, most vegetables will neither require thickening agents nor liquids to thin them. If necessary, the cooking juice can be used as to thin the puree.
3. With a blender or food processor, blend/pulse for as long as necessary to obtain a smooth puree. For perfectly smooth mashed potatoes, opt for a mixer, pestle or food mill, but do not overdo it, as it can make the food mixture sticky.
4. Adding a small quantity of margarine or butter (about 5 ml for 200 g of pureed vegetable) not only enhances the taste, but also greatly improves the texture (emulsion).

Tips

- Taste before serving in order to make sure the desired texture and taste have been obtained. Adjust the seasoning as necessary.
- Serve the different components of the plate separately. You can use an ice cream scoop to serve. Purees can also be served in decorative glasses, plates with compartments or ramekins.
- Improve the appearance of pureed dishes by simply adding a drizzle of sauce or brightening them with a drop of food colouring.

Pureed Meat

1. Slow and low-temperature cooking methods such as simmering or braising are preferred. Heat the meat before altering the texture. Serve immediately or refrigerate. Be careful not to reheat pureed meat more than once due to the risk of bacterial contamination.
2. Drain the required amount of meat according to the number of servings. Cut the meat into 2.5 cm-pieces or grind/mince before processing.
3. Start by pulsing at low speed to break up the meat. Add the liquid (or sauce) gradually. At this stage, do not add too much liquid in order to prevent having to use a thickener later. If the mixture is too liquidy to start with, the pieces of meat won't breakdown properly. Too much sauce also reduces the nutritional value.
4. Continue at high speed until the texture is smooth.
5. While blending, scrape the sides inside the bowl every 30 seconds to ensure a uniform, smooth, and lump-free texture. For a smooth texture, keep the processor running for several minutes.
6. If necessary, use a thickening agent to obtain the desired texture. In order to avoid ending with a sticky puree, pulse while adding the thickener.
7. When using a blender, air bubbles sometimes form. For best results and an optimal pureed texture, remove them with a spatula.

Pureed Fish

1. Keep the fish covered while steaming and reserve the cooking juice. Be careful not to overcook.
2. When it comes to getting a smooth and homogenous product, mixing time is crucial. Place the fish and sauce, or cooking juice, in the food processor/blender (using the cooking juice allows to have the full nutritional value). Start at low speed, increasing to high, and blend until the mixture is smooth.
3. You can use grilled or breaded fish, but the breadcrumbs and flour can give it a thicker and sticky consistency.
4. Always make sure there are no fishbones. The use of deboned fish filets can increase safety.

Pureed Pasta

1. For pureed pasta or rice, be sure to cook it for a sufficient amount of time to make it easier for you to transform it into a pureed texture. A ratio of 1/3 of pasta to 2/3 sauce is recommended. Start at low speed, increasing to high, and blend/process until the mixture is as smooth as possible.
2. In the case that the consistency of the mixture is too thick, add vegetable juice, cream, margarine, or broth to thin the mixture.
3. For a less sticky puree, reduce the quantity of starchy foods (e.g. add more sauce to the pasta, use half of the pie crust, etc.)
4. Purees that are prepared ahead of time and cooled thicken. If you've made the puree the day before, keep in mind that it'll be thicker the following day after it has been chilled.

NUTRITIONAL VALUE
Calculate 75-90 g (2 ½ - 3 oz) of cooked meat per person before processing.

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Modified diets for people with swallowing difficulties (dysphagia)

Your healthcare professional may have recommended that you follow a specific diet texture because of changes to your swallowing. There is a range of modified texture and consistency diets that can be adapted depending on how easily you can swallow and chew (regular, tender, soft, minced, or pureed).

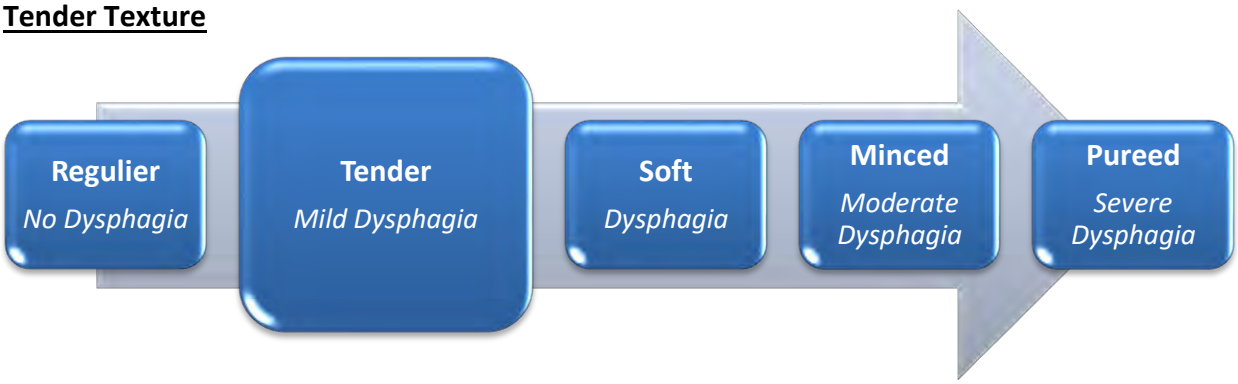
Here is a list of the modified textured diets to be used as a guide at home when choosing foods and meals that you can safely eat. Follow the recommendations followed by your healthcare provider as there may be foods on this list that you can or cannot eat depending on your own needs. If you recognize that your swallowing abilities have changed and that you are having trouble eating or swallowing certain foods, please contact your healthcare provider. You may need to be reassessed for your swallowing. **For your own safety, please do not attempt to modify your diet on your own, always refer to your health care provider for questions and concerns.**

Modified texture and adapted diets change often and throughout the course of ALS, so have your needs re-evaluated often!

For pre-made modified food options, view the **Resources in your community** section of this toolkit. There you will find a list of available resources in your community. **Ask your local home care (CLSC) dietitian-nutritionist or social worker for other available resources in your community (meals-on-wheels, frozen meals) that may be of help to you.**

Recommended serving sizes for each food group is also included for each adapted diet texture. Each food group has a range of recommended serving sizes. People with smaller frames may require fewer servings per day, while those trying to gain weight might require more servings per day.
Review this with your dietitian-nutritionist to know what the right amount of daily servings and calories is best for you.

Tender Texture



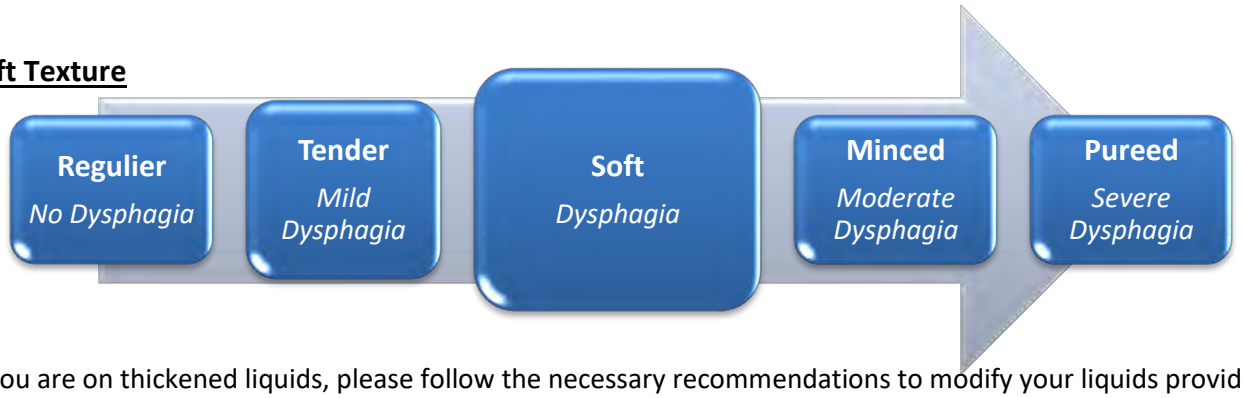
If you are on thickened liquids, please follow the necessary recommendations to modify your liquids provided by your health professional.
Foods followed by a "*" should be considered as thin liquids and modified as needed.

Review this list with you dietitian-nutrition so that they can personalize your diet

Food group & Servings	Foods to include	Foods to exclude
Dairy products & alternatives **2-3 per day** -1 cup (250ml) milk, soy milk or milk alternative -3/4cup (175g) yogurt -1/2cup (125ml) cottage/ricotta cheese -1/2cup (125ml) ice cream, frozen yogurt or milk dessert	-ice cream*, frozen yogurt*, ice milk* without nuts or dried fruits -various cheese without nuts or dried fruits -various yogurts without nuts or dried fruits, with fruits that are permitted -various puddings without nuts or dried fruits	-ice cream*, frozen yogurt*, ice milk* with nuts or dried fruits -various cheese with nuts or dried fruits -various yogurts with nuts, dried fruits, granola, or coconut -various puddings with nuts or dried fruits
Fruits **2-4 per day** -1 medium fruit -1/2 cup (125ml) of pureed or canned fruit -1/2 cup (125ml) fruit juice -1/2cup (125ml) sorbet	-drained canned fruit -unpeeled, fresh, ripe fruit -citrus fruits, watermelon -fresh grapes without seeds, tender, peeled apple, cantaloupe -pureed fruit or sauce	-dried fruits (raisins, banana slides, apricots, prunes, dates, cranberries)
Vegetables **3-5 per day** -1/2 cup (125ml) cooked or pureed vegetables -1/2 cup (125ml) of vegetable juice	-vegetables cooked al dente -lettuce, raw vegetables: peeled cucumbers, chopped tomatoes, radishes -varies potatoes	-raw vegetables: broccoli, celery carrots, cauliflower

<u>Tender Texture</u> **Mixed dishes**	-mixed dishes with tender meat, chicken, fish, vegetables -sandwich or croissant with sliced meats, eggs or minced meats (hamburger) -meat pie (Tourtière) -meatloaf or salmon loaf, meatballs -Shepard's pie	-other mixed dishes -club sandwich (bacon)
Meat & alternatives **2-3 per day** -2 eggs -75g (2 ½ oz) meat -3/4 cup (175ml) legumes or tofu -1/2 cup (125ml) pureed meat	-various eggs or egg dishes -tender, braised, stewed or boiled meat or chicken -liver pâté, creton -fresh fish without bones -lobster, shrimp, scallops -sausages -legumes -creamy peanut & nut butters -silken or firm tofu	-grilled or very tough meats -dried sausages -peanut & other crunchy nut butters -nuts & seeds
Grain products **6-11** -1/2 cup (125ml) pasta, rice, other grains -3/4 cup (175ml) hot or cold cereal -1 medium muffin (about 6cm or 2 ½ inches in diameter)	-muffin or cake without seeds, nuts or dried fruit -all pastas -millet, bulgur -risotto, white rice, brown rice, wild rice, couscous -bread without nuts or seeds -croissant, pancakes, waffles, french toast, soft bagels -crackers -hot cereals: oatmeal, cream of wheat, baby cereal -cold cereals, without nuts, seeds, or dried fruit, in milk -puff or flaky pastry -soft cookies without nuts	-muffin, cake, breads, cold cereals with seeds, nuts or dried fruit -pumpernickel bread -tradition bagels -crispy, crunchy cookies (biscotti)
Other	-chocolate without nougat or caramel -crisps, chips	-chocolate with nougat or caramel -adhesive candies: jelly beans, liquorice, caramel -pop corn -pretzels, nachos

Soft Texture



If you are on thickened liquids, please follow the necessary recommendations to modify your liquids provided by your health professional.
Foods followed by a "*" should be considered as thin liquids and modified as needed.

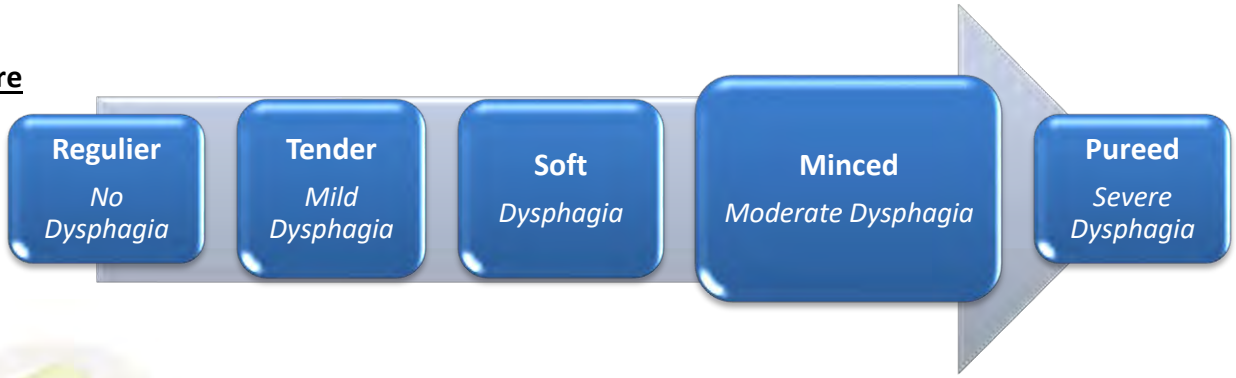
Review this list with you dietitian-nutrition so that they can personalize your diet

Food group & Servings	**Foods to include**	**Foods to exclude**
Dairy products & alternatives **2-3 per day** -1 cup (250ml) milk, soy milk or milk alternative -3/4cup (175g) yogurt -1/2cup (125ml) cottage/ricotta cheese -1/2cup (125ml) ice cream, frozen yogurt or milk dessert	-ice cream*, frozen yogurt*, ice milk*, without hard pieces - fresh cheese Minigo, Quark, Cottage, grated Parmesan, Ricotta, cream cheese, brie, camembert, sliced, soft cheeses (light cheddar, brick, gouda) -various puddings, without dried fruits, nuts or seeds -commercial yogurts with fruit pieces, without dried fruits or nuts, with fruits that are permitted	-ice cream*, frozen yogurt*, ice milk*, with nuts, dried fruits or caramel -firm cheese, aged Cheddar, Parmesan, Gruyere, fondues, cheese with seeds or dried fruits -puddings with dried fruits, nuts or seeds -commercial yogurts with granola, nuts, fresh fruit, seeds, or chocolate chips
Fruits **2-4 per day** -1 medium fruit -1/2 cup (125ml) of pureed or canned fruit -1/2 cup (125ml) fruit juice -1/2cup (125ml) sorbet	-fresh fruits: banana, avocado, peeled & sliced apple, berries -canned fruits: apricots, pears, peaches, fruit salad, mandarins, crushed pineapple -ripe, peeled fruit: mango, kiwi, papaya, melons, cantaloupe, -pureed fruits or sauces -sorbets*, gelatine*, jello-O	-fresh fruit: grapes, clementines, oranges, grapefruit, apples with skins -fresh fruit salad or tropical -fresh or canned pineapple, not crushed -dried fruits: raisins, dates, apricots, prunes, cranberries
Vegetables **3-5 per day** -1/2 cup (125ml) cooked or pureed vegetables -1/2 cup (125ml) of vegetable juice	-well cooked vegetables -creamed corn -mashed potatoes, fries, boiled potatoes, hash browns	-al dente cooked vegetables -corn on the cob or grains -raw vegetables -lettuce -bean sprouts -peas

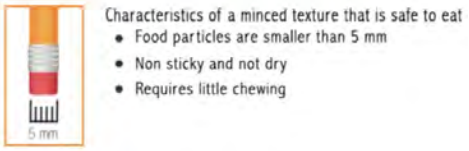
<u>Soft Texture</u> **Mixed dishes**	-sandwiches: egg salad, tuna, fish mouse, minced meats -meatloaf or salmon loaf -meat pie (Tourtière) -meatballs -Shepard's pie with creamed corn	-Shepard's pie with corn grains -other mixed dishes
Meat & alternatives **2-3 per day** -2 eggs -75g (2 ½ oz) meat -3/4 cup (175ml) legumes or tofu -1/2 cup (125ml) pureed meat	-scrambled, poached, boiled eggs, omelettes, quiches -braised, stewed meat -brown chicken meat, minced white chicken meat -liver pâté, pâté, creton, sausage meat with casing -fresh or canned fish, without bones -poached, baked, boiled fish -canned, crumbled tuna -chopped seafood -canned beans -baked beans -silken tofu, hummus	-eggs in vinegar -grilled, roasted, barbecued, fried, browned meats -sausages -grilled, barbecued, fried fish -whole seafood -nuts & seeds -peanut & nut butters -semi-firm, firm tofu
Grain products **6-11** -1/2 cup (125ml) pasta, rice, other grains -3/4 cup (175ml) hot or cold cereal -1 medium muffin (about 6cm or 2 ½ inches in diameter)	-hot cereal: oatmeal, baby cereal, cream of wheat -cold cereal without nuts, seeds or dried fruit -sliced bread, without seeds or nuts -french toast, pancakes -muffin without nuts, seeds or dried fruit, soaked in milk, cream or yogurt as needed -cake without dried fruits, nuts -Arborio rice, white rice, risotto, millet, couscous, barley -small pasta with sauce -tea biscuits -soda crackers -trifle with fruits	-granola, cereal with nuts, seeds or dried fruit, cereal with psyllium -sliced bread, muffin or cake with seeds or nuts, dried fruit -pumpernickel or rye bread -crusty bread -bagels -croissants or waffles -Melba toast® -Rusti® type of cracker and/with seeds -Wild or brown rice -puff or flaky pastry -whole wheat or large pasta (lasagne, rigatoni, etc) -pasta baked in the oven with cheese (au gratin)

Other	aerated chocolate Aero® or Mirage®	-other chocolates: Caramilk®,Toblerone®, etc -chocolate with dried fruit or nuts -nachos, chips, pretzels -popcorn -flaky pastries

Minced Texture



If you are on thickened liquids, please follow the necessary recommendations to modify your liquids provided by your health professional.
Foods followed by a "*" should be considered as thin liquids and modified as needed.



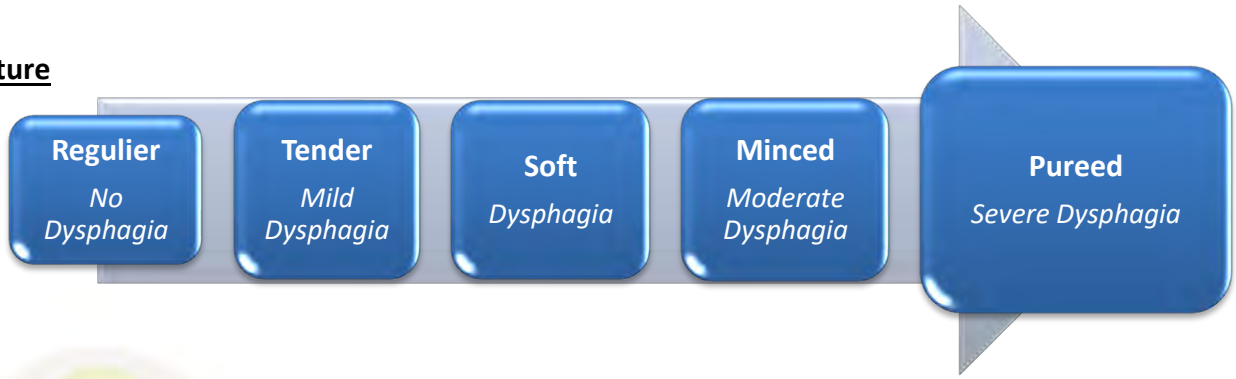
This texture includes finely chopped food, into small pieces of less than 5mm. The chopped texture is lumpy and requires very little chewing

Review this list with you dietitian-nutrition so that they can personalize your diet

Food group & Servings	Foods to include	Foods to exclude
Dairy products & alternatives **2-3 per day** -1 cup (250ml) milk, soy milk or milk alternative -3/4cup (175g) yogurt -1/2cup (125ml) cottage/ricotta cheese -1/2cup (125ml) ice cream, frozen yogurt or milk dessert	-smooth puddings, custards, tapioca, without any pieces of fruits, candies, caramel or nuts -ice cream*, frozen yogurt*, ice milk* without pieces -fresh cheese Minigo, Quark, Cottage, grated Parmesan, Ricotta -commercial yogurt with small pieces of fruit (less than 5 mm)	-puddings with pieces of fruits, candies or nuts & rice puddings -ice cream, frozen yogurt, ice milk with pieces -cheese, sliced or firm (cheddar fort, parmesan, gruyere) -commercial yogurt with pieces of fruit larger than 5 mm
Fruits **2-4 per day** -1 medium fruit -1/2 cup (125ml) of pureed or canned fruit -1/2 cup (125ml) fruit juice -1/2cup (125ml) sorbet	-pureed fruits & sauces without pieces, sorbet*, gelatine* -ripe bananas, avocado -peeled, ripe, minced fruits -soft, drained, canned fruits (pears, peaches, apricots)	-other fresh fruits -dried fruits -fresh or canned pineapple -fresh or canned mandarins, grapefruit, oranges, clementines

Vegetables(<u>Minced</u>) **3-5 per day** -1/2 cup (125ml) cooked or pureed vegetables -1/2 cup (125ml) of vegetable juice	-mashed potatoes or boiled potatoes crushed with a fork with milk, cream or sauce -pureed vegetables -well-cooked, minced vegetables -creamed corn	-other potatoes (fries, oven baked) -other vegetables under cooked, in pieces -raw vegetables, lettuce -corn on the cob or grains
Mixed dishes	-Minced mixed dishes -Shepard's pie with cream of corn -chicken, meat or salmon pie, without crust -meatloaf or salmon loaf with sauce	-regular mixed dishes -Shepard's pie with grain corn -chicken, meat or salmon pie, with crust -soup with large chunks
Meat & alternatives **2-3 per day** -2 eggs -75g (2 ½ oz) meat -3/4 cup (175ml) legumes or tofu -1/2 cup (125ml) pureed meat	-scrabbled egg, plain omelette, soufflé or quiche, with small pieces (less than 5mm), without a crust -liver pâté -poached or oven baked fish, crumbed canned tuna, other minced fish -minced crab, lobster, scallop -meat (beef, pork, veal, lamb) or brown chicken meat, minced served with sauce -silken tofu, hummus, beans crushed with a fork or pureed	-hard-boiled egg, omelette or quiche with cheese or vegetables & crust -peanut & other nut butters -seeds -grilled fish -whole seafood -other whole meats -white chicken meat -other, whole legumes -firm tofu
Grain products **6-11** -1/2 cup (125ml) pasta, rice, other grains -3/4 cup (175ml) hot or cold cereal -1 medium muffin (about 6cm or 2 ½ inches in diameter)	-hot cereals: oatmeal, cream of wheat, baby cereal -cold cereals without nuts or dried fruits, mixed with thickened milk or cream -Arborio rice -well cooked, small pasta with sauce, without pieces -cake or muffin, without icing or nuts, mixed with thickened milk, cream, yogurt or pudding or pureed -trifle with minced fruit	-cereal with nuts, seeds, dried fruits -cereal with psyllium -bread, rolls, crackers, dry cereal, tea biscuits -Whole wheat pasta or large pasta (fettuccini, lasagne, rigatoni) -Wild rice, brown rice, couscous, bulgur, barley -cake with nuts or dried fruits
Other	Aerated chocolate Aero® or Mirage®	Other chocolates & candies

Pureed Texture



Review the document "How to puree and modify your meals" for instructions on how to make your own pureed foods at home

If you are on thickened liquids, please follow the necessary recommendations to modify your liquids provided by your health professional.

Foods followed by a "*" should be considered as thin liquids and be modified as needed.

This texture includes cooked and pureed foods with no lumps or chunks without lumps and bumps. The puréed texture is smooth and does not require chewing.

Review this list with you dietitian-nutrition so that they can personalize your diet

Food group	Foods to include	Foods to exclude
Dairy products & alternatives **2-3 per day** -1 cup (250ml) milk, soy milk or milk alternative -3/4cup (175g) yogurt -1/2cup (125ml) cottage/ricotta cheese -1/2cup (125ml) ice cream, frozen yogurt or milk dessert	-smooth puddings, custards and yogurts without any pieces of fruits, candies or nuts -ice cream*, frozen yogurt*, ice milk* without pieces -fresh cheeses (Minigo, Quark) and pureed cottage cheese	-puddings, custards and yogurts with pieces of fruits, candies or nuts -rice or tapioca puddings -ice cream, frozen yogurt, ice milk with pieces - cream cheese, soft cheese, sliced or firm cheeses
Fruits **2-4 per day** -1 medium fruit -1/2 cup (125ml) of pureed or canned fruit -1/2 cup (125ml) fruit juice -1/2cup (125ml) sorbet	-pureed fruits & sauces without pieces, sorbet* -mashed bananas	-other fruits in pieces

(Pureed Texture) **Vegetables** **3-5 per day** -1/2 cup (125ml) cooked or pureed vegetables -1/2 cup (125ml) of vegetable juice	-mashed potatoes -pureed, well-cooked vegetables	-other potatoes -other vegetables in pieces -creamed corn
Meat & alternatives **2-3 per day** -2 eggs -75g (2 ½ oz) meat -1/2 cup (125ml) pureed meats -3/4 cup (175ml) legumes or tofu	-pureed meats (chicken, beef, pork, fish, eggs) & mixed dishes -pureed hummus, tofu and beans	-minced, sliced or whole pieces of beef, chicken, pork or fish -peanut and other nut butters (smooth or crunchy) -seeds
Grain products **6-11** -1/2 cup (125ml) pasta, rice, other grains -3/4 cup (175ml) hot or cold cereal -1 medium muffin (about 6cm or 2 ½ inches in diameter)	-hot cereals: pureed oatmeal, cream of wheat, baby cereal -pureed cold cereal, blended to a powder and mixed with thickened milk, thickened cream or yogurt -well cooked pasta -pureed cake or muffin, without icing or nuts, mixed with thickened milk, cream, yogurt or pudding	-regular oatmeal (large flakes) -other grains (rice, quinoa, bulgur, millet, couscous, barley etc.) -bread, rolls, crackers, dry cereal

Problematic foods for people with swallowing difficulties

Some foods are harder to chew, move in your mouth and swallow. Review the list with your health care professional to see which ones are still safe for you to eat. If your healthcare provider has also recommended that you eat a modified or adapted diet, review this section of the nutritional toolkit too.

Foods that may be more difficult to eat:

- Hard foods: nuts, seeds, candies, raw vegetables,
- Crunchy foods: toast, chips
- Stringy, fibrous texture: string beans, pineapple, lettuce, celery, oranges, watermelon
- Mixed consistency: cereal that does blend into milk (granola, muesli), watery soups with noodles, meats or vegetables, stew with lumps, yogurt with pieces of fruit, candy or cereal
- Crumbly, flaky foods: pie crusts, dry cookies, day old muffins or cupcakes, dry minced meats, crackers, croissant
- Dry foods: dried meats, popcorn, toast, dry cereal, graham crackers, Melba toast, fried noodles or rice,
- Vegetable and fruit skins or seeds: grapes, beans, peas, sweet corn, apples, pears, berries
- Husks: corn on the cob
- Sticky foods: nut butters, caramel
- Soft, sticky, doughy, fresh bread: white bread, doughnuts, cinnamon rolls
- Foods that melt: ice cream, popsicles, Jell-O, sherbet, frozen yogurt
- Very spicy foods
- Acidic foods: some dressings, pickled items

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IMPORTANT: PLEASE READ

This toolkit section includes some suggestions for community resources, food and related product distribution locations for accessing modified textured meals and products, as well as, medical suppliers. Most of the pharmacies, meals on wheels community programs and specialized medical supplies centres and retailers can also provide these kinds of supplies. The aim of the content is to provide a comprehensive listing of province-wide resources and is not sponsored in any way.

If you have found a resource that has been particularly helpful, tell us about it!

Where to find food thickeners, thickened beverages and other nutritional products in your community?

Food thickeners and thickened products

Nestlé Health Science Products

- Website and online ordering information:
- https://www.nestlehealthscience.ca/en/brands/resource-thickenup/index
- Ask your pharmacist if they can order the products for you
- (These products are sold also sometimes available at Walmart and Costco)

Well.ca

- Range of Resource® thickener products and other powder thickeners
- Available to order online: https://well.ca/brand/resource.html
- Free shipping with a minimum purchase of $29

SimplyThick®

- Gel food thickener
- Nectar and honey consistency thickening products available in a range of formats
- http://www.simplythick.com/
- Recipe booklet: available online
- https://www.ergogrip.ca/img/category/description/brochures/simplythick-gel-food-thickener-brochure.pdf

Stomomédical

https://www.stomomedical.com/collections/nutrition

Laval- Nord Shore

3241 Avenue Jean-Béraud, Laval, QC H7T 2L2
Orders by phone : 450-786-0786 or Toll free : 1-866-986-0786
Business hours: Monday to Friday: 8:30am to 6pm
Saturday: 9am to 1pm

Longueuil – South Shore

157, rue Saint-Charles Ouest, Longueuil, QC, J4H 1C7
450-928-4848 or Toll free : 1-866-986-0786
Business hours: Monday to Friday: 9am to 6pm
Saturday: 9am to 3pm

Stomomédical

Free delivery throughout Quebec with purchases that have a minimum order of $75 before taxes

- **Fee of $ 8 plus tax for purchases where the minimum order is not reached**
- **Delivery time of 1-2 business days**

Products available : ****Please take note that prices may have changed since the publication of this toolkit.**

Oasis Nutrisolution® Hydra + Thickened Juice Honey or Nectar consistency* Cranberry Juice **Please note that once opened, this product can be kept for 72 hours in the refrigerator** 1L per unit/case of 12 • 83.40 $ per case of 12	Oasis Nutrisolution® Hydra+ Milk beverage Honey or Nectar consistency* **Please note that once opened, this product can be kept for 72 hours in the refrigerator** 1L per unit/12 per case • 6,95 $ per 1L unit • 83. 40 $ per case of 12
Oasis Nutrisolution® Hydra + Thickened Lemon Water-Honey or Nectar consistency* Product is gluten-free, lactose free and Kosher **Please note that once opened, this product can be kept for 72 hours in the refrigerator** 1L per unit/12 per case • 6.95 $ per unit of 1L • 83.40 $ per case of 12	Beneprotein Resource® by Nestlé Health Science Concentrated source of whey protein Available in 227g container • 24.63$ per container of 227g
Resource® ThickenUp Clear by Nestlé Health Science Available in 125g container • 17.36 $ per 125g container Box of 33.6g /24 sachets of 1.4g/sachet • 14.72 $ per box/24 sachets	Resource® ThickenUp by Nestlé Health Science Available in 227g container • 7.20 $ per 227g container

For more information on Oasis Nutrisolution®Hydra + products, please visit this link:
https://lassondeservicealimentaire.ca/en/sector/ready-to-care/
Where to purchase to have your order delivered to your home:
https://lassondesanteetnutrition.ca/en/hydra/

Some oral supplements, enteral feeding formulas are also available (tubing, backpacks and vinyl bags of 500 and 1000 mL for gravity or pump feeding) http://www.stomomedical.ca/en/dysphagia-and-feeding.html.
For suggestions of medical equipment suppliers for people covered by the Ministerial Enteral Feeding Program who would like to obtain additional equipment, please also consult the list of medical equipment suppliers found in the practical guide - QUEBEC MINISTERIAL ENTERAL FEEDING PROGRAM (Section 5 of this toolkit or at: https://www.chusj.org/CORPO/files/5b/5b5335c4-f74e-46d3-b74d-e316712bb676.pdf

ProAssist -***Conseils et équipements médicaux***

- https://www.pro-assist.ca/fr/nutrition-specialisee
- Website support: 1-844-522-1268

Succursale de Montréal

- 3545, rue Berri, Montréal, (Québec) H2L 4G3
- (514) 849-7573 or Toll free 1-800-823-7573 or by Email: infomtl@pro-assist.ca
- Store hours: Monday to Wednesday: 9am to 5pm; Thursday and Friday: 9am to 6pm; Saturday: 9am to 12pm; Sunday: Closed

Succursale de Québec

- 355, rue du Marais, Local 130, Québec (Québec) G1M 3N8
- (418) 522-1268 or Toll free 1-800-463-5318 or by Email: infoqc@pro-assist.ca
  Store hours: Monday to Wednesday: 9am to 5pm; Thursday and Friday: 9am to 6pm; Saturday: 9am to 12pm; Sunday: Closed
- Customer Service: Monday to Friday: 8:30am to 5pm
- List of Products available : https://www.pro-assist.ca/fr/nutrition-specialisee

  Orders over $75 are shipped free of charge. Purolator and Canada Post ship within Canada. Exceptions apply (bulky/heavy products, for example).

Thick-It

- Thickened beverage products in honey or nectar consistencies
- https://supportsource.ca/
- 1-866-210-9285 or customerservice@supportsource.ca

Products available:

****Please take note that prices may have changed since the publication of this toolkit.**

Thick-It® Available in a 284g container • 11.50 $ per 284g container	Thick-It® Clear Advantage™ Available in a 113g container • 18.30 $ per 113g container • 62.79 $ per case of 4 containers
Thick-It® AquaCareH_2O Beverages – Thickened artesian mineral water Honey or nectar consistency Gluten free and Kosher product **Please note, once opened this product can be kept for 24 hours at room temperature or 14 days in the refrigerator** • 1.89L per unit/4 per case – 19.47 $ • 236mL per unit/24 per case – 54.04 $	Thick-It® AquaCareH_2O Beverages – Thickened coffee (regular or decaffeinated) Honey or nectar consistency Gluten free and Kosher product **Please note, once opened this product can be kept for 24 hours at room temperature or 14 days in the refrigerator** • 1.89L per unit/4 per case – 30.74 $ • 236mL per unit/24 per case – 57.82 $
Thick-It® AquaCareH_2O Beverages – Thickened Cranberry Juice Honey or nectar consistency Gluten free and Kosher product **Please note, once opened this product can be kept for 24 hours at room temperature or 14 days in the refrigerator** • 1.89L per unit/4 per case – 25 $ • 236mL per unit/24 per case – 55.47 $	Thick-It® AquaCareH_2O Beverages – Thickened Apple Juice Honey or nectar consistency Gluten free and Kosher product **Please note, once opened this product can be kept for 24 hours at room temperature or 14 days in the refrigerator** • 1.89L per unit/4 per case – 32.07 $ • 236mL per unit/24 per case –61.06 $
Thick-It® AquaCareH_2O Beverages – Thickened Orange Juice Honey or nectar consistency Gluten free and Kosher product **Please note, once opened this product can be kept for 24 hours at room temperature or 14 days in the refrigerator** • 1.89L per unit/4 per case – 32.26 $ 236mL per unit/24 per case – 63.19 $	

Other nutritional products

Nestlé Health Science

Beneprotein®

BENEPROTEIN® 100% high quality whey protein powder provides the protein needed to help preserve muscle. BENEPROTEIN® powder mixes instantly with a wide variety of hot and cold foods and beverages. It can be added to hot chocolate, tea, cottage cheese, applesauce, egg salad, yogurt and more. Suitable for gluten-free and kosher diets.

Available at local pharmacies and specialized supply stores

- Sometimes reimbursable by the RAMQ with a prescription (*conditions apply)
- Ranges from 20 to 25 $ per 227g container
- For more product information: https://www.nestlehealthscience.ca/en/brands/beneprotein

Boost®

When diet's not enough, get the protein, vitamins and minerals you need to keep doing what you love.

- https://www.madewithnestle.ca/boost
  Also available in a variety of pharmacies and stores (Walmart, Costco
  (contient du lait et du soja - disponible dans une variété de saveurs)

  - BOOST® Original (237mL) – 230 calories and 10 grams of protein
  - BOOST® High Protein (237mL) – 240 calories and 15 grams of protein
  - BOOST® Protein + Shake (325mL) – 270 calories and 27 grams of protein
  - BOOST® Pudding (142 g) - 230 calories and 6.8 grams of protein
  - BOOST® Plus Calories (237mL)- 360 calories and 14 grams of protein

Abbott

Ensure®

Nutritious drinks - complete and balanced diet.

- https://ensure.ca/en and Ensure® Club: https://ensure.ca/en/ensure-club
- **Also available in a variety of pharmacies and stores (Walmart, Costco)**

(suitable for gluten free, lactose free & kosher diets – available in a variety of flavours)

- Ensure® Regular (235mL) – 235 calories and 9.4 grams of protein
- Ensure® High Protein (235 mL) - 225 calories and 12 grams of protein
- Ensure® Protein Max (235 mL) – 350 calories and 20 grams of protein
- Ensure® Plus Calories (235 mL) – 355 calories and 14 grams of protein
- Ensure® Pudding (113 g) – 170 calories and 4 grams of protein

Meal boxes and food subscription boxes in your community

Meal kits and other food subscription boxes in Quebec have blossomed from locally run businesses by ma-and-pa entrepreneurs, to nationwide mega-companies. When speaking of "Meal Boxes", we are specifically talking about or referring to is a subscription to a meal kit service, i.e. ready-to-cook baskets: you sign up on a website, you choose your meals/recipes for the week, and then everything you need to prepare this meal kit is shipped to your door. With such a variety of meal kit and pricing options in Quebec, food subscription boxes are becoming a practical and time-saving solution for busy households where families and caregivers need a helping hand and some respite in their daily lives.

The meal kits for the week will arrive in an insulated box that keeps your meats cool with frozen ice packs, and the rest of your meal comes in self-contained bags. Simply store in your fridge, and when suppertime arrives, pluck out the bag, and get cooking!
The boxes are designed to keep everything cool no matter how hot it gets outside. They come complete with colorful recipe cards that are clear and simple to follow, even for beginners: these step-by-step instructions are a real lifesaver. In fact, for many people, this system works a little like an introductory cooking class. The bags come with all the ingredients you need, except for a few basic kitchen items such as salt, sugar, oil or baking paper. Most ready-to-cook meals take 20 to 45 minutes "from fridge to table".

Below is a list of food subscription box and meal kit companies that deliver within the greater area of Montreal, as well as, across other regions within the province of Quebec.

Cook It

- 279 Sherbrooke West #301, Montréal (Québec) H2X 1Y2
- (514) 544-2665 or 1 (877) 559-0546, info@chefcookit.com
- https://www.chefcookit.com/en
- Miss Fresh was acquired by Cook It
- Cook It is quick to point out that their fruits and vegetables come from Chez Louis in the Jean-Talon market, that their fish comes from Poissonnerie Falero, and most importantly, that most of their meats come from La Maison du Rôti – building on Quebecers' passion for quality ingredients.

Good Food

- https://www.makegoodfood.ca/en/home
- 1(855)515-5191
- chef@marchegoodfood.ca
- Get farm-fresh ingredients to cook delicious recipes, delivered for FREE to your doorstep

Hello Fresh

- https://www.hellofresh.ca/?locale=en-CA
- Each week, you can customize your menu and choose from 25 recipes.

Greater Area of Montréal

Lufa Farms

- https://montreal.lufa.com/en/
- Help and/or FAQ : https://montreal.lufa.com/fr/lufa-faq
- A network of hundreds of pick-up locations across Quebec.
- Your greenhouse grown produce basket is delivered to the pick-up location of your choice or directly to your door for only $5. Take a look at their map to see the most convenient location for you.

Prixmium Fruits & Vegetables (Distribution)

- 514-377-8883 or https://www.prixmium.ca/contactez-nous/
- https://www.prixmium.ca/
- 511 Boulevard Lebeau, Saint-Laurent, Québec H4N 1S
- ServicesClients@prixmium.ca
- Zone de : https://www.prixmium.ca/zone-de-livraison/
- Quelques plats de style libanais prêt-à-manger : https://www.prixmium.ca/product-category/pret-a-manger/

Bon C Bon Aliments Inc. – Prepared Meals

- 514-358-2669 or https://www.boncbon.com/pages.php?pageid=34
- https://www.boncbon.com/
- 9049 Rue Airlie, (LaSalle)Montréal, QC H8R 2A4
- Delivery Zones: https://www.boncbon.com/zone.php

Repas Gourmet Sublime Creations

- 514.318.4591 or info@sublimecreations.com
- https://www.creationssublime.com/
- 3415 Boulevard Concorde, Laval, Québec H7E 2C3
- Delivery Zones: https://www.creationssublime.com/deliveryzones
- Épicerie essentielle avec commandes : https://www.creationssublime.com/essential-groceries

MB: Please also refer to additional community resources in this section: Meals on Wheels; Campbell's Epikura and Trepurée® products.

Meals on Wheels and Pureed Meals in Your Community

Meals on Wheels is a service that provides hot meals and is delivered to the homes of people with a temporary or permanent loss of autonomy. It is a supportive service that helps those with a loss of independence to continue to live at home rather than in care institutions. This service aims to promote their autonomy and is an essential component of home support. If you are a person diagnosed with ALS, who is losing your independence, you may be eligible for a Meals on Wheels service. It also provides respite and makes it possible for family caregivers to take a break by freeing them from the task of meal preparation. There is usually a charge for the service, which may vary from one organization to another.

The program provides support to people for their nutritional needs and is available to:

- seniors;
- people who are convalescing;
- people with a disability
- pregnant women
- family members who are caregivers;

The clienteles served and the eligibility conditions may vary from one Meals on Wheels provider to another. At times, accessing the Meals on Wheels service requires a medical or social service referral. If this is the case, consult the healthcare team at the ALS clinic or the CLSC that cares for you. More information is available on the respective websites of each Meals on Wheels provider.

To benefit from a Meals on Wheels service in your geographic area, contact one of the organizations listed below:

Regroupement des popotes roulantes
5800, rue Saint-Denis, local 602
Montréal (Québec)
H2S 3L5
Frédérique Filiatrault (*Agente de liaison*)
1 877 277-2722, p. 205
514 382-0310, p.205
regroupement@prasab.org
www.popotes.org

For those with Internet access, the Regroupement des popotes roulantes has a page on their website where you can find the nearest meal service (within 16 regions of Quebec), with the associated contact information: To locate a Meals on Wheels service near you visit: http://popotes.org/trouve

Where to find Campbell's Trepuree® in your community?

- 12 meal choices
- Each meal includes a portion of meat, vegetables and starch
- ***Please note that prices indicated may vary from the time this toolkit was published***

Region of Montréal

L'Association des Popotes Roulantes du Montréal Métropolitain

1919, rue Saint-Jacques, Montréal (Québec) H3J 1H2

- **514-937-4798**, aprmm@videotron.ca
- Order 12 or 24 meals ($37/$74) at any time - $3.08/per 250g meal
- Delivery possible in some Montreal neighborhoods (Ahuntsic, Anjou, Centre-Sud, Outremont, Plateau Mont-Royal, Rosemont-Petite Patrie, Sud-Ouest, Villeray) for a delivery fee of $2.50
- Does not deliver every day to every neighborhood, delivery is confirmed when the order is made
- Possibility to pick up orders on site
- Online orders: http://www.popoteroulante.org/bondecommande_trepuree.php
- http://www.popoteroulante.com

Centre d'action bénévoles Ouest-de-l'Île

1, rue de l'Église, Sainte-Anne-de-Bellevue (Québec) H9X 1W4

- **514-457-5445, poste 225**
- **Orders require a medical or social referral and must be placed before Thursday at noon please**
- On-site purchase or delivery in the West Island
- Hours of operation Monday to Friday, 8:30am to 4pm (Fridays during the summer 8:30am to 1pm)
- Price: $62 for 24 servings and $3 for delivery
- Deliveries are made on Wednesdays and Thursdays
- https://cabvwi.org/fr/programmes-et-services/#Repas-surgeles-et-purees

Region of Montréal/Laval/Brossard

Mayrand – Magasin Entrepôt d'Alimentation

9701, boul. Louis-H.-La Fontaine, Anjou, QC H1J 2A3

2151, boul. Lapinière Suite S100, Brossard, QC J4W 2T5 (Mail Champlain)

3615, Autoroute Jean-Noël Lavoie, A-440, Laval, QC H7P 5P6

- **514-255-9330** ou http://www.mayrand.ca/
- Campbell's Trepuree® Assorted Carton of 24 x 250g (12 menus -2 meals of each): 62.99 $
- **No delivery service-No membership required-Open 7 days a week**
- Hours of operation Monday to Wednesday and Saturday: 7am to 6pm; Thursday and Friday: 7am to 9pm; Sunday: 10am to 6pm

Region of Laval

Le Centre SCAMA

3168, boul. Cartier Ouest, Laval (Québec) H7V 1J7

- 450-681-4240, courriel : info@centrescama.org
- Purchase on-site or delivery for $ 2 in Chomedy: Price for 24 x 250g is $ 71
- http://infoaineslaval.qc.ca/

Résidence Le Maria Chapdelaine

1850, boul. Lévesque Est, Laval (Québec) H7G 4X4

- 450-668-6052 ou 450- 662-9605
- **No delivery service**
- Contact Josée Perrault, between 8-10 a.m. and 2-4 p.m.
- Order on Wednesday

Region of Montérégie - Saint-Jean-sur-le-Richelieu

En passant… Comptoir Santé *(Propriétaire: Sophie Tougas, nutritionist and member of the OPDQ)*

378, boul. Saint-Luc, bureau 100, Saint-Jean-sur-le-Richelieu (Québec) J2W 2A3

- 1-450-349-1750 or 1-888-848-1750, Email : sophie.tougas@enpassant.ca
- Opening hours: Tuesday to Friday from 10am to 7pm, and Saturday and Sunday from 10am to 5pm
- Order by phone and delivery 48 hours following the order either at home or in the workplace.
- All items are not always in stock at the store. However, you can order them within a certain delay.
- http://www.enpassant.ca/
- Minimum order: $30 (St-Luc, St-Jean, Iberville and l'Acadie sectors), with a $5 delivery fee
- For orders over $65, delivery fees are $2.
- Prices for 24 x 250g size vary from $78 to $89 depending on the choice of meals
- (see details in En passant - Order Form)

Region de l'Estrie/Sherbrooke

Sercovie

300, rue du Conseil, 2e étage, rue Sherbrooke (Québec) J1G 1J4

- 819-565-1066, courriel : administration@sercovie.org
- $ 5.75 per meal/ $ 125 for 24 units of your choice
- Choice of 14 individual meals
  http://sercovie.org/services-alimentaires/repas-trepuree

Capitale-Nationale Region

La Baratte

2120, rue Boivin, Sainte-Foy (Québec) G1V 1N7

- 418-527-1173 or infos@labaratte.ca
- www.labaratte.ca or https://www.labaratte.ca/nos-services
- Open Monday to Friday from 8am to 3:30pm.
- Delivery (price varies by geographic area) from $5
- Campbell's Trepuree® products are available in 24-serving (case) sizes for $83.
- See La Baratte order form for pricing details. https://docs.wixstatic.com/ugd/1bc0a8_5df9128581454d77b5d7fb9e105eb97d.pdf

Preparation and Handling Guide

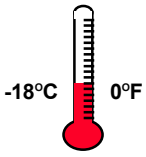
Preparation

1. Temper sealed Trepuree® entree at 4ºC (40ºF) or below for 24–48 hours. **DO NOT REMOVE CLEAR FILM SEAL BEFORE COOKING.**
2. Choose a recommended cooking method below. **In all methods, ensure that a minimum internal temperature of 74ºC (165ºF) is reached in all strips.** Handle with care after cooking as dishes are hot.
   - **Conventional or Convection oven:** Preheat oven to 150ºC (300ºF). Place **sealed** dishes on baking tray. Heat for 45–50 minutes in conventional oven or 35-45 minutes in convection oven until a minimum internal temperature noted above is reached.
   - **Rethermalization carts:** Retherm instructions vary by equipment manufacturer. Please contact your equipment manufacturer for specific heating instructions to achieve desired internal temperature noted above
   - **Microwave:** Microwave **sealed** dishes on FULL (100%) power for 1.5–2 minutes OR 70% power for 2 to 2.5 minutes until minimum internal temperature noted above is reached. Let stand prior to serving 1 to 2 minutes. Note that cooking time depends on the wattage of the microwave unit, thus must test on own microwave equipment to ensure that minimum internal temperatures noted above are met in all strips.

Pack Size/Portions:

Pack Size/Portions
24 x 250 g (9 oz) single-serve pureed entrees per case

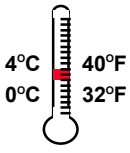
Storage



Frozen

Shelf Life: 15 months

1. Keep frozen until required (**below -18ºC /0ºF**).
2. **Expiry** date on film & case.
3. Return any damaged cases.

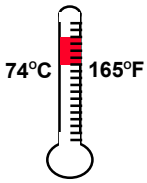


Refrigerated (unopened)

Shelf Life: 24–48 hours

1. Store **at 4ºC (40ºF) or below.**
2. Do **not refreeze**
3. Record storage date
4. Discard if not used within 48 hours.

Post Cooking Procedures



Holding Time/Temperature

1. Hold at minimum 74ºC (**165ºF)** for maximum 2 hours.
2. Keep covered.
3. Discard if not served within 2 hours.

For further information or questions, visit www.campbellsfoodservice.ca, contact your Campbell's representative or call 1-800-461-7687

Where to find Epikura in your community?

Epikura offers a complete line of reshaped therapeutic foods for mild to severe dysphagia. Minced or pureed, Epikura foods are characterized by a texture index for safe swallowing.

- Site internet: https://www.epikura.com/home
- Choice of delivery anywhere in Quebec or pick-up at their offices:
  4305, autoroute des Laurentides, Laval, Québec, H7L 5W5
- For more information contact Epikura 1-877-457-8468 or order directly online:
  https://www.epikura.com/where-to-buy-epikura
- Selection of various meal boxes, trays, cakes, fruits, raw vegetables
- To access videos on how to prepare Epikura foods:
  https://www.youtube.com/channel/UCVz0gWB3Jy0KW6J-i5Mb7jg/videos
- ***Please note that prices indicated may vary from the time this toolkit was published***

Region of Montréal

Vagabond 'âge distribution

- Delivery only
- 514-704-4574
- info@vagabondage.net
- 9am-9pm

Region of Montréal/Laval/Brossard

Mayrand – Magasin Entrepôt d'Alimentation

9701, boul. Louis-H.- La Fontaine, Anjou, QC H1J 2A3
2151, boul. Lapinière Suite S100, Brossard, QC J4W 2T5 (Mail Champlain)
3615, Autoroute Jean-Noël Lavoie, A-440, Laval, QC H7P 5P6

- **514-255-9330** ou http://www.mayrand.ca/
- **No delivery service – No membership card required - Open 7 days**
- Business hours - Monday to Wednesday and Saturday :7am to 6pm;
  Thursday and Friday: 7am to 9pm; Sunday : 10am to 6pm

Epikura Product	Price/case	per unit	Details
PUREED VEGETABLE #2 EPIKURA 36S	41,99 $		Purée asparagus, cauliflower, peas 3X12X60G
PUREED PROTEIN #1 EPIKURA 24S	68,99 $		Pureed ham, turkey, hamb.steak 3X8X130G
PUREED PROTEINE #2 EPIKURA 24S	68,99 $		Pureed chicken, roast beef, pork 2X8X130G & 1X8X125G
PUREED PINEAPPPLE EPIKURA 24X52G	32,99 $		
PUREED TURKEY&CAROT SCE DI 8X190G	62,99 $	8,99 $	
PUREED CAKE MOUS CHOC CAF 25X90G	30,99 $		
PUREED CAKE MOUS YAN&FRAM 25X90G	30,99 $		
PUREED CAKE MOUSSE ORANGE 25X90G	30,99 $		
PUREED HAMB STEAK&BEANS 8X190G	62,99 $	8,99 $	
PUREED VEGETABLE #1 EPIKURA 36S	37,99 $		Pureed carrot,broccoli,green bean 3X12X60G
PUREED PEACH EPIKURA 24X60G	32,99 $		
PUREED CKN&PEAS SCE ROST 8X185G	62,99 $	8,99 $	
PUREED PEAR EPIKURA 24X60G	32,99 $		
PUREED TOURT&CARROT EPI 8X215G	62,99 $	8,99 $	

Region of Laval

Expo-Médic

139 boul. Concorde Est, Laval (Québec) H7G 2C3

- 450-975-2299 or 1-800-567-2299
- Delivery available
- For information and price list: http://expomedic.ca/aliments-surgeles-epikura

Metro Plus Dépatie

1100 Boulevard de l'Avenir, Laval (Québec) H7N 6L2

- 450-687-8233 or www.metro.ca/trouver-une-epicerie/133

Stomomédical

3241 Avenue Jean-Béraud, Laval (Québec) H7T 2L2

- 1-866-986-0786

Region of the Laurentians

Centre Josée Pressé

590, des Anémones, Mont-Laurier (Québec) J9L 3G3

- 819-440-7801

Region de Montérégie

La Croisée de Longueuil-La petite cuillère

1230, rue Green, Longueuil (Québec) J4K 4Z5

- 450-748-4918 or petitecuillere@lacroiseedelongueuil.qc.ca
- Order by telephone, minimum purchase required of 35 $. Purchase onsite available.
- Do not always have a full inventory in stock, mostly meat selections.
- Delivery on Wednesdays, to homes in the within the agglomeration of Longueuil for 3 $ à 4 $ depending on the distances.
- Epikura products are avaialble in four-portion formats (sheet) or by the case :
- **Meats**: Pack of 4 units (13 $ à 19 $) or 16 units per case (53.50 $ à 76 $)
- **Vegetables**: Pack of 4 units (7 $ à 10.50 $) or 24 units per case (28.50 $ à 43 $)
- **Fruits**: Pack of 4 units (11.50 $) or 24 units per case (46 $)

En passant… Comptoir Santé (*Owner*: Sophie Tougas, nutritionist and Member of the OPDQ)

378, boul. Saint-Luc, bureau 100, Saint-Jean-sur-Richelieu (Québec) J2W 2A3

- 1-450-349-1750 or 1-888-848-1750, Email : sophie.tougas@enpassant.ca
- Business hours : Tuesday to Friday from 10amto 7pm, and Saturday/Sunday from 10am to 5pm
- Orders by telephone and delivery within 48 hours following the order, either at home or at work.
- All items are not always in stock at the store. However, you can order them within a certain time frame.
- http://www.enpassant.ca/

Région de Montérégie (*suite*)

En passant… Comptoir Santé (*Owner*: Sophie Tougas, nutritionist and Member of the OPDQ)

- Minimum order: $30 (Areas of St-Luc, St-Jean, Iberville et l'Acadie), with a delivery fee of $5 . For orders of $65 or more, the delivery fees are $2.
- Prices and sizes vary depending on the Epikura product choice:
- (Refer to En passant - Order Form).
- Products are available in four-serving sizes or by the case:
- **Meats:** 4-pack ($15-$20) or 16-pack per case ($55-$76)
- **Vegetables** (hot): 4-pack ($6 to $7.50) or 24 units per case ($32 to $42)
- **Vegetables** (cold): 4-pack ($6 to $9) or 24 units per case ($34 to $52)
- **Fruit**: 4-pack ($8.25) or 24 units per case ($47)

Outaouais Region

Les Entreprises Médicales de l'Outaouais

131, boul. Gréber, Gatineau (Québec) J8T 3R1

- 819-205-9111 or Toll free: 1-800-363-3498, ou par courriel : gatineau@lesemo.com
- Business hours: Monday to Friday from 8:30am to 5pm
- Delivery is free for orders of $125 or more, and occurs within 24 to 48 hours following the order.
- https://lesemo.com/en/contact-us/

Centre-du-Québec Region

Centre d'action bénévole Drummond – Popote Roulante

157, rue Lindsay, bureau 200, Drummondville (Québec) J2C 1N7

- 819-472-6101
- This service is provided from Monday to Friday, deliveries before noon, between 10:30am and Noon.
- **Meats**: Price per unit ($2.25 to $3.00)
- **Vegetables** (hot and cold): Price per unit ($0.80 to $1.15)
- **Fruit**: Price per unit ($1.25)
- http://www.cabdrummond.ca/ServicesIndividus.php

Carotte joyeuse

525, ch. du Port, Nicolet (Québec) J3T 1W3

- 819-293-6544, info@carottejoyeuse.ca
- Epikura products are available in four-serving sizes or by the case:
- **Meats**: 4-piece sheet ($11.75-$15.25) or 16-piece case ($44-$58)
- **Vegetables** (hot): 4-unit sheet ($5.25 to $7) or 24 units per case ($25 to $36)
- **Vegetables** (cold): 4-unit sheet ($5.75) or 24 units per case ($29)
- **Fruits**: 4-unit sheet ($7.50) or 24 units per case ($38 to $39)
- Epikura products are available in four-serving sizes or by the case:
- Some products are available by special order only. Consult the comprehensive list of Epikura products (https://carottejoyeuse.ca/epikura/produit/).

Centre-du-Québec Region *(Suite)*

Carotte joyeuse(*Continued***)**

- Advice and preparation of Epikura products: https://carottejoyeuse.ca/epikura/mode-d-emploi/

Carrefour d'entraide bénévole des Bois-Francs – Popote Roulante

40, rue Alice Victoriaville (Québec) G6P 3H4

- 819-758-4188, or carrefour@cebboisfrancs.org
- Orders must be placed by Wednesday at 11:30 a.m. for delivery the following Tuesday.
- The Meals on Wheels service offers food including Epikura, delivered to your home once a week. A free delivery service is offered to the Arthabaska MRC region on a pre-determined day (Tuesdays between 1:30 and 3:15 pm). However, a minimum order of $20 is required.
- **Meat**: Price per unit ($3.60 to $4.45)
- **Vegetables** (hot and cold): Price per unit ($1.10 to $1.45)
- **Fruit**: Price per unit ($1.10 to $1.40)
- https://www.cebboisfrancs.org/popote-a-texture-adaptee.html
- Video*: La popote à texture adaptée, comment ça marche?* https://www.youtube.com/watch?v=EE3JMl9QKAE

Capitale-Nationale Region

La Baratte

2120, rue Boivin, Sainte-Foy (Québec) G1V 1N7

- 418-527-1173 or infos@labaratte.ca
- www.labaratte.ca or https://www.labaratte.ca/nos-services
- Open Monday to Friday from 8am to 3:30pm.
- Delivery (price varies according to geographic area) starting at $5
- Epikura products are available in four portion (sheet) sizes:
- **Meats**: 4-piece sheet ($13.25 to $18.75)
- **Vegetables** (hot): 4 unit sheet ($4.40 to $9.75)
- **Vegetables** (cold): Sheet of 4 units ($6.75 to $9.25)
- **Fruits**: Sheet of 4 units ($7.25 to $7.75)
- See La Baratte order form for pricing details: https://docs.wixstatic.com/ugd/1bc0a8_5df9128581454d77b5d7fb9e105eb97d.pdf

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Recipes to Cook, Share and Enjoy!

<u>Recipes available online</u> :

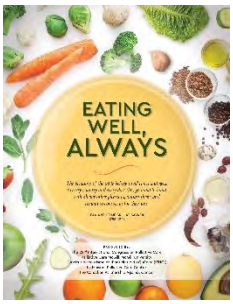
- Boost® Recipes and some preparation videos: https://www.madewithnestle.ca/boost#recipes

- Ensure® Recipes: https://ensure.ca/en/recipes

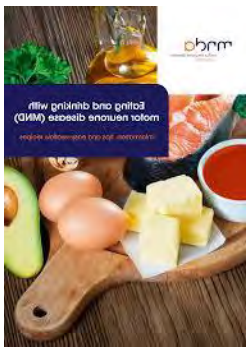
- Spin-A-Smoothie Recipes by the Dairy Farmers of Canada : https://dairyfarmersofcanada.ca/sites/default/files/2018-09/Mar%20spin%20a%20smoothie%20EN%20pdf.pdf

- Purée que c'est bon (uniquely in French) : https://pureequecestbon.fsaa.ulaval.ca/

- Eating Well, Always : https://www.mcgill.ca/palliativecare/files/palliativecare/pal2019_recipe_book_eng_final_0.pdf
  These recipes have been adapted to be enjoyed by people who are very affected by the disease and for whom eating and swallowing are problematic. A few suggestions to maximize the pleasure of these recipes are to serve small portions (100-150 g) on small plates, to take care of the presentation and to preserve the appetite by taking the medication only at the end of the meal. Above all, the authors hope that you will be able to preserve the pleasure of eating with family and friends.



- Eating and Drinking with MND https://z9t2c4x9.stackpathcdn.com/app/uploads/Eating-and-drinking-guide-2020-V1.pdf
  A short video about this guide : https://www.youtube.com/watch?v=woxkKqoOhCw
  Filled with information, tips, and practical recipes, it is designed to help you keep eating and drinking with ALS for as long as possible. Recipes include dishes from families affected by motor neurone disease, professionals and celebrity chefs. This guide has been endorsed by The British Dietetic Association.



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- FYI For Your information- High Calorie And Easy to Chew Recipes (ALS Association) Compiled by Dietetics Interns at Stony Brook and updated in 2012 https://www.als.org/navigating-als/resources/fyi-high-calorie-and-easy-chew-recipes

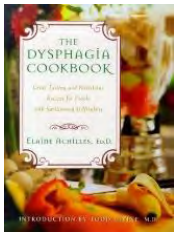
- Meals For Easy Swallowing, Muscular Dystrophy Association, ALS Division 2005 https://www.mda.org/sites/default/files/publications/Meals_Easy_Swallowing_P-508.pdf

- Dysphagia-diet.com (en anglais) : https://www.dysphagia-diet.com/t-recipes.aspx

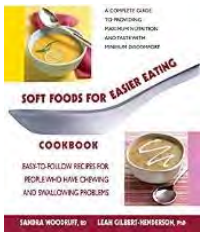
Cookbooks

(Consult your local library to see if these cookbooks are available)

- *The Dysphagia Cookbook,* Elayne Achilles, Ed. D. Cumberland House Publishing (2004) ISBN: 1581823487
  Intended for people on a soft-textured diet
  Some adjustments to the recipes may be necessary for a pureed diet.



- *Soft Foods for Easier Eating Cookbook,* Sandra Woodruff, R. D. et Leah Gilbert-Henderson, Ph. D. Square One Publishers (2009) ISBN - 13:9780757002908
  An easy-to-follow guide that offers maximum nutrition and taste with minimal discomfort. The book includes simple strategies for living with chewing and swallowing difficulties, and offers guidelines for modifying recipes to achieve a soft, smooth texture, and for increasing or decreasing calories, fats, and carbohydrates.



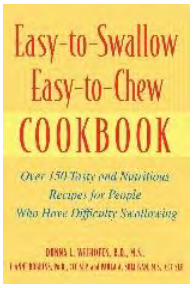
- *Saveurs partagées : la gastronomie adaptée aux troubles de la déglutition*, Sidobre Pascal; Chevallier Christian, De Boeck Supérieur (2012 France) (In French)
  This collection of recipes, created by two cooks with swallowing disorders, is intended for people for whom eating in a normal consistency has become difficult, as well as for those around them. Intended for people for whom eating in normal consistency has become difficult as well as for their entourage. The medical and paramedical team of the Voice and Swallowing Unit of the Larrey Hospital (University Hospital Center of Toulouse) collaborated in this work. The dietician gives an update on the dietary balance specific to the situation of oropharyngeal dysphagia. The speech therapist explains the principles of modification of consistency, texture of food and viscosity of beverages allowing food adaptations. Then the two cooks share their personal and professional experience to propose an original creation of 80 recipes and their variants, mixed and chopped, from starters to desserts, for all seasons. Then, there are menus to be shared in all conviviality and with great pleasure. These recipes have been chosen for their high nutritional value in order to help people who do not eat much to maintain a sufficient energy intake. The way the dishes are prepared allows the taste qualities of the food to shine through. Simple or more elaborate, with traditional or original foods, they can help you rediscover the pleasure of dining alone or with your family.

- *La purée dans tous ses états,* Danielle Daunais et Daniel Lavoie, nutritionnistes, La Direction des communications du CHUM (2013) (In French)

Pureed food in all its forms! How can you ensure a balanced diet, rich in energy and protein, when you have to eat pureed food? Two CHUM nutritionists offer diversified menus for breakfast, lunch and dinner.

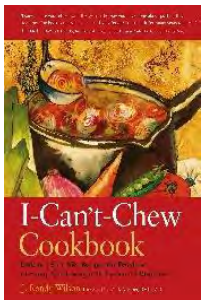
Sold at the Université de Montréal, $24.25 (shipping included)
Order form available in this Section.

- *Easy-to-Swallow, Easy-to-Chew Cookbook: Over 150 Tasty and Nutritious Recipes for People Who Have Difficulty Swallowing* Donna L. Weihofen, R.D., M.S, JoAnne Robbins, Ph.D., CCC-SLP, and Paula A. Sullivan, M.S., CCC-SLP. John & Wiley & Sons Canada (2002) ISBN: 0471200743



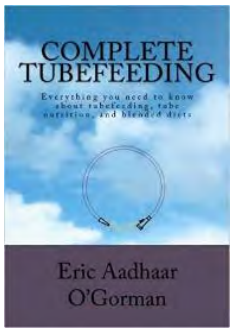
The first part of the book contains information on how we swallow and gives tips on how to manage some of the problems of swallowing. The second part contains approximately 150 easy-to-prepare recipes based on common foods. Each recipe includes complete nutritional information. This book is intended for someone who is on a "soft mechanical" diet or simply needs easy-to-chew foods. It does not fully address purees and how to modify each recipe for a "pureed" diet.

- *The I-Can't-Chew-Cookbook: Delicious Soft Diet Recipes for People with Chewing, Swallowing, and Dry Mouth Disorders*, J. Randy Wilson Turner Publishing (2003) ISBN: 9781630267155



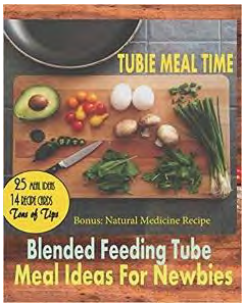
When his wife was diagnosed with TMJ (temporomandibular joint) problems and required surgery, the oral surgeon told Randy Wilson that his wife should eat soft foods for six months. The author took this as a challenge and developed 200 appealing and nutritious soft meals. The self-published version of the book has sold 33,000 copies. It has been endorsed by oral surgeons, exhibited at conventions of the National Oral Surgeons, the American Dental Association and the Registered Dietitians Association. The book contains helpful tips, a foreword by an oral surgeon and a chapter by a dietitian. It is spiral bound so that it stays flat while you cook. This is not a liquid diet book, nor is it a recipe book for blenders. The recipes are all accompanied by nutritional analysis. This book offers new and creative ways to prepare food for the person on a soft diet. The rest of the family will also enjoy these recipes.

- *Complete Tubefeeding: Everything you need to know about tubefeeding, tube nutrition, and blended diets,* Eric Aadhaar O'Gorman, CreateSpace Independent Publishing Platform (2012) ISBN 13: 9781470190224

  Complete Tubefeeding is the definitive guide for anyone living with a feeding tube or preparing to receive one, as well as for those who care for them. The author, a happy tubefeeder himself, combines the best and latest medical research with his own and others' real-life experiences with tubefeeding. This helpful manual provides comprehensive and compassionate coverage of all aspects of tube feeding and tube nutrition, including: The different types of enteral feeding tubes, their placement, use, and maintenance, with many helpful tips and tricks to make life with a feeding tube as easy as possible. Tube feeding, with sections on commercially available formulas and a detailed approach to a mixed diet (sometimes called a blended diet).

- *Tubie Meal Time: Blended Feeding Tube Meal Ideas For Newbies*, Petty Colors, Petty Colors Publishing LLC (2017) ISBN13: 9780998948331

  If you are new to preparing your own meals for tube feeding, this book will save you a lot of time in trial and error. This is a must-have book! Because it shows simple and economical ways to prepare meals that you probably never thought of. Plus, it has some very helpful tips from real caregivers! Have fun with this book and don't think too much. Good luck on your mixed meal recipe journey! This book has been updated with new tips and recipes as of 1/2020

<u>Applications with recipes adapted for swallowing disorders</u>

- ***<u>Mixiton</u>***
  - https://www.arsla.org/accompagner/mixiton-app/
  - Free application for the pleasure of your taste buds (*Free and available for download on Google Play and the App Store*)
  - French, English and Spanish

- ***Eating with MND***
  - https: //eatingwithmndapp.mndassociation.org/
  - (*Free and available for download on Google Play and the App Store*)
  - English

Applications that can help with food choices

- ***EWG(Environmental Work Group) Healthy Living***
    - https://www.ewg.org/apps/
    - o EWG's "Shopper's Guide to Pesticides in Produce™," updated annually since 2004, ranks the pesticide contamination of 46 popular fruits and vegetables. The guide is based on test results from the U.S. Department of Agriculture and Food and Drug Administration on more than 46,000 produce samples.

    - o Recognized for: "The Dirty Dozen and Clean 15™"
    - The Dirty Dozen™ is a brand term used to define the twelve crops on which farmers typically use the most pesticides, as opposed to the Clean 15™ which is also a brand term to describe the fifteen fruits and vegetables with the lowest amount of pesticide residue. This guide helps you determine which foods are best purchased in organic form.
    - English (*Free and available for download on Google Play and the App Store*)

- ***Food Hero***
    - https://foodhero.com/
    - o Application to fight against food waste
    - o FoodHero was designed to reduce food waste, the application allows merchants (Metro and IGA) and consumers to save money, while acting in favor of the planet.
    - English and French
    - (*Free and available for download on Google Play and the App Store*)

Another useful resource:

- ***Dysphagia Solutions***
    - https://dysphagiasolutions.wordpress.com/author/lauramatds/
    - o Tips, recipes and support for living with a swallowing problem through videos and information from Laura Michaels, an Ohio-based nutritionist and board member of the National Foundation of Swallowing Disorders. On this site, she discusses preparing modified textures and provides access to preparation videos.

BON DE COMMANDE

La purée dans tous ses états!

Daniel Lavoie, Dt.P., M. Sc.
Danielle Daunais, Dt.P.

Éditeur : Direction des communications du CHUM

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Pavillon Jeanne-Mance, porte 7356
3840 rue St-Urbain
Montréal (Québec)
H2W 1T8

Nom : _____ Ville : _____

Adresse : _____ Code postal : _____

_____ Téléphone (jour) : _____

_____ Courriel : _____

Pour tous renseignements supplémentaires veuillez contacter le Service de nutrition clinique au 514-890-8000 poste 15249.

Merci de votre intérêt!

High Calorie Nutritious Smoothie Recipe

Ideas tested by Karen Sheffler, MS, CCC-SLP, BCS-S of SwallowStudy.com on a daily basis!

(This recipe is shared with the permission of Karen Sheffler, MS, CCC-SLP, BCS-S of SwallowStudy.com)

Warnings:

- *Your doctor and dietitian can help you estimate the number of calories and protein you will need and any dietary restrictions you should follow.*
- *Check with your doctor about your sugar/carbohydrate intake if you are diabetic. Bananas and other fruits are loaded with natural sugars.*
- *Check with your doctor if you are on a medication that restricts your intake of leafy greens (i.e., if you are prescribed and taking blood thinners such as Coumadin/Warfarin).*
- *Your Speech-Language Pathologist can help advise you on **how thick** the smoothie should be to ensure safe swallowing.*

1. ***Base ingredients:***

   To thicken (choose one or all of these depending on your desired thickness):

   • **1/2 Banana** (to make this easy, when bananas start getting too brown, chop them in chunks and put them in freezer in a freezer bag)

   • **1/2 of an avocado**

   • **1 cup (250 ml) of plain yogurt** with NO sugar added (Greek yogurt for more protein)

   Add a Liquid (choose what type of smoothie you want – milk-based or juice-based):

   • **1 cup (250 ml) of a dairy or non-dairy milk depending on your tolerance**
   (non-dairy ideas: almond, cashew, rice, coconut, oat or hemp milk)

   • **or 1 cup (250 ml) of juice** (a natural juice "nectar," like mango nectar, will make the drink thicker too).

   • Avoid liquids that have added sugars. Check for "no sugar added" on the label/container.

2. ***Add More Protein of your choice:***

   • Add 1 cup (250ml) of Ensure®, Boost®, or another supplement recommended by your physician and/or dietitian.

   • Scoop of Protein powder (i.e., brown rice protein, hemp protein, or other – follow serving size on container)

   • Silken tofu

   • Ice cream

3. ***Add optional powders (one or all depending on dietary needs):***

   • Fiber powder of your choice (follow serving size on container)

   • Chia seeds (a teaspoon(5ml) of ground chia seeds)

   • Ground flax seeds or flax seed oil

   • Wheat Grass powder (follow serving size)

4. ***Add fruit of your choice to taste:***
   - Handful of fresh or frozen berries
   - Handful of fresh or frozen chunks of mango
   - Peeled peaches
   - Melons
   - Peeled apple slices

5. ***Greens:***
   Pre-chopped greens (kale, turnip greens, beet greens, or spinach) can be kept in the freezer to add **one handful** to your smoothie.
   Frozen greens blend up easily in a blender. It is a great way to hide extra nutrition in your smoothie. When kale is fully blended into your smoothie, you cannot taste it!

6. ***Add a little Pizazz!***
   - Pinch of grated ginger (might go well with your mangos or peaches)
   - Radishes: you may need an actual Juicer (not just a blender), then you could liquify sliced radishes, carrots, beets for even more vegetables.

   Blend on high with pulse setting first, then leave on high for at least a minute, or until fully blended. You may need to carefully push down ingredients from the side of the blender with a rubber (or silicone) spatula to combine all the ingredients of the smoothie.

The Community's "Favorite" Recipes

CHEESECAKE

- 1 package of 250g of cream cheese
- 1 cup of 35% whipping cream
- 1 can 300mL sweetened condensed milk (Eagle Brand)
- 1 bag gelatin (Knox)

In a bowl, dissolve gelatin in 50 mL of water. Add 50 mL of boiling water.
Place cheese, cream, dissolved gelatin and condensed milk in blender until smooth.
Pour into a container and refrigerate for 2 to 3 hours.
Serve with fruit coulis or chocolate sauce.
Makes 8 servings

1 serving:
341 calories
6g protein
24g carbohydrates
25g fat

Source : La purée dans tous ses états, CHUM

MANGO PUDDING

- 1 package 600g frozen mangoes, thawed
- 1 can 300mL sweetened condensed milk (Eagle Brand)
- 1 - 300g container of Ricotta cheese
- 3 tbsp. lime juice

In a blender, puree all ingredients until very smooth (at least 2 minutes).
Chill for 2 hours or more. Serve.
Makes 8 servings.

1 serving:
240 calories
7g protein
36g carbohydrates
8g fat

Source: Canadian Goodness, Dairy Farmers of Canada.

PEACH SILK PUDDING

- 1 300g container of soft tofu
- 1 can (398mL) sliced peaches including juice
- 2 tbsp of sugar
- 1 bag of 4 servings of instant vanilla pudding
- 1 cup of 35% whipping cream

Whip the cream in a bowl.
In blender, puree peaches, sugar, soft tofu and pudding powder.
Stir mixture into whipped cream.
Refrigerate. Makes 6 servings.

1 serving :
200 calories
3g protein
31g carbohydrates
8g fat

Source: Tofu Simply Delicious, Ontario Soybean Grower's Marketing Board.

CHOCOLATE PUDDING

- 1 container of 200g of soft tofu
- 1 can of sweetened condensed milk (Eagle Brand)
- 3 tbsp cocoa
- 1 jar of marshmallow cream

In blender, puree all ingredients.
Refrigerate. Makes 8 servings.

1 serving:
310 calories
6g protein
50g carbohydrates
8g fat

Source: Geneviève Lapointe, Nutritionist CHUQ

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Letter For Your Treating Physician & Healthcare Team

Reprinted and translated by the ALS Society of Quebec with the permission of the authors: SwallowSafely.com

Date: _____

Dear Dr./Mr./Ms._____

I am concerned about swallowing in (*Name of Person/Date of Birth):* _____

She/He is my: □ Mother □ Father □ Spouse Other: _____

I have noticed these problems over the past: _____ weeks _____months.

Circle those that apply:

difficulty swallowing coughing choking gagging wheezing

teary eyes runny nose chest pain nasal regurgitation

weight loss recurrent fever hurts to swallow sore throat refuses food

drooling voice change hoarse weak gurgly nasal

frequent throat clearing tired out by eating nausea loss of taste or smell

bites tongue burps frequently food feels stuck/won't go down food sticks to throat

difficulty with: juice meat pills other: _____

embarrassed to eat in public difficulty with favorite foods eats very slowly

tired out by eating struggles to eat eats rapidly dehydration

sore gums loose dentures bad breath recent fall gets dizzy with swallowing

other observations:_____

She/He has these medical problems: _____

_____

Her/His last hospitalization was (*Date& Hospital)* _____

for these reasons: _____

She/He is taking the following medications (*prescribed, over the counter, and research meds)*:

_____ _____

_____ _____

I am most concerned about: □ choking □ nutrition □ hydration □ aspiration □ pneumonia

□ difficulty swallowing pills □ other: _____

I look forward to hearing from you at your earliest convenience.

You can reach me in the following ways:

Home Telephone: ( ) -

Mobile Telephone: ( ) -

E-Mail:

FAX: ( ) -

Mailing Address:

Thank you very much for your attention and concern.

Sincerely,

_____
Signature

_____
Printed Name

GUIDELINE CPD

Canadian best practice recommendations for the management of amyotrophic lateral sclerosis

Christen Shoesmith MD, Agessandro Abrahao MD MSc, Tim Benstead MD, Marvin Chum MD MSc, Nicolas Dupre MD MSc, Aaron Izenberg MD, Wendy Johnston MD, Sanjay Kalra MD, Desmond Leddin MB MSc, Colleen O'Connell MD, Kerri Schellenberg MD MMedEd, Anu Tandon MD, Lorne Zinman MD MSc

■ Cite as: *CMAJ* 2020 November 16;192:E1453-68. doi: 10.1503/cmaj.191721

This guideline is available in French at www.cmaj.ca/lookup/doi/10.1503/cmaj.191721-f

CMAJ Podcasts: author interview (in English) at www.cmaj.ca/lookup/doi/10.1503/cmaj.191721/tab-related-content

Amyotrophic lateral sclerosis (ALS) is a debilitating, progressive disease with degeneration of motor neurons in the brain and spinal cord causing weakness, muscle atrophy, fasciculations and spasticity.[1] Onset in the limbs, with extremity weakness and impairment in mobility, is the most common presentation, occurring in about 70% of patients.[2] Bulbar onset with oropharyngeal muscle involvement affecting swallowing and speech occurs in about 25% of cases.[2] In addition to motor impairment, degeneration in the frontal and temporal lobes, resulting in cognitive or behavioural impairments, occurs in up to 50% of patients.[3] Over time, strength progressively declines, and patients typically die from respiratory failure within 5 years of diagnosis.[2] Despite increased research efforts in recent years, treatment options for ALS remain limited, and patient care is focused primarily on managing symptoms and optimizing function and quality of life.[2]

An estimated 3000 Canadians are currently living with ALS.[4,5] Advocacy groups and clinicians caring for patients with ALS have strongly supported the development of best practice recommendations for the care and management of these patients in Canada. Although ALS clinical practice guidelines have been published in the United States[6,7] and in Europe,[8,9] to date there have been no published guidelines explicitly for the care of patients with ALS in Canada.

In addition to providing an update on the evolving standard of care in ALS, the best practice recommendations in this guideline serve to address several issues important to Canadians, such as caregiver support, medication alignment and medical assistance in dying (MAiD). Developing the first Canadian ALS guideline is a critical step in an iterative process whereby these recommendations can be updated as evidence evolves, and research priorities can be identified and prioritized to fill knowledge gaps.

Because the rigorous standards of evidence-based medical recommendations are not met in most areas of ALS care, many of the recommendations presented are expert consensus on good practice. Typically, symptom management in ALS is extrapolated from evidence in other disease states. The recommendations presented in this guideline are based on best available evidence and expert consensus on best practices, and thus reflect the real-life experiences of Canadian clinicians caring for patients with ALS. This article is a summary of the full guideline, which is available on the ALS Canada website (www.als.ca/bpr-appendix).

KEY POINTS

- Management of patients living with amyotrophic lateral sclerosis (ALS) requires specialized multidisciplinary holistic care.
- Disease-modifying pharmacologic therapies to treat ALS include riluzole and edaravone.
- Close attention to nutritional support and respiratory care is required for optimal care in ALS.
- Multiple treatments are available to ease the symptoms of ALS.
- Palliative care and caregiver support are important components of assisting patients along their journey with ALS.

Scope

The purpose of this guideline is to provide ALS clinicians, allied health professionals and primary care providers with best practice recommendations for the care and management of patients living with ALS in Canada, inclusive of all genders, ages and stages of the disease. This guideline is intended to develop a national standard to improve quality of care for patients, families and caregivers living with ALS. Advocacy groups (e.g., ALS Society

of Canada [ALS Canada], provincial ALS societies), health authorities, governments and policy-makers will be better able to establish benchmarks and advocate for standards of care.

Recommendations

The care and management of patients with ALS should always be patient focused, with attention to holistic and emotional aspects of well-being. It is the patient who ultimately decides on their treatment; this includes the option of declining interventions.

The recommendations for the management of patients with ALS in Canada are in Table 1, grouped by topic, and indicating the level of evidence. If evidence was insufficient or absent for a key question, we made recommendations based on expert consensus through review of the available literature and clinical experience in ALS or extrapolated from treatment of other more common diseases.

Table 1 (part 1 of 6): Recommendations with level of evidence grade for the management of patients with amyotrophic lateral sclerosis*

Recommendations
Communication of diagnosis
• The approach to communicating the diagnosis should be tailored to the patient's individual needs (EC).
• The diagnosis of ALS should be confirmed by a neurologist or physiatrist with training and expertise in ALS (EC). Patients referred for confirmation of an initial diagnosis of ALS should be seen in an ALS specialty clinic within 4 weeks (EC). Timely clinical contact by the specialty ALS clinic after confirmation of diagnosis is recommended (EC).
• Discussion about ALS treatments and ALS research should occur. Patients should be provided with written information about ALS resources (paper- or Internet-based) and encouraged to register with their local and national ALS society (EC).
• Discussions on prognosis are important and should be tailored to the individual but need not be discussed at initial diagnosis unless specifically requested (EC).
Disease-modifying therapies
• Disease-modifying therapies should be prescribed by clinicians with experience in managing patients with ALS (EC).
• Riluzole:
◦ Riluzole has demonstrated efficacy in improving survival in ALS (level A).
◦ There is evidence that riluzole prolongs survival by a median duration of 3 months (level A).
◦ Riluzole should be started soon after the diagnosis of ALS (EC).
◦ Regular monitoring of potential adverse effects of riluzole is important (EC).
◦ There is insufficient evidence to suggest that riluzole loses clinical efficacy with progression of disease, including development of respiratory insufficiency (EC).
• Edaravone:
◦ In a select group of patients, intravenous edaravone has been shown to slow decline on the ALSFRS-R scores compared against intravenous placebo, over a 6-month period (level B). (These patients have shown benefit from edavarone: disease duration < 2 y, FVC > 80%, all ALSFRS-R subcomponents scores > 2, and demonstrated steady decline in the ALSFRS-R over a 3-mo interval.)
◦ Evidence for benefit of intravenous edaravone at other stages of ALS has not been demonstrated (EC).
◦ As with any other therapies, individualized goals, risks and benefits should be carefully considered and discussed before intravenous edaravone is initiated (EC).
• Physicians are encouraged to have an open dialogue with their patients about the potential risks and benefits of unapproved therapies (EC).
Multidisciplinary care
• Patients with ALS should be referred to specialized ALS multidisciplinary clinics for optimized health care delivery (level B).
• Patients and health care authorities should be educated on the rationale for patient attendance at a multidisciplinary clinic. Benefits include:
◦ Survival benefit (level B).
◦ Fewer and shorter hospital admissions than patients not attending such clinics (level B).
◦ Increased use of adaptive equipment (level C).
◦ Increased use of riluzole, percutaneous feeding tubes and NIV (level B).
◦ Enhanced QOL (level C).
• Multidisciplinary care should be delivered through a team-based approach, with physicians and other health professionals addressing issues including communication, nutrition, swallowing, mobility, activities of daily living, respiratory care, cognition, psychosocial issues, medical management and end-of-life care (EC).
• The frequency of multidisciplinary clinic visits will be dictated by the patient's needs and rate of progression (EC).
• A dedicated nurse or other clinic allied health care professional should be available to support patients and their family members for ALS issues between clinic visits (EC).
• Telemedicine and telehealth monitoring are feasible and may be able to supplement clinic-based multidisciplinary care (level C).

Table 1 (part 2 of 6): Recommendations with level of evidence grade for the management of patients with amyotrophic lateral sclerosis*

Recommendations
Respiratory management

Screening
• Patients with ALS need regular respiratory monitoring at baseline and every 3 months, or as clinically indicated (EC). Regular respiratory monitoring should include:
  • Symptom review, including dyspnea, orthopnea and morning headaches (level C).
  • Measurement of sitting FVC or slow vital capacity (level B).
  • One or more of the following: SNIP, supine FVC or MIP (level C).
  • Arterial blood gases, venous blood gas or transcutaneous CO_2, when hypercapnia is suspected or when bulbar impairment precludes accurate testing (level C).
  • PCF measurement to assess cough effectiveness (level C).
  • Nocturnal oximetry or overnight polysomnography, when symptomatic sleep-disordered breathing is suspected and other daytime indications for NIV initiation are not present (level C).

Ventilation
• NIV is the standard of care to treat respiratory insufficiency in ALS, both to lengthen survival and treat symptoms (level B).
• Criteria for NIV initiation are any of the following:
  • Symptoms of respiratory insufficiency, including orthopnea (level B).
  • SNIP ≤ 40 cm H_20 or MIP ≤ 40 cm H_20 (level C).
  • Upright reliable† FVC < 65% (EC).
  • FVC sitting or supine < 80% with symptoms or signs of respiratory insufficiency (level B).
  • Daytime hypercapnia pCO_2 > 45 mm Hg (level B).
  • Abnormal nocturnal oximetry or symptomatic sleep-disordered breathing (level B).
• A respiratory specialist should be consulted to initiate NIV (EC).
• In any patient with the above indications, NIV should be initiated within 4 weeks. Severely symptomatic patients will need more urgent initiation. An overnight polysomnogram is not required for initiation of NIV (EC).
• Ensure in-home‡ NIV respiratory support for education, titration and troubleshooting (EC).
• Patients should be informed that use of NIV may change the survival trajectory in ALS and the end-of-life experience (EC).
• NIV enhances QOL in patients with ALS who have respiratory insufficiency (level B).
• There should be ongoing assessments by a specialized respiratory therapist who can optimize modes, pressure and interfaces of NIV. Monitoring should include device download and may include nocturnal oximetry (level C).
• Oxygen should not be considered a routine treatment for chronic respiratory insufficiency. In patients with ALS with acute hypoxemia, management of respiratory insufficiency with NIV needs to be considered first. If hypoxemia remains after optimal NIV pressure is applied, the etiology of the hypoxia needs to be assessed and supplemental oxygen can be considered (EC).
• Diaphragm pacing should not be used in ALS because it is not effective and likely harmful in patients with ALS (level B).
• NIV is the recommended treatment for ventilation even when ventilation is required 24 hours per day (EC).
• Mouthpiece ventilation can be considered in carefully selected patients as a form of NIV during the day in addition to nocturnal NIV (EC).
• In respiratory impairment that cannot be effectively managed by NIV, invasive ventilation is an option in carefully selected patients. Discussions pertaining to goals of care and advanced directives should occur well in advance of respiratory failure (EC).
• Patients need to understand that ALS will continue to progress even with ventilatory support (EC).
• Advanced care planning discussions should include explicit information about all respiratory interventions. Discussions should include the fact that intubation may be irreversible depending on the disease stage, and palliative options for breathlessness (please refer to the Palliative Care section). Discussions should also include the option of removing any treatment that has been initiated (EC).
• Tracheostomy can be considered for upper airway obstruction with vocal cord paresis; however, discussions of long-term invasive ventilation should also occur (EC).

Airway clearance management • Lung volume recruitment strategies (level C) and manual assisted coughing (EC) should be initiated when patients report difficulty clearing airway secretions. • MIE twice daily should be considered for secretion clearance in patients with ALS who have reduced PCF (< 270 L/min). Increased MIE frequency should occur during an acute chest infection (EC). • Ensure in-home‡ respiratory support of MIE for education, titration and troubleshooting (EC). • Pharmacotherapy with mucolytics (i.e., guaifenesin or N-acetylcysteine), a β-receptor antagonist (e.g., metoprolol or propranolol), nebulized saline or nebulized ipratropium can be considered (EC).

Table 1 (part 3 of 6): Recommendations with level of evidence grade for the management of patients with amyotrophic lateral sclerosis*

Recommendations
Nutritional management
Monitoring and enteral intervention
• Nutritional status should be monitored by weight and BMI every 3 months, or as clinically indicated (level B); TDEE may be considered (level B).
• Nutritional interventions, including dietary alteration and consideration of referral for enteral tube insertion, are indicated at diagnosis or at follow-up if there is: (1) increased risk of aspiration despite consistency modifications and compensatory recommendations (EC); (2) ≥ 5%–10% reduction in weight from usual or baseline weight (level C); (3) ≥ 1-point reduction in BMI from usual or baseline BMI (level B); (4) BMI < 18.5 (level B); or (5) TDEE exceeds daily energy intake (EC).
• Information regarding potential benefits and risks of enteral feeding tubes should be provided early in the course of ALS management (EC).
• A decrease in FVC approaching 50% should prompt consideration of referral for enteral tube insertion, even in the absence of dysphagia. An FVC < 50% should not necessarily preclude the recommendation of enteral feeding tube insertion as long as respiratory status is carefully monitored during and after the procedure (level C). NIV may improve safety of RIG or PEG insertion in patients with respiratory impairment (EC).
• Regular monitoring of swallowing safety should be performed by a certified swallowing clinician (level B). Objective measures of swallowing impairment (modified barium swallow or FEES) can be used early and during the course of ALS management (EC).
Maximum allowable delay for PEG or RIG
• Once a decision is made to insert an enteral feeding tube, insertion should be performed within 4 weeks. The ALS team should have access to endoscopists or radiologists who have interest and expertise in tube insertion (EC).
Feeding tube insertion
• There is insufficient evidence to recommend PEG or RIG as the usual procedure for gastrostomy insertion (level C). There is weak evidence that RIG may be safer in patients with ventilatory impairment, as RIG does not require substantial sedation (EC).
• Once a feeding tube is placed, an experienced clinician (endoscopist or radiologist) should be readily available to address immediate and late tube complications. There should be regular support by a registered dietitian with respect to the enteral feeds prescribed (EC).
• Nasogastric tube feeding is not a preferred long-term option and should be reserved for those patients where no other procedure is possible and enteral nutrition is still desired (level C).
Diet modifications and nutrition support
• High-calorie diets can be used to improve nutritional indicators (level B) and possibly survival (level C). High-calorie and high-carbohydrate diets may be better than high-calorie and high-fat diets (level B).
• Parenteral nutrition is a potential source of nutrition in patients who cannot successfully have an enteral nutrition source; its use should be reserved for exceptional circumstances (EC).
Venous thromboembolism
• There is likely an increased risk of VTE in patients with ALS. The risk appears heightened in ALS with leg onset and in patients with poor mobility (EC).
• Clinicians are encouraged to consider VTE as a potential cause for new leg pain or new leg swelling in patients with ALS (EC).
• There is no evidence to suggest screening for thromboembolism in asymptomatic patients with ALS (EC).
• VTE prophylaxis has not been evaluated in patients in ALS and is not recommended in patients who have not been admitted to hospital (EC).
• If VTE occurs in a patient with ALS, they should be anticoagulated as per standard VTE guidelines (EC).
Medication alignment
• Primary care physicians and specialists should perform intermittent medication reviews and consider discontinuing any nonessential medications (EC).
• Symptom management medications should be continued (EC).
• Primary prevention medications should be discontinued if duration of effect is longer than the expected survival (EC).
• Patients and health care professionals can be reassured that premorbid statin administration does not appear to contribute to the development of ALS (level B).
• There is insufficient evidence to recommend discontinuation of statins in all patients with ALS. Discontinuation of statins may be considered based on the patient's expected survival and their cardiovascular risk (EC).

The following sections provide background and expand on selected recommendations with supporting evidence. The evidence tables in Appendix C of the full guideline (available at www.als.ca/bpr-appendix) provide details of supporting evidence for all recommendations listed in Table 1. For a complete discussion of the evidence supporting the recommendations, please see Appendix A (www.als.ca/bpr-appendix).

Communication of diagnosis

The manner in which the diagnosis of ALS is delivered is a source of discontent for many patients and caregivers.[10,11] Recommendations have been formulated that outline a comprehensive approach to diagnosis delivery in the context of ALS.[8] One of the most important concepts for clinicians to consider is tailoring the diagnosis delivery to the individual needs of the patient. If a

Table 1 (part 4 of 6): Recommendations with level of evidence grade for the management of patients with amyotrophic lateral sclerosis*

Recommendations
Symptom management
Pain • Pain is a recognized consequence of ALS, with many potential causes (EC). • Patients must be queried regularly about pain symptoms. Pain should be regularly assessed and treatments should be tailored toward the specific cause (EC).
Fasciculations • In most patients, fasciculations do not need medication management (EC). • If fasciculations cause substantial distress, gabapentin can be considered (level C).
Sialorrhea • Anticholinergic medications are the first-line therapy of sialorrhea. Individual medication choices should be tailored to patient factors (EC). • If one anticholinergic medication is ineffective, switching to another anticholinergic medication should be considered (EC). • Oral suction can be used as an adjunct therapy in managing sialorrhea (EC). • Botulinum toxin is effective for management of sialorrhea in ALS (level A). It can be used as second-line therapy and should be considered after feeding tube insertion because of the theoretical risk of worsening swallowing or airway integrity (EC). • Focal salivary gland radiation is an option for management of sialorrhea (level C) as second- or third-line therapy.
Pseudobulbar affect • Patients and families should be educated that pseudobulbar affect is a symptom of ALS and does not necessarily represent a symptom of depression or impaired cognition (EC). • Pseudobulbar affect does not require treatment unless it is distressing to the patient (EC). • If treatment is warranted, medications that may co-treat concomitant symptoms (e.g., amitriptyline for sleep and mood effect, SSRI for depression) may be considered (EC). • Dextromethorphan (20 mg) combined with quinidine (10 mg) can be used for treatment of pseudobulbar affect (level B).
Spasticity • Stretching can be useful for managing spasticity (level C). • If pharmacologic management of spasticity is required, baclofen, tizanidine, botulinum toxin, benzodiazepines and cannabinoids could be considered (EC). • There is insufficient evidence to recommend intrathecal baclofen for spasticity management in patients with ALS (EC).
Cramps • Muscle cramps need to be differentiated from other causes of pain (EC). • First-line management could include tonic water, gabapentin and baclofen (EC). • Second-line treatment could include quinine, levetiracetam and mexiletine (EC).
Depression • Depression should be treated in ALS, as it has a substantial impact on patient well-being (EC). • SSRIs or SNRIs can be used to treat depression in ALS (EC). • Nonpharmacologic supports could be considered, such as those offered through psychology, social work, psychiatry or spiritual care (EC).
Anxiety • Anxiety should be treated in ALS as it has a substantial impact on patient well-being (EC). • It is important to determine if anxiety is related to respiratory insufficiency and, if present, treat appropriately (EC). • If depression is concurrently present, an SSRI should be prescribed (EC). • Benzodiazepines can exacerbate respiratory insufficiency (EC). • Nonpharmacologic supports can be considered, such as those offered through psychology, social work, psychiatry or spiritual care (EC).
Insomnia • There are multiple causes of insomnia, such as respiratory insufficiency and depression, that should be appropriately investigated (EC). • Respiratory investigations and sleep studies could be considered to determine the type and cause of insomnia (EC). • Pharmacologic management of insomnia will depend on the cause (EC).
Fatigue • Reversible causes of fatigue should be considered, such as respiratory insufficiency, sleep disorders, depression, medication adverse effects and riluzole use (EC). • In patients developing fatigue while taking riluzole, reducing or discontinuing the drug may be considered (level C). • Having an occupational therapist discuss energy conservation techniques with patients may be considered (EC).

Table 1 (part 5 of 6): Recommendations with level of evidence grade for the management of patients with amyotrophic lateral sclerosis*

Recommendations
Dysarthria
• Patients with dysarthria should be regularly followed by a speech language pathologist to ensure timely communication interventions (EC).
• Use of augmentative and alternative communication devices should be offered to eligible patients in early disease stages (EC). Patients in later disease stages will also benefit from communication devices and strategies (EC).
• The choice of communication devices should be tailored to the patient's needs and abilities (EC). Patients with cognitive impairment may need individualized strategies for communication (EC).
• Augmentative and alternative communication strategies may reduce caregiver stress (EC).
• Voice amplification should be offered to patients with reduced vocal projection (EC).
• Voice banking should be offered to appropriate patients (EC).
• Providing access to different modes of communication, including social media, can allow independence, participation and better QOL (EC).
Exercise

• In early ALS, regular moderate-intensity exercise is probably beneficial for function and QOL (level B). A personalized exercise program, including strength and aerobic training, should be suggested to patients who are able to participate (EC):
  • Submaximal effort for resistance should be encouraged.
  • Moderate-intensity physical activities are those that will cause adults to sweat a little and to breathe harder.

• Moderate-intensity exercise is well tolerated and not harmful in ALS (level B):   • Post-exercise fatigue or pain should resolve in 30 minutes and not interfere with daily activities; the exercise program should be adjusted otherwise.
• A regular stretching and range-of-motion program is recommended for management of spasticity (level C), pain (EC) and prevention of contractures (EC).   • Stretching and range-of-motion exercise can be done independently (active), with assistance (passive) or in combination (active-assist)
Cognition and behaviour
• Screening for cognitive and behavioural impairment should be performed in patients with ALS early in their disease (level B).
• If there is concern about cognition or behaviour at any point, specific assessments should take place with the person and their family members or caregiver, as appropriate (EC).
• There are no studies on the use of pharmacologic agents to manage cognitive or behavioural impairment in ALS.
• Because the presence of frontotemporal dementia negatively affects survival, ACP should be done early in the disease (EC).
• The presence of cognitive or behavioural impairment should not necessarily preclude the recommendations for NIV or gastrostomy insertion. However, the challenges of intervention compliance with cognitive or behavioural impairment should be discussed with the patient and family before deciding to proceed with an intervention (EC).
• A multidisciplinary approach can be considered to manage particularly problematic behaviours. Involving a behavioural specialist (such as an occupational therapist or psychologist) or psychiatrist for assistance may be considered (EC).
Caregivers
• Health care providers should be attentive to the needs and emotional well-being of caregivers. Caregivers should be involved in planning for the impact of ALS on both the patient and themselves (EC).
• Multidisciplinary clinics should be aware of the financial strain on caregivers and provide information on existing relief programs where possible (EC).
• Assessment of caregiver burden, coping strategies, mood and family dynamics would assist in identifying caregivers and families in need of respite and supportive services. Local ALS societies may have resources for family members and caregivers (EC).

patient is overwhelmed by the diagnosis of ALS, then the diagnosis could be delivered in a stepwise fashion, without divulging all of the information at once.[12] Conversely, patients may feel that they did not receive enough information when receiving their diagnosis. Patients and caregivers wish to be informed about current research, treatments and prognosis when receiving a diagnosis of ALS.[13]

In a study of satisfaction with the manner of disclosure of the diagnosis of ALS, 41% of patients indicated that they received insufficient information, and one-third stated that they were not given a contact for follow-up.[10] Furthermore, about 75% of patients and caregivers had questions that arose immediately after they received the initial diagnosis.[11] These findings highlight the need for clinicians to address sources of information, community support and provide timely follow-up after the diagnosis is first discussed. Patients report better satisfaction with the delivery of an ALS diagnosis if they believe that the clinician has understood their feelings.[13] An additional source of frustration for patients was the delay in receiving confirmation of a diagnosis, including wait times to see an ALS specialist.[10] The working

Table 1 (part 6 of 6): Recommendations with level of evidence grade for the management of patients with amyotrophic lateral sclerosis*

Recommendations
Palliative care
Timing
• Palliative care of patients with ALS can be provided throughout the disease course by ALS clinic staff, palliative care practitioners and family physicians (EC).
• Palliative care should be introduced if there is severe physical (i.e., pain, dysphagia or dyspnea), psychosocial or existential distress (EC).
• To ensure integrated continuity of care, community palliative care services could be introduced before advanced-stage ALS (EC).
Treatments
• Clinicians must clarify with their patient who is experiencing breathlessness whether the goal of care is prolonging life versus comfort-focused care for a good death (EC).
• Clinicians should assess and relieve factors contributing to breathlessness, such as oral secretions and anxiety (EC).
• Opioids can be titrated to relieve breathlessness (EC).
• Air flow across the face to help with breathlessness may be considered (EC).
• Conversations about ACP should be initiated early in the disease or whenever the patient inquires. Ongoing discussions about ACP and goals of care should be part of routine ALS follow-up (EC).
• Patients should be encouraged to discuss their preferences about end-of-life care with family members and caregivers (EC).
• Palliative care should be integrated into routine patient management before the terminal phase of ALS (EC).
• Use of NIV and PEG tubes should be continued in palliative care for symptom relief and QOL, as dictated by patient preference (EC).
Withdrawal of ventilatory support
• Withdrawal of continuous ventilatory support should be performed only after consultation and planning with a health care professional with expertise in ventilation withdrawal and palliative sedation (EC).
• Adequate anticipatory symptom control with opioids and benzodiazepines should be achieved before withdrawal of ventilation occurs (EC).
• Debriefing and psychosocial support for family and health care providers should be offered (EC).
Bereavement
• Psychosocial support for bereaved caregivers should be provided. Early discussion about and support for the bereavement process could be initiated even before the patient's death (EC).
Medical assistance in dying
• Discussions about MAiD should be directed to a physician or nurse practitioner, abiding by regional guidelines (EC).
• Physicians caring for patients with ALS are required to provide access to information about MAiD when requested (EC).
• Clinicians should not assume that questions about MAiD constitute a request for MAiD. However, questions about MAiD should also open a discussion about end-of-life care and ACP (EC).
• Patients pursuing MAiD should be provided concurrent palliative and supportive care (EC).
Organ donation
• Patients with ALS may be accepted as solid organ donors, as determined by their local organ donation organization (EC).
• Patients with ALS cannot donate tissue, such as corneas, skin or bone (EC).
• Clinics should direct inquiries about donation to their provincial organ donation organization (EC).
• Patients may be able to donate their tissues upon death for ALS research (EC).

Note: ACP = advanced care planning, ALS = amyotrophic lateral sclerosis, ALSFRS-R = Amyotrophic Lateral Sclerosis Functional Rating Scale–Revised, BMI = body mass index, EC = expert consensus, FEES = fibreoptic endoscopic evaluation of swallowing, FVC = forced vital capacity, MAiD = medical assistance in dying, MIE = mechanical insufflation-exsufflation, MIP = maximal inspiratory pressure, NIV = noninvasive ventilation, PCF = peak cough flow, pCO_2 = partial pressure of carbon dioxide, PEG = percutaneous endoscopy gastrostomy, QOL = quality of life, RIG = radiologically inserted gastrostomy, SNIP = sniff nasal inspiratory pressure, SNRI = serotonin–norepinephrine reuptake inhibitors, SSRI = selective serotonin reuptake inhibitor, TDEE = total daily energy expenditure, VTE = venous thromboembolism.
*See Box 2 for criteria for levels of evidence supporting the recommendations.
†If pulmonary testing is not reliable (i.e., in patients with bulbar impairment or with severe cognitive impairment), clinicians must rely on symptoms or other measures for respiratory screening.
‡The patient's home can be a house, apartment, long-term care facility or hospice.

group agreed that a maximum wait time of 4 weeks for a consultation to confirm a diagnosis of ALS was reasonable.

Disease-modifying therapies

Health Canada approved riluzole as a treatment for ALS in 2000. Based on a class I meta-analysis of 4 randomized controlled trials (RCTs), riluzole has a modest benefit on survival compared with placebo, with a hazard ratio (HR) of 0.84 (95% confidence interval [CI] 0.698 to 0.997), representing a 9% gain in annual probability of survival. This translates to an increase in median survival from 11.8 to 14.8 months.[14] Recent registry-based cohort studies (all class III) have estimated an improvement in median survival with riluzole treatment of 7.3 months,[15] 10 months[16] or 12 months,[17] but other studies have found no effect on survival.[18–21] Findings

from other class III cohort studies reported HR estimates of 0.34,[22] 0.71,[23] 0.79[24] and 0.81,[25] which translates to an estimated absolute increase in annual survival that ranges from 10% to 50%.

No controlled trials have examined whether riluzole extends life at a specific stage or all stages of ALS. A post-hoc analysis of the original dose-ranging study suggests that riluzole may be effective at prolonging survival only at later disease stages (defined by nutritional or respiratory failure sufficient to require intervention),[26] but results from other cohort studies differ, showing that it may be effective only at earlier stages,[27] or that its effect on survival is short lived.[28] Nevertheless, decades of experience worldwide have shown riluzole to be generally well tolerated with prolonged use and with regular monitoring of liver enzymes and blood counts, as well as screening for nausea and fatigue (class I).[14]

Health Canada approved edaravone to treat ALS in October 2018. A single class I study in a generalized ALS population did not demonstrate overall benefit of edaravone in slowing progression of the ALS Functional Rating Scale–Revised (ALSFRS-R) score over 6 months[29] but did suggest benefit in a subgroup of patients (see Table 1 for characteristics of this subgroup). This beneficial effect on the slowing of the progression of the ALSFRS-R score was subsequently confirmed in a second class I study that restricted recruitment to patients with characteristics of the subgroup from the first study.[30] The second study demonstrated a mean reduction in the change in ALSFRS-R score over 6 months of 2.49 (95% CI 0.99 to 3.98). At this time, the available evidence suggests a level B evidence rating of "probably effective" in a select group of patients with ALS.

Multidisciplinary care

Patients with ALS should be regularly followed by a multidisciplinary ALS clinic, along with their primary care provider. Multidisciplinary care should be delivered through a team-based approach, with physicians and other health professionals addressing a broad range of issues, including communication, nutrition, swallowing, mobility, activities of daily living, respiratory care, cognition, psychosocial issues, medical management and end-of-life care. Patients followed through a multidisciplinary clinic have been shown to have better outcomes, including improved survival, fewer hospital admissions, increased use of adaptive equipment and enhanced quality of life, than those not followed in a multidisciplinary clinic.[31–33] One prospective cohort study showed that patients followed in a multidisciplinary clinic lived 7.5 months longer than those followed in a general neurology clinic.[32]

Telemedicine and telehealth monitoring are feasible and may be able to supplement clinic-based multidisciplinary care.[34] Management of patients with ALS should be a collaboration between the family physician and the ALS clinic, with the ALS clinic staff available for remote consultation between patient visits.

Respiratory management

The Canadian Thoracic Society (CTS) guideline group recently reviewed the respiratory management of patients with ALS on home mechanical ventilation.[35] We decided to make our recommendations on respiratory management (Table 1, Figure 1) consistent with the CTS guideline. We made a few additions to the CTS recommendations, including a statement on avoiding the use of oxygen for respiratory symptoms in patients with ALS, timing of initiation of interventions and managing secretions. We also thought it was important to adjust the minimum forced vital capacity (FVC) criterion for initiation of noninvasive ventilation in asymptomatic patients to 65% of predicted, from the CTS recommendation of 50%, because available evidence suggests early initiation improves survival.[36] Patients with an FVC of greater than 65% predicted can be started on noninvasive ventilation if any of the other initiation criteria are met, as consistent with the CTS guideline. Our group also unanimously agreed that if criteria for initiation of noninvasive ventilation are met, patients should be initiated on noninvasive ventilation within 4 weeks.

It is important to acknowledge that noninvasive ventilation can change the natural disease trajectory of ALS. For example, increasing reliance on noninvasive ventilation converts it into life-support technology. In patients reliant on noninvasive ventilation, natural death may not occur while using the technology; death may occur only if there is an active decision to discontinue the ventilation support. Patients should be counselled that they may need to take an active decision as to the timing of discontinuing the ventilatory support, unless they wish prolonged survival.

Difficulty with secretion management is common among persons living with ALS, and is a cause of distress, reduced quality of life and impairment of respiratory function. The CTS guideline did not explicitly address airway clearance management. To address this important issue, we reviewed available evidence and clinical experience. We recommend that lung volume recruitment techniques be introduced whenever patients present with symptoms of retained airway secretions or difficulty in clearing secretions. Such techniques can be combined with manual assisted coughing and be performed independently by patients or with assistance of care providers. If patients develop impaired peak cough flow (< 270 L/min), then mechanical insufflation–exsufflation twice daily should be considered for secretion clearance, and more frequently during an acute respiratory infection.

We also attained consensus that providing adequate in-home respiratory support of noninvasive ventilation and mechanical insufflation–exsufflation for education, titration and troubleshooting is essential, regardless of whether the patient resides in their own home, long-term care facility or hospice.

Nutrition management

The nutrition recommendations (Table 1, Figure 2) largely follow those outlined in the AAN guideline.[6] Differences from the AAN recommendations include the addition of an expert consensus statement on the 4-week maximum allowable delay for a feeding tube insertion after criteria have been met, and a statement on the availability of appropriate follow-up after insertion for immediate or late complications. The recommendations also include a statement about nutritional components, and note that high-calorie diets can be used to improve nutritional indicators and possibly survival.[37,38] High-calorie and high-carbohydrate diets may be better than high-calorie and high-fat diets.[39]

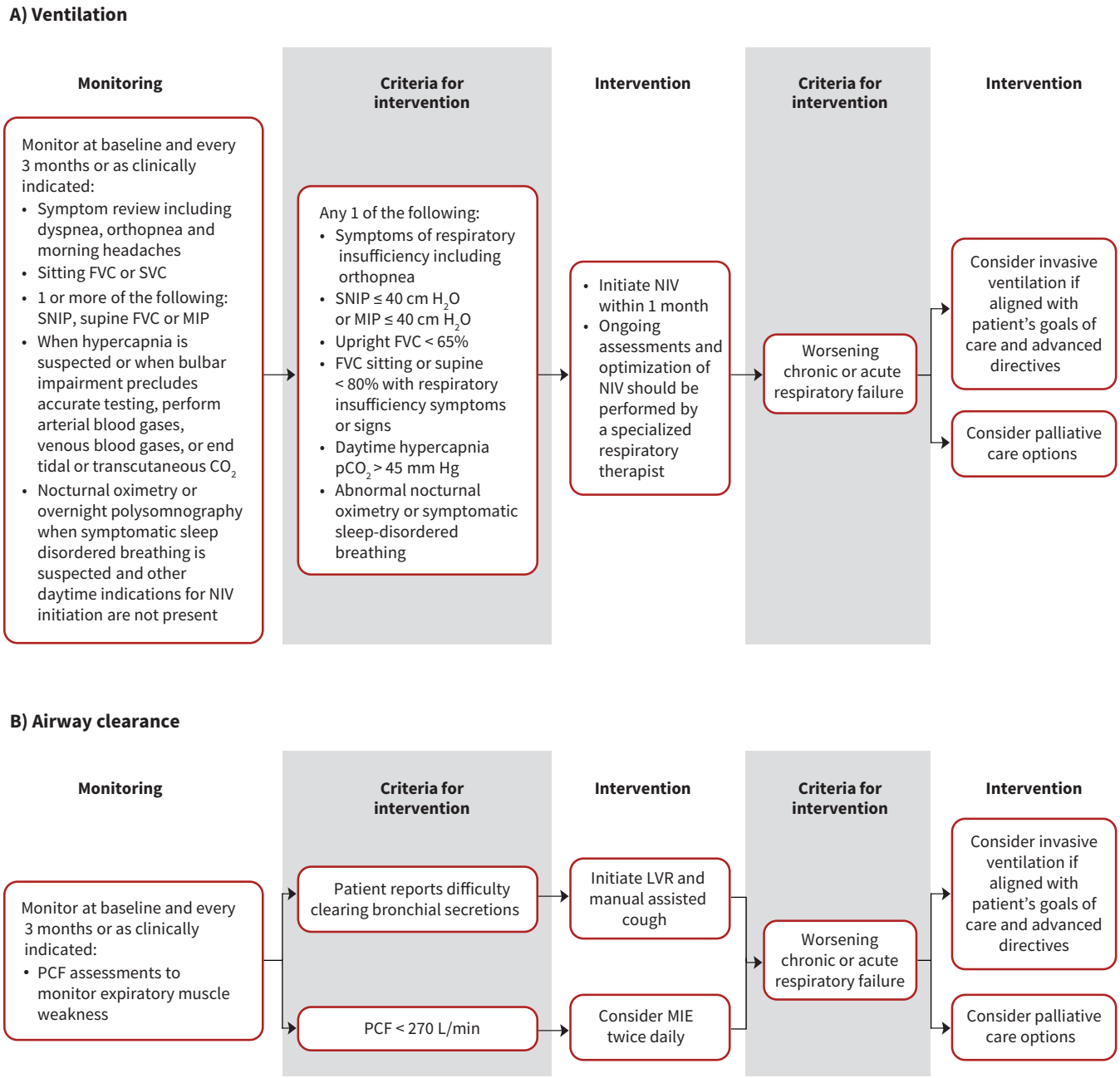

Figure 1: Respiratory decision tree: Summary of recommendations for respiratory management in patients with amyotrophic lateral sclerosis (ALS), including ventilation (A) and airway clearance (B). Note: FVC = forced vital capacity, H_2O = water, LVR = lung volume recruitment, MIE = mechanical insufflation–exsufflation, MIP = maximal inspiratory pressure, NIV = noninvasive ventilation, PCF = peak cough flow, pCO_2 = partial pressure of carbon dioxide, SNIP = sniff nasal inspiratory pressure, SVC = slow vital capacity.

Venous thromboembolism

There is likely an increased risk of VTE in patients with ALS.[40,41] The risk appears heightened in ALS with leg onset and in patients with poor mobility.[40] Despite this elevated risk, there are no studies to support primary VTE prophylaxis. At this time, primary VTE prophylaxis is not recommended because the risk–benefit ratio of potential adverse consequences from falls versus VTE prevention in patients with ALS is uncertain.

Medication alignment

When patients come to an ALS clinic, they are often on multiple medications. Some of these medications may be considered nonessential, particularly considering the average survival of patients with ALS. Through expert consensus, we developed several statements that address the need for regular review of the medications that a patient is taking and suggest discontinuation of any nonessential medications that are not providing symptomatic

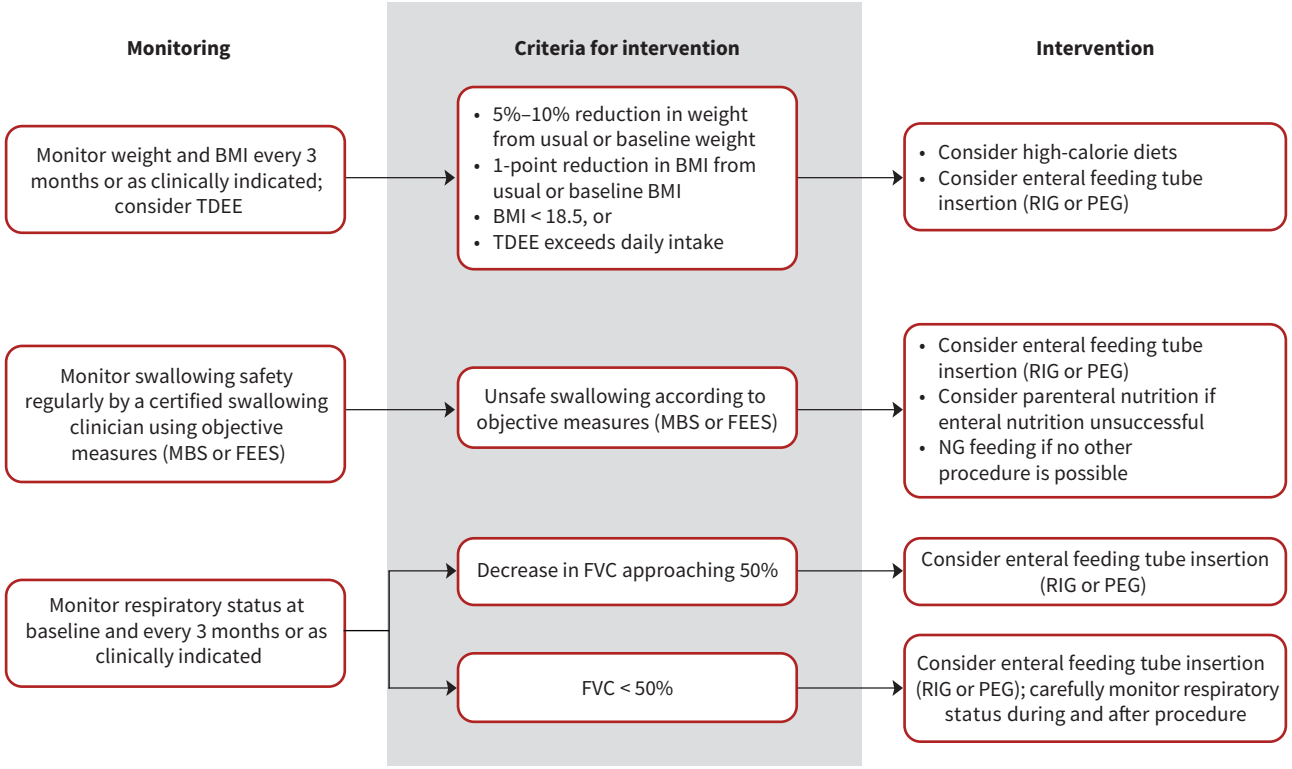

Figure 2: Nutrition decision tree: Summary of recommendations for nutritional management in patients with amyotrophic lateral sclerosis (ALS). Note: BMI = body mass index, FEES = fibre-optic endoscopic evaluation of swallowing, FVC = forced vital capacity, MBS = modified barium swallow, NG = naso-gastric tube, PEG = percutaneous endoscopy gastrostomy, RIG = radiologically inserted gastrostomy, TDEE = total daily energy expenditure.

relief or appropriate therapeutic benefit in the context of an individual patient's expected survival.

Symptom management

Patients with ALS often have multiple uncomfortable symptoms that severely impair quality of life, including pain, fasciculations, sialorrhea, pseudobulbar affect, spasticity, cramps, depression, anxiety, insomnia and fatigue. Several clinical trials have explored treatment options for sialorrhea[42] and pseudobulbar affect.[43] However, management of most ALS symptoms has not been rigorously evaluated. As a consequence, most of the recommendations for symptom management were decided by expert consensus and supported by treatment suggestions made in the ALS and palliative care literature. Cost and access to treatments affected our ordering of the recommendations and were weighted more highly than direct evidence if an evidence-supported treatment was expensive. Our recommendations did not include the option of cannabis to treat specific ALS symptoms, because of lack of evidence in the literature. However, the working group is aware that cannabis is being used to manage several ALS symptoms.

Dysarthria

The ability to communicate thoughts and needs to others is vitally important to individuals. ALS often impairs the ability to communicate verbally because of dysarthria.[2] Multiple available interventions can be initiated to support communication, including low-tech options, such as letter- or picture-boards, and high-tech options, such as speech synthesizers and eye-gaze tracking. As individuals with ALS experience loss of function, some modes of communication may no longer be viable. Providing access to different modes of communication, including social media, can allow independence, participation and better quality of life.[44] Communication devices may also benefit caregivers, as the burden on caregivers was found to be reduced when patients used an eye-tracking assistive device.[45]

Exercise

Research on exercise in ALS has not demonstrated harm and some evidence has suggested that there is a potential benefit for patients in terms of function and quality of life.[46,47] A personalized exercise program, including strength and aerobic training, should be encouraged for patients who are able to participate. A regular stretching and range-of-motion program is recommended for management of spasticity and pain, and prevention of contractures.

Cognition and behaviour

Detectable frontotemporal dysfunction can occur in about 50% of patients with ALS.[3] The frontotemporal dysfunction can present with cognitive impairment or behavioural impairment, which in 20% of patients is severe enough to reach criteria for dementia.[3]

Although there are many tools available to screen for cognitive or behavioural impairment, there is no standard tool to use. At this time, there are no effective drug treatments for cognitive or behavioural impairment in ALS. A multidisciplinary approach can be considered to manage particularly problematic behaviours.

The presence of executive dysfunction or dementia in ALS is associated with poor survival.[48] The presence of cognitive or behavioural impairment should not necessarily preclude implementing the recommendations for noninvasive ventilation or gastrostomy insertion. However, the challenges of intervention compliance with cognitive or behavioural impairment should be discussed with the patient and family before deciding to proceed with an intervention.

Caregivers

Informal caregivers are affected by caring for the person with ALS. Many studies have demonstrated the impact of ALS on caregiver quality of life and the correlates of caregiver burden,[49] but also the value of caregiving.[50] Advanced disability (a low ALSFRS-R score) and cognitive impairment increase caregiver strain.[51] Interventions to mitigate the impact on caregivers have been insufficiently studied to make specific recommendations. People with ALS are aware of and affected by the burden on their caregivers.[52] Health care providers, therefore, need to be attentive to the physical and emotional well-being of the caregivers, and involve them in planning for the impact of ALS on both the patient and themselves.

Palliative care

Expert opinion supports early integration of palliative care for patients with ALS.[8,53] However, palliative and end-of-life care are sensitive topics and variably received by patients.[54] Therefore, early introduction of palliative care must be initiated with consideration of the patient's evolving needs and expectations.[55] At the very least, experts have advocated that it is appropriate to initiate discussions about palliative care if the topic is raised by patients or caregivers, and if there are indications of advanced disease or disability.[53]

Advance care planning helps establish care preferences before the disease is advanced and communication is impaired. There is evidence to suggest that these discussions are best initiated when the patient has accepted that death will eventually occur.[56] However, there is a general reluctance among clinicians to broach the topic, as it may be perceived to indicate the imminence of death.[57] Standardized tools for advance care planning are thought to be useful for stimulating these discussions, rather than for generating specifics of an advanced directive.[56,58,59] Thus, discussions may be integrated into routine ALS follow-up to invite open conversation, and should take into account the patient's readiness and style of decision-making.

Medical assistance in dying (MAiD) was legalized in Canada in 2016. We have made specific recommendations as to how requests for MAiD should be addressed, both to support patient choice at end of life, and to provide guidance in this new practice, which may be a source of clinical uncertainty and discomfort to some practitioners.

We also present recommendations on the potential option of organ donation at the time of death and the process that should be followed for donation.

Methods

The concept for this guideline was concurrently fostered by ALS Canada and Canadian ALS clinicians within the Canadian ALS Research Network (CALS; now merged with ALS Canada). The guideline was developed using the Guideline International Network–McMaster Guideline Development Checklist,[60] for guidance on all aspects of guideline development, including planning, formulation of recommendations, implementation and evaluation. A complete description of the guideline methodology is available in the full guideline (www.als.ca/bpr-appendix).

Guideline panel composition

A working group of 13 Canadian ALS clinicians (the authors), chaired by C.S., led the development of this guideline. Neurologists and physiatrists who were active in the Canadian ALS Research Network and could represent the geographic diversity of Canada were invited to participate in the working group. Clinicians with previous experience with guideline development were particularly encouraged to participate. The working group also included a gastroenterologist (D.L.) and a respirologist (A.T.) with ALS expertise. Early in the guideline development process, 2 other Canadian ALS clinicians were involved, but they removed themselves from the project because of the time commitments required.

Selection of key questions

In 2014, we selected clinical questions of interest for the guideline by surveying clinicians and staff at all 19 Canadian multidisciplinary ALS clinics via an emailed survey. The survey included a list of the key questions used to develop the American Academy of Neurology (AAN) Practice Parameters[6,7] and European Network for the Cure of ALS guideline,[8] as well as additional questions that members of the working group had derived based on their own clinical experience. We asked survey participants to rate the importance of these questions for inclusion in the guideline.

Questions included in the literature review were those questions rated highly by participants on the survey; the working group further refined these questions. The selected clinical questions were grouped by topic including communication of diagnosis, disease-modifying therapy, multidisciplinary care, respiratory management, nutrition management, symptom management, cognitive impairment, risk of venous thromboembolism (VTE), exercise, palliative care and caregiver support.

Literature search

In 2015, the Centre for Effective Practice, a consulting firm with substantial guideline development experience, conducted literature searches for the selected clinical questions using MEDLINE, Embase and CINAHL databases. The centre developed the search terms for each clinical question through review of the search terms

that had been used for the AAN guideline[6,7] and in consultation with the working group. The centre performed a second literature search in December 2018 to search for papers published after the initial search in 2015. For clinical questions addressed in the AAN guideline, literature searches were restricted to publications dated from 2007 to December 2018. For new clinical questions that had not been addressed in the AAN guideline or European Network for the Cure of ALS guideline, literature searches were restricted to publications dated from 1998 to December 2018. The search strategies are available in Appendix A of the full guideline (www.als.ca/bpr-appendix).

Quality assessment

The working group was divided into topic groups, with 2 members per group. For questions grouped under a major topic, 2 members of each topic group screened the retrieved abstracts separately based on the inclusion criteria and relevance to the clinical question. Inclusion criteria included published ALS guidelines, ventilation guidelines, RCTs, case–control studies, cohort studies, systematic reviews and meta-analyses. Publications had to be published in English or French and available in full text. Single-case reports, review articles, publications available only in abstract or proceeding forums, and thesis data not published elsewhere were excluded. Publications felt by at least 1 of the abstract reviewers to meet the inclusion criteria were reviewed in full by the topic group for inclusion criteria and data quality and assigned a class of evidence based on criteria modified from the AAN Clinical Practice Guideline Process Manual (2011 Edition) to rate therapeutic studies (Box 1). The evidence tables are available in Appendix B of the full guideline (www.als.ca/bpr-appendix).

Development of recommendations

The working group met regularly at face-to-face meetings at least annually in Toronto, and through regular group teleconferences to discuss the specifics of guideline statements. Each topic group drafted preliminary guideline statements for each clinical question after considering previously published guideline statements[6–8] and updated evidence.

The working group reviewed these draft statements and refined them on an iterative basis, ideally until consensus was obtained. If consensus could not be reached among the working group, we agreed that a decision would be made based on a two-thirds majority (66%) vote. However, there was consensus on all statements and so no vote was held.

We assigned each statement a level of evidence, which included the option of expert consensus (Box 2). The working group felt strongly that in the absence of published evidence, best practice recommendations based on expert consensus should be included, rather than no recommendation provided. Given that there is limited evidence from clinical trials to direct care in ALS, the working group members thought it important that the recommendations be a practical guide to the care of patients with ALS, rather than simply a review of the evidence. We made expert consensus statements based on nonclinical trial literature in ALS, evidence in other diseases or current Canadian ALS clinical practice. We discussed the order of the statements in the recommendations table at length to reflect their clinical

Box 1: Criteria for rating therapeutic studies*[61]

Class	Description
I	• Randomized controlled clinical trial (RCT) in a representative population • Masked or objective outcome assessment • Relevant baseline characteristics are presented and substantially equivalent between treatment groups, or there is appropriate statistical adjustment for differences • Also required: a. Concealed allocation b. Primary outcome(s) clearly defined c. Exclusion and inclusion criteria clearly defined d. Adequate accounting for dropouts (with at least 80% of enrolled participants completing the study) and crossovers with numbers sufficiently low to have minimal potential for bias
II	• Cohort study meeting criteria a–d (see class I) or an RCT that lacks 1 or 2 criteria b–d (see class I) • All relevant baseline characteristics are presented and substantially equivalent among treatment groups, or there is appropriate statistical adjustment for differences • Masked or objective outcome assessment
III	• Controlled studies (including well-defined natural history controls or patients serving as their own controls) • A description of major confounding differences between treatment groups that could affect outcome • Outcome assessment masked, objective or performed by someone who is not a member of the treatment team
IV	• Did not include patients with the disease • Did not include patients receiving different interventions • Undefined or unaccepted interventions or outcome measures • No measures of effectiveness or statistical precision presented or calculable

*Modified with permission from AAN (American Academy of Neurology). 2011. Clinical practice guideline process manual, 2011 Ed. St. Paul (MN): The American Academy of Neurology; 2011. Available online at www.aan.com/siteassets/home-page/policy-and-guidelines/guidelines/about-guidelines/11guidelinedevmanual_v408_web.pdf. Accessed 2020 Sept. 11.

importance and the order in which a practitioner would consider interventions when caring for patients.

After the statements we developed for the respiratory questions had obtained consensus support from our working group, the Canadian Thoracic Society (CTS) published a guideline on the respiratory care of patients with ALS.[35] The working group decided it was important for our recommendations to be consistent with this guideline. To accomplish this, we compared each of the recommendations in the CTS guideline with our draft statements. Our working group accepted most of the CTS recommendations without changes, apart from slight wording alterations for consistency. We asked the CTS ALS committee to review our suggested statements, including those expert consensus statements where questions deemed important in our survey had not been addressed by the CTS guideline; their feedback led to some minor changes in our wording.

Review process

We developed an executive summary of the guideline statements and the working group reviewed it. When the working group was satisfied with the recommendation statements, including the wording, order and evidence ranking, we emailed this executive draft summary to members of the Canadian ALS Research Network (which includes all multidisciplinary ALS clinics in Canada) and topic experts external to the working group (i.e., with expertise in gastroenterology, respirology, palliative care and physiatry) for open-ended feedback. We asked the ALS clinics to share the executive draft summary with their allied health staff and request additional open-ended feedback from them as well. The working group discussed each comment received to determine whether changes were required to the recommendation statements and if so, how the statements should be revised.

Using the revised executive draft summary, a second round of external review followed, in which we asked key stakeholders within each provincial ALS society to participate. We emailed the revised executive draft summary to each of the provincial ALS societies along with an attached survey with open-ended questions. We asked each society to solicit feedback from its members, including 1 patient living with ALS in its province. All comments received were individually considered by the working group and changes were implemented at its discretion through a robust discussion about the feedback. The changes made according to the feedback received involved wording changes for the most part. We made no substantial changes.

We prepared a complete version of the guideline and all working group members reviewed it for final approval.

Management of competing interests

All members of the working group performed their tasks voluntarily and did not receive honoraria for their involvement. ALS Canada and the Canadian ALS Research Network funded the development of the guideline, including travel for face-to-face meetings and preparation of the manuscript for publication.

ALS Canada is a grassroots donor–funded organization and part of the funding for this project came from donations during the Ice Bucket Challenge. ALS Canada assisted with logistic support but did not contribute to the content of the recommendations. The Canadian ALS Research Network was a nonprofit organization of ALS clinicians and researchers formed to increase clinical ALS research in Canada and funded by stipends given by biotechnology companies to review clinical trial proposals for Canadian ALS clinics (it has subsequently merged with ALS Canada). Although members of CALS participated in the development of the guideline, CALS had no role in approving guideline recommendations.

We discussed competing interest management during the planning phase of the guideline; competing interests were defined as a financial relationship with a company. At that time, there was only 1 drug approved by Health Canada for the treatment of ALS: riluzole. None of the working group members had conflicts related to the drug riluzole, which has been available for more than 20 years. We solicited other potential conflicts of interest from the working group at the beginning of this project, and no conflicts were present.

In 2017, during the guideline development process, the US Food and Drug Administration approved edaravone to treat ALS. Its manufacturer, Mitsubishi Tanabe Pharma, sponsored scientific advisory committees regarding the use of edaravone in patients with ALS in Canada. Health Canada approved the drug in October 2018 and it became commercially available in Canada in November 2019. Some working group members sat on the Mitsubishi Tanabe Pharma scientific advisory committees for edaravone (C.S., M.C., A.I., W.J., C.O., K.S., L Z.), which they disclosed to the working group. All members of the working group discussed at length the statements in this guideline regarding edaravone. During review of the draft guideline, feedback from members of the Canadian ALS Research Network and key stakeholders regarding the edaravone statements was deliberated by working group members who did not have conflicts of interest with

Box 2: Criteria for levels of evidence in guideline recommendations*

Level	Type of evidence
A	At least 2 consistent class I studies
B	At least 1 class I study or 2 consistent class II studies
C	At least 1 class II study or 2 consistent class III studies
Expert consensus	Consensus among Canadian amyotrophic lateral sclerosis clinical experts where evidence meeting criteria for Level A through Level C is lacking

*See Box 1 for definitions of study classes.

Mitsubishi Tanabe Pharma, defined as having received any honoraria from the company. Final decisions regarding the edaravone statements were made by working group members without potential conflicts. Other than edaravone, there are no other potential conflicts with the statements in this guideline.

Implementation

These best practice recommendations are a resource to guide the care of patients with ALS across Canada. The guideline will be made publicly accessible through the ALS Canada website (www.als.ca). ALS Canada will also support the dissemination of the guideline among members of the ALS community, including clinicians, allied health professionals, researchers, patients and their caregivers, through distribution to provincial ALS societies, the Canadian ALS Research Network and attendees of the annual ALS Canada Research Forum. Directors of ALS clinics and ALS clinicians will be encouraged to present the guideline to their clinic teams and relevant stakeholders within their communities. ALS Canada will assist the guideline authors with producing 1-page summary documents of some key clinical areas of the guideline for dissemination to stakeholders.

The working group would support a health impact project assessing patient survival, patient-perceived quality of life and other specific outcomes after the implementation of the guideline compared with before its publication.

The working group expects that evidence to support ALS management will evolve over time and anticipates that the recommendations will have to be revised approximately every 5 years.

Other guidelines

Several ALS clinical practice guidelines have been published in countries other than Canada, including the AAN Practice Parameters (2009),[6,7] the European Federation of Neurological Societies guideline on the clinical management of amyotrophic lateral sclerosis (2012),[8] and the motor neurone disease assessment and management guideline developed by England's National Institute for Health and Care Excellence (2016).[9]

One of the goals for the Canadian guideline was to update the existing North American guidelines, specifically the 2009 AAN recommendations.[6,7] As described in the Methods section, literature searches for this Canadian guideline on clinical questions addressed in the 2009 AAN recommendations were restricted to new evidence only (i.e., after 2007), and all evidence was classified using AAN criteria.

In the AAN guideline, recommendations had to be supported by evidence; thus, no guidance was provided in the absence of evidence (e.g., using expert consensus). In contrast, the European Federation of Neurological Societies guideline provided consensus recommendations in the absence of evidence. We also resolved to offer guidance based on expert consensus in the absence of evidence.

Another goal for the Canadian guideline was to address ALS issues not covered in other guidelines. The European Federation of Neurological Societies guideline did not address several issues for patients with ALS that are important in Canada, such as medication alignment and MAiD. Similarly, guidance on some ALS issues, such as disease-modifying treatments and exercise, was not provided in the National Institute for Health and Care Excellence guideline.

As discussed earlier, the CTS published a guideline on home mechanical ventilation for patients with ALS in early 2019.[35] In collaboration with the CTS, we ensured that our recommendations for respiratory management were consistent with recommendations in the CTS guideline, but added some consensus recommendations (e.g., on airway clearance).

Gaps in knowledge

This guideline confirms that high-quality evidence is lacking for most topics in ALS management; most recommendations provided are based on expert consensus among the working group. The need for further research in ALS management remains, and more evidence-based recommendations will be critical for improving the standards of patient care in Canada and internationally. This guideline can help point the clinical research community, nationally and internationally, to areas of research priorities on disease management.

We acknowledge that we were not able to cover all topics of ALS management in this guideline and that subsequent revisions could include topics not currently covered.

Conclusion

We hope that the development of the first Canadian ALS guideline is an important step forward for improving the lives of patients with ALS living in Canada. The predominance of expert consensus statements relative to evidence-based statements in this guideline not only highlights the need for more research in ALS management but also emphasizes the challenges ALS clinicians face in managing patients with a severe disabling disease. This guideline will enable ALS clinics across Canada to meet a common national standard, and to adapt as this standard continues to evolve over time. In doing so, ALS clinicians can offer the best possible care to their patients and help them to navigate this exceedingly complex and devastating disease.

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Competing interests: Christen Shoesmith, Aaron Izenberg, Wendy Johnston, Colleen O'Connell, Kerri Schellenberg and Lorne Zinman were members of a scientific advisory committee for Radicava (edaravone; Mitsubishi Tanabe Pharma Canada). Christen Shoesmith reports being a site principal investigator for several multicentre amyotrophic lateral sclerosis (ALS) clinical trials. In the last 36 months, Dr. Shoesmith has participated in clinical trials sponsored by Biogen, Cytokinetics, ALS Pharma and Orphazyme. Marvin Chum reports receiving a grant from Bernice Ramsay ALS Clinical Research Fellowship, outside the submitted work. Aaron Izenberg reports receiving personal fees from Biogen, Roche, Alnylam, Genzyme, Takeda and Mitsubishi Tanabe Pharma, outside the submitted work. No other competing interests were declared.

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Patient Education Office

Should I have a RIG? (feeding tube to my stomach)

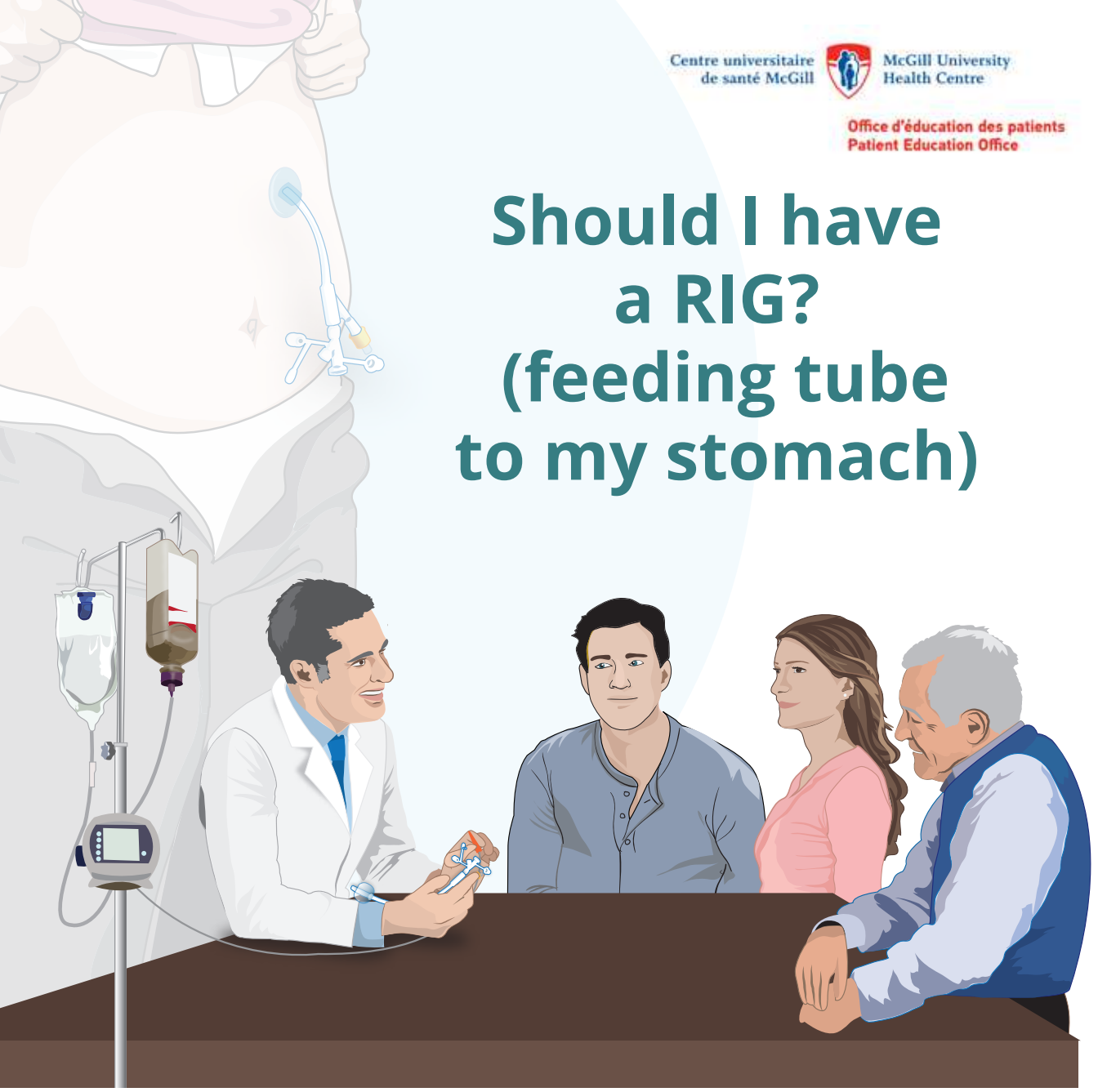
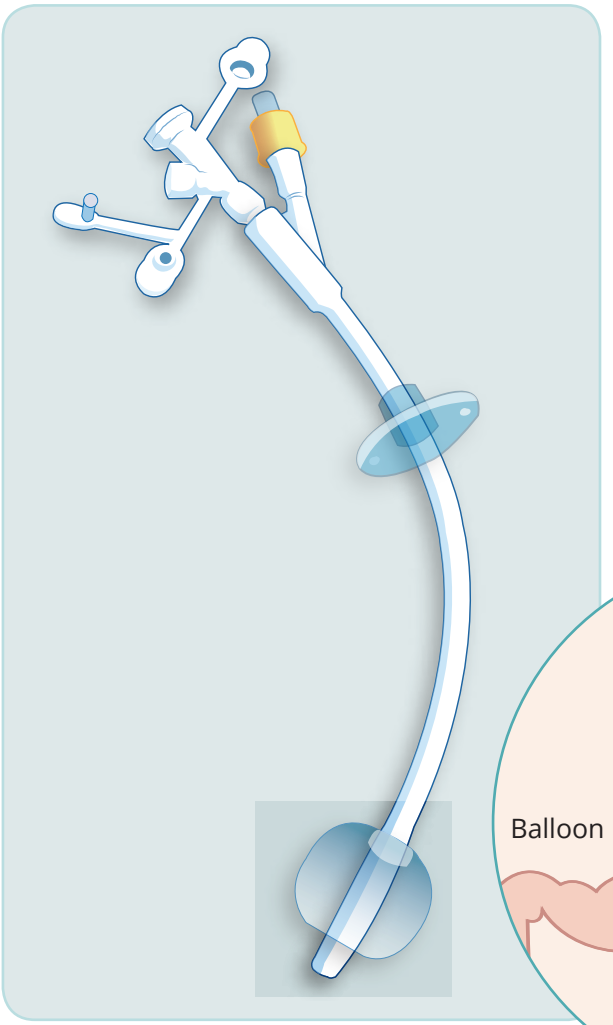


Table of Contents

Introduction

This booklet will cover what you need to know about the RIG procedure, how it works, its limits, benefits, as well as other options. Your treatment team will review this with you closely. They will help you decide the best treatment option for you.

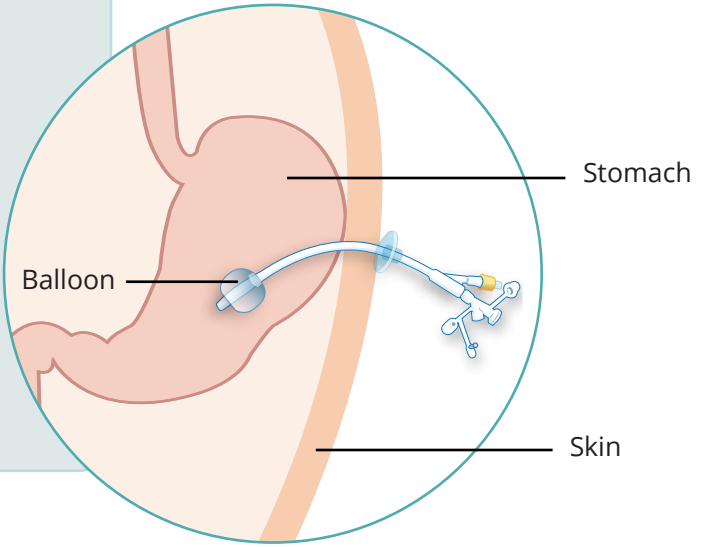


What is a RIG?

RIG is short for **Radiologically Inserted Gastrostomy**. Sometimes it is called PEG or gastrostomy tube.

It is a thin tube that goes through your skin into your stomach.

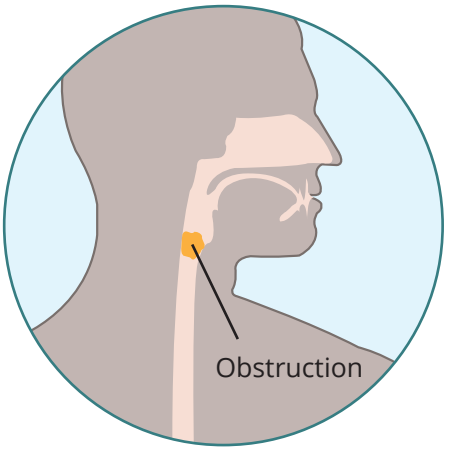
It is a way of sending food, fluid or medicine into your stomach.



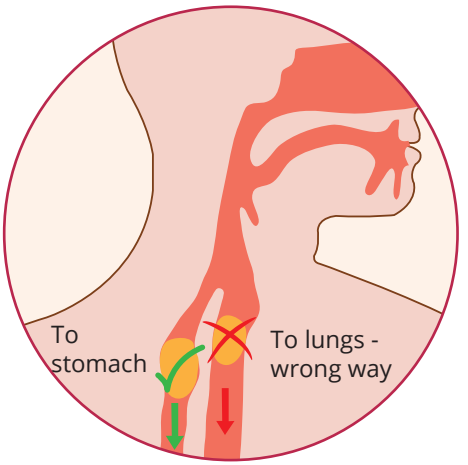
Why do I need it?

A RIG can help:

If you have trouble swallowing



If you have a blockage at the back of your throat, in your mouth or in your esophagus, which prevents food from getting into your stomach



If there is a risk of food and drink going the wrong way into your lungs.

If you have a naso-gastric tube, this tube can only stay for a short time.

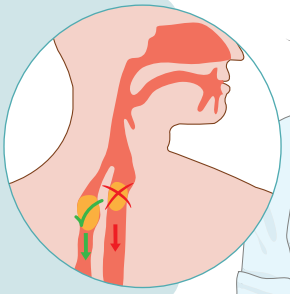
What do I need to know before I decide?

Before you decide if you want to have the tube put in, a doctor will tell you about the procedure and talk to you about the risks and benefits. Please do not be afraid to ask questions. This is your chance to make sure you understand and agree with what will happen.

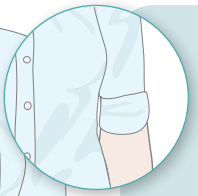
If you decide to go ahead, you will be given a date and time for the tube to be put in. If you are going home after the procedure, you will need to arrange for someone to drive you.

What are the benefits?

Getting a RIG can help you:

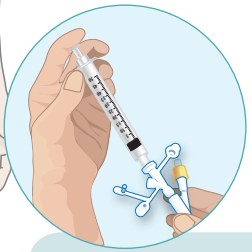


- Lower the risk of food and drink 'going the wrong way' into your lungs

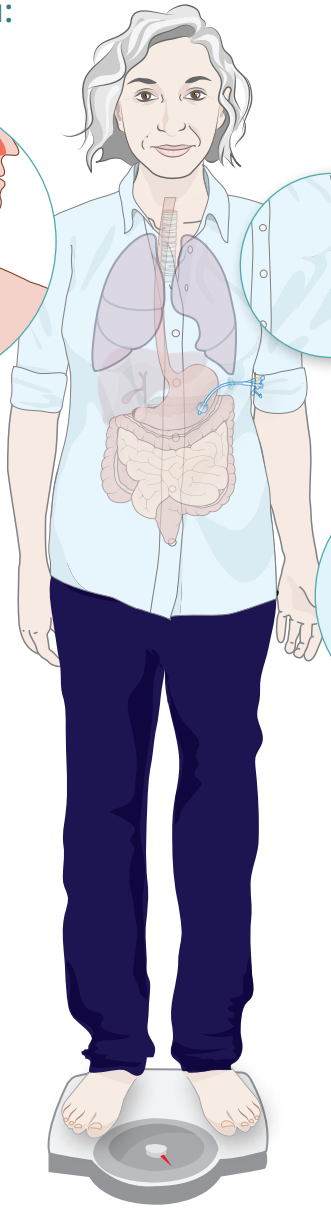


- RIG tubes can be tucked away under your clothes - no one will know you have one unless you choose to tell them

- Keep you well hydrated when it is unsafe for you to drink



- Take your medications (they are given through your RIG tube). Consult your pharmacist about which medications can be given through your tube



- Get the calories and nutrients that you need

- Safer and more comfortable than a tube in your nose.

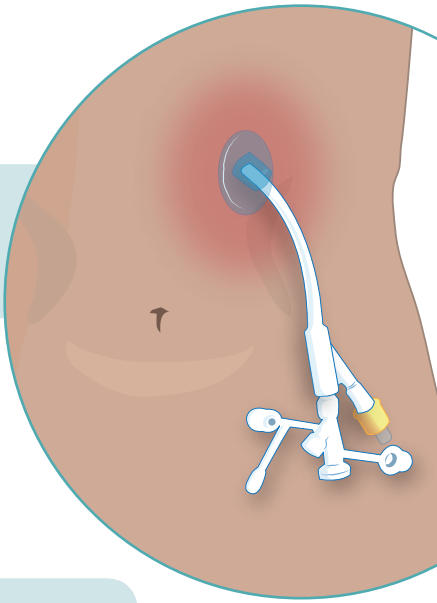
- Keep your weight stable

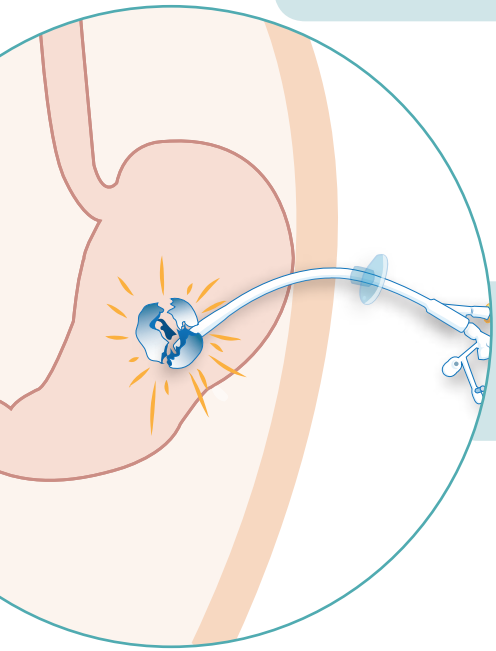
What are the risks and problems?

Although the procedure is quite safe and major problems are rare, there are risks involved. If you have a major problem you need to talk to your doctor or nurse.

Minor problems

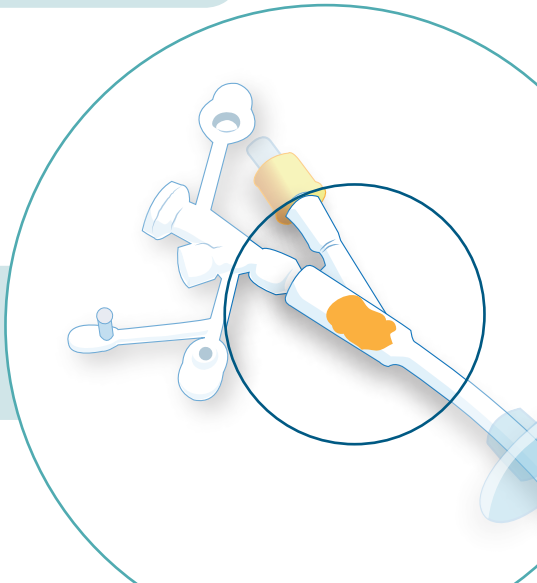
Leakage or infection around the tube. This can lead to red and sore skin.





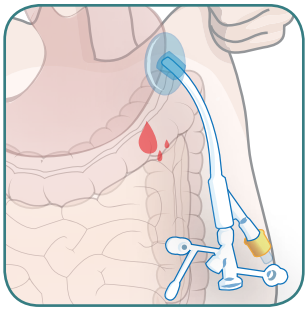
Risk that the balloon holding the tube in place can deflate and the tube may fall out.

The tube may become blocked.

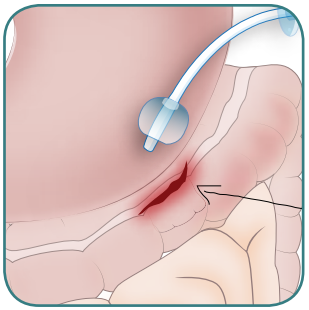


Larger problems

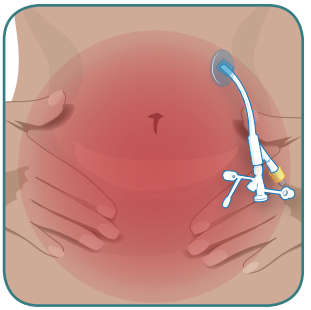
Some people (6 out of 100) develop one of these problems.



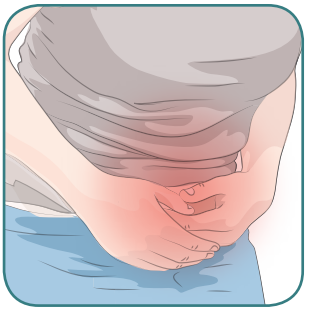
Bleeding



A hole in your intestines



Swelling or infection in your abdomen



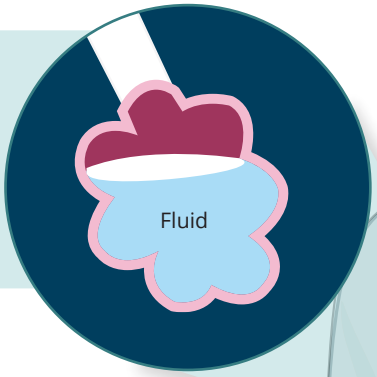
Pain

Less than 1 in 100 people die from having a RIG placed. If the tube cannot be placed safely in your stomach, a member of your healthcare team will talk about other options with you.

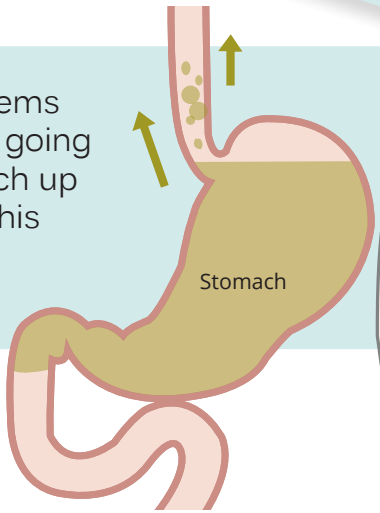
It is important that you are aware of and understand these risks and benefits before you agree to have a RIG tube put in. Your healthcare team will talk about this with you.

What are the limits?

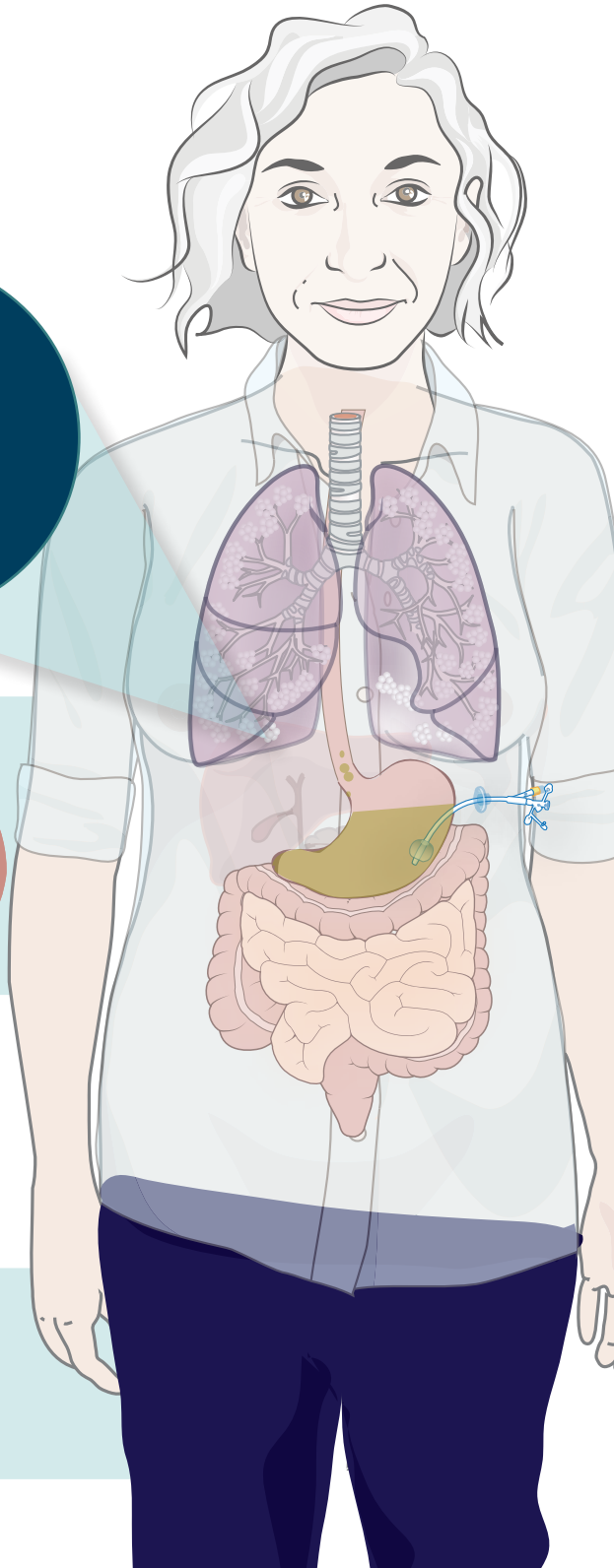
You may still swallow some fluids into your lungs such as your saliva. This can lead to pneumonia.



If you have problems with food or acid going from your stomach up into your throat, this will not be fixed by having a RIG.

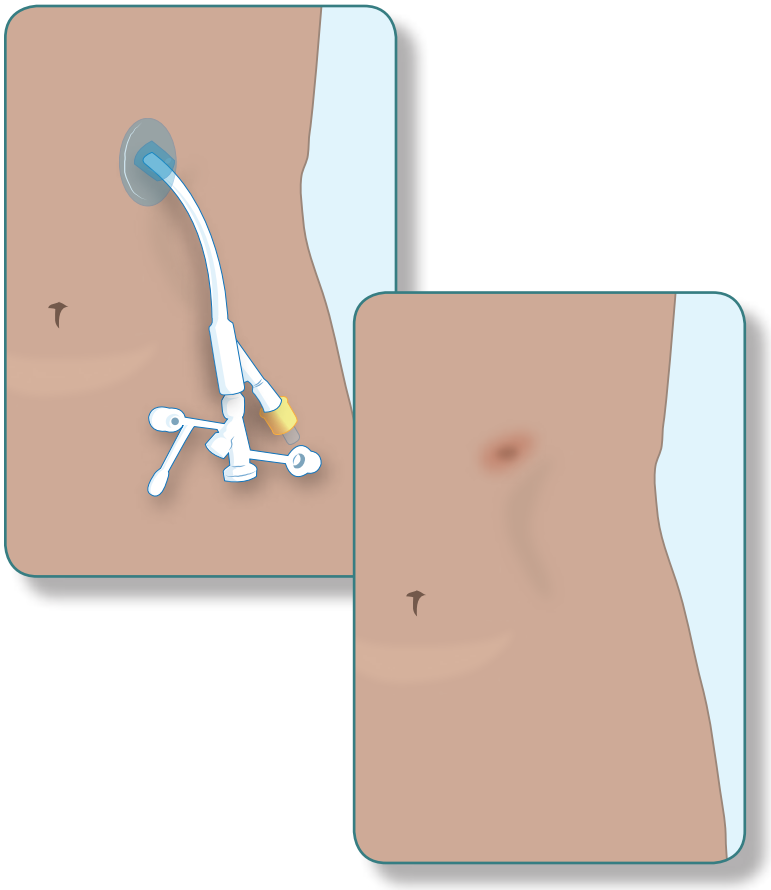


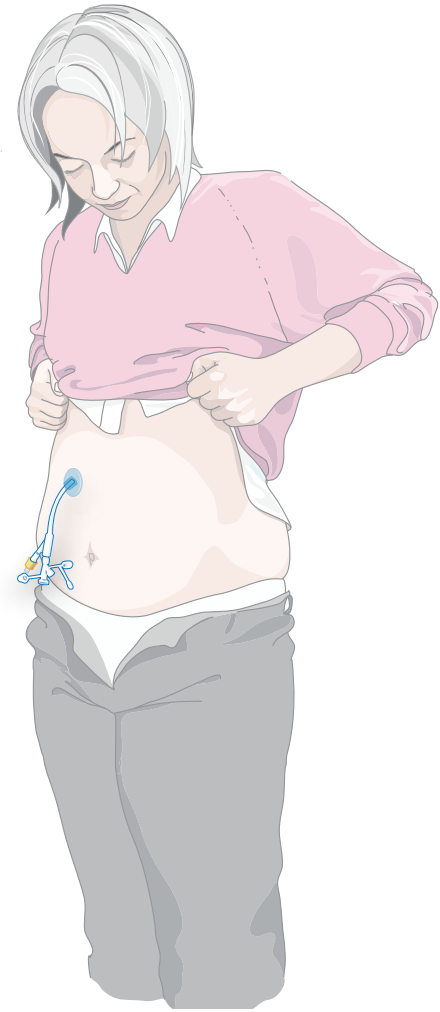
RIG feeding will not change the outcome of your disease or condition.



How long will I have it?

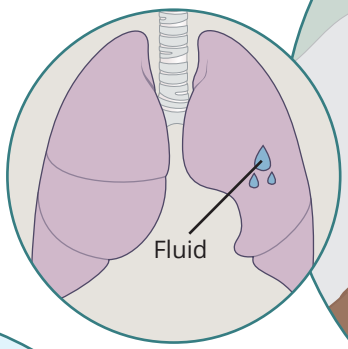
Sometimes a RIG can be removed if your ability to swallow returns. Sometimes the RIG will stay in for good.

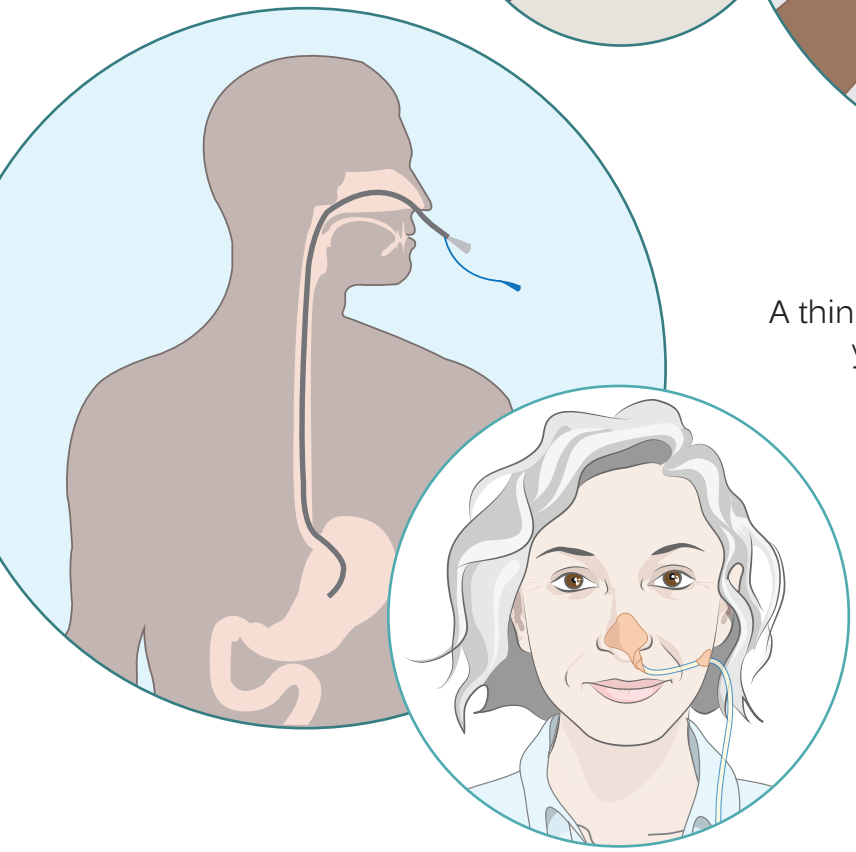




What are my other options?

You can continue eating by mouth, with the risk of food and fluids going into your lungs. However, when liquids or food go into your lungs it may cause you to get pneumonia and may require antibiotics.



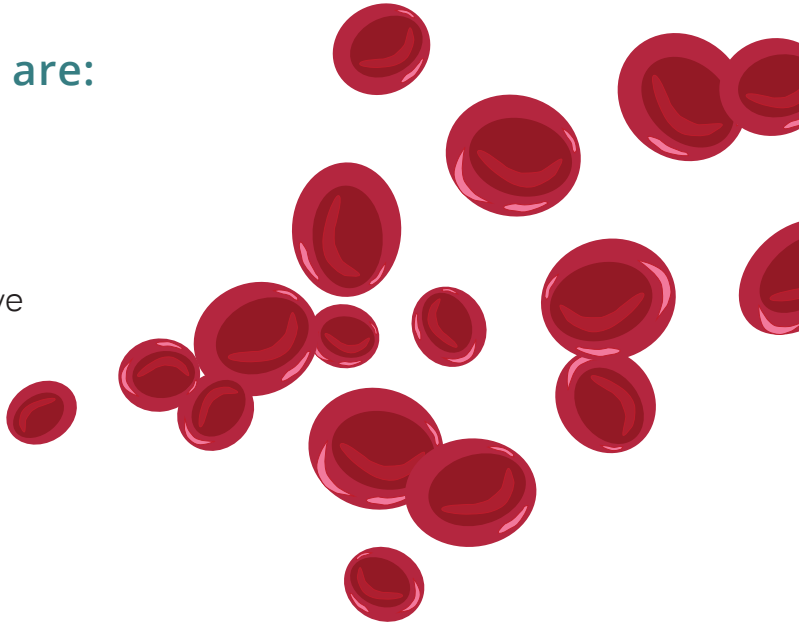


A thin tube that goes through your nose and into your stomach can be used. This is called a naso-gastric tube. **This can only be used for a short time.**

Alerting my Healthcare Team

Tell your team if you are:

- Diabetic
- Pregnant
- Allergic to any medications
- Have had any reaction to dye used in X-ray
- Taking any blood thinners



Have a list of all medications you are taking

This should be reviewed in case any need to be stopped before the procedure. For example, blood thinners need to be stopped a few days before the procedure.

You can ask your pharmacist to print you a list of any medications you are taking.

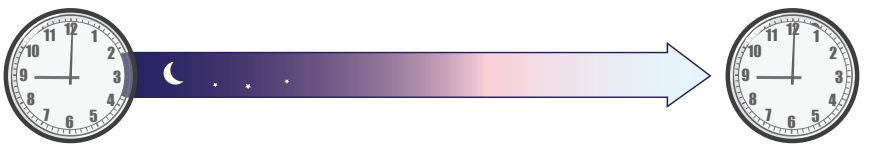
The RIG Procedure

How to prepare:

- Bring a list of medications you are taking
- On the day of the procedure take the medication your doctor approved with a bit of water.

- Do not eat or drink for **12 hours** before the procedure
- Stop tube-feeding **12 hours** before the procedure
- Stop blood thinners as instructed by your healthcare team

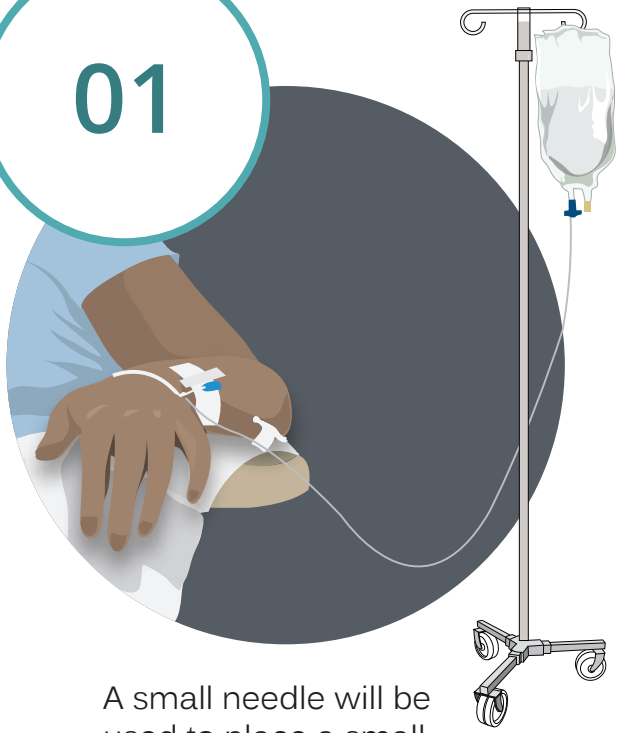
Stop blood thinners



12 hours before procedure

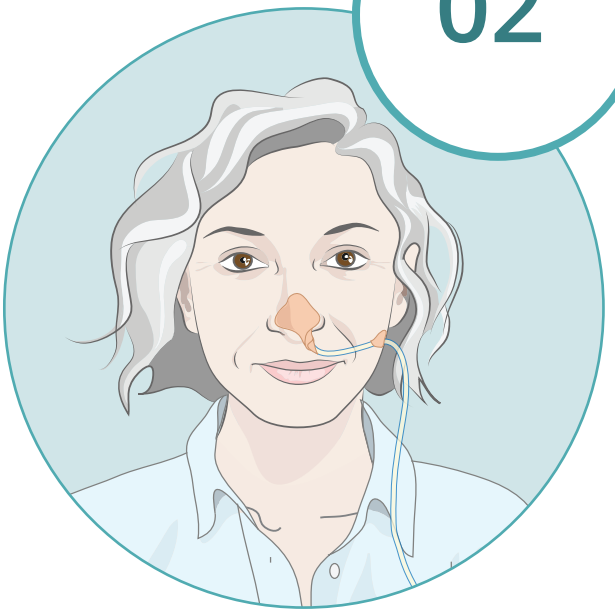
What will happen?

01



A small needle will be used to place a small tube in your vein for medicine and fluid.

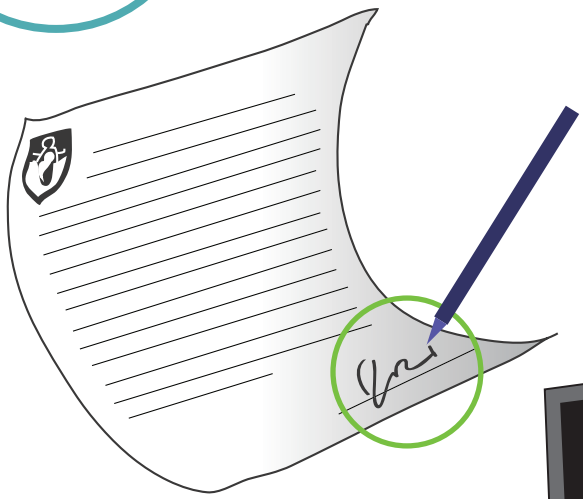
02

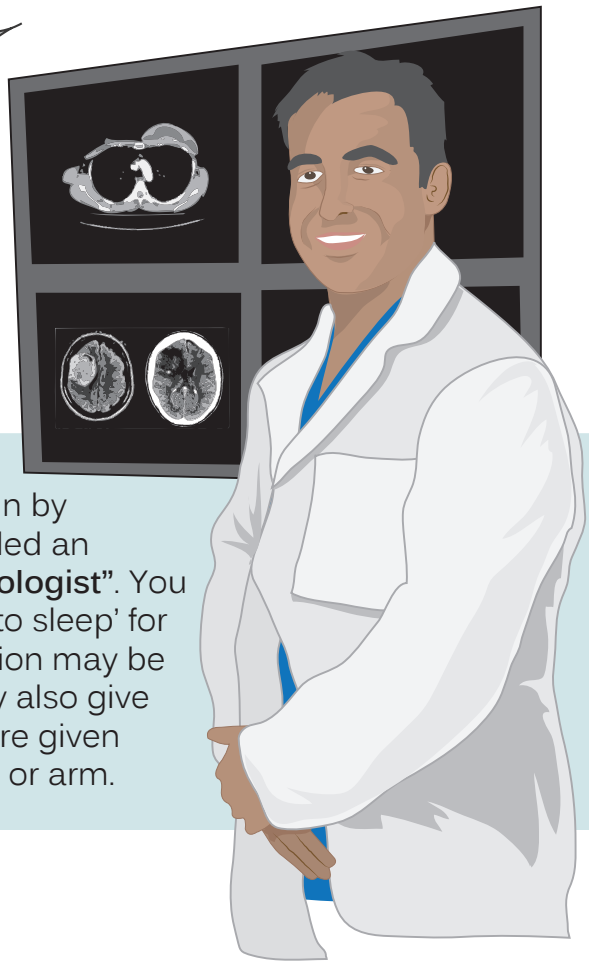


A long thin tube will be placed through your nose into your stomach.

03

You will go to the X-ray department. Once in the X-ray department you may be asked again if you fully understand the procedure. You will be asked to sign a consent form.

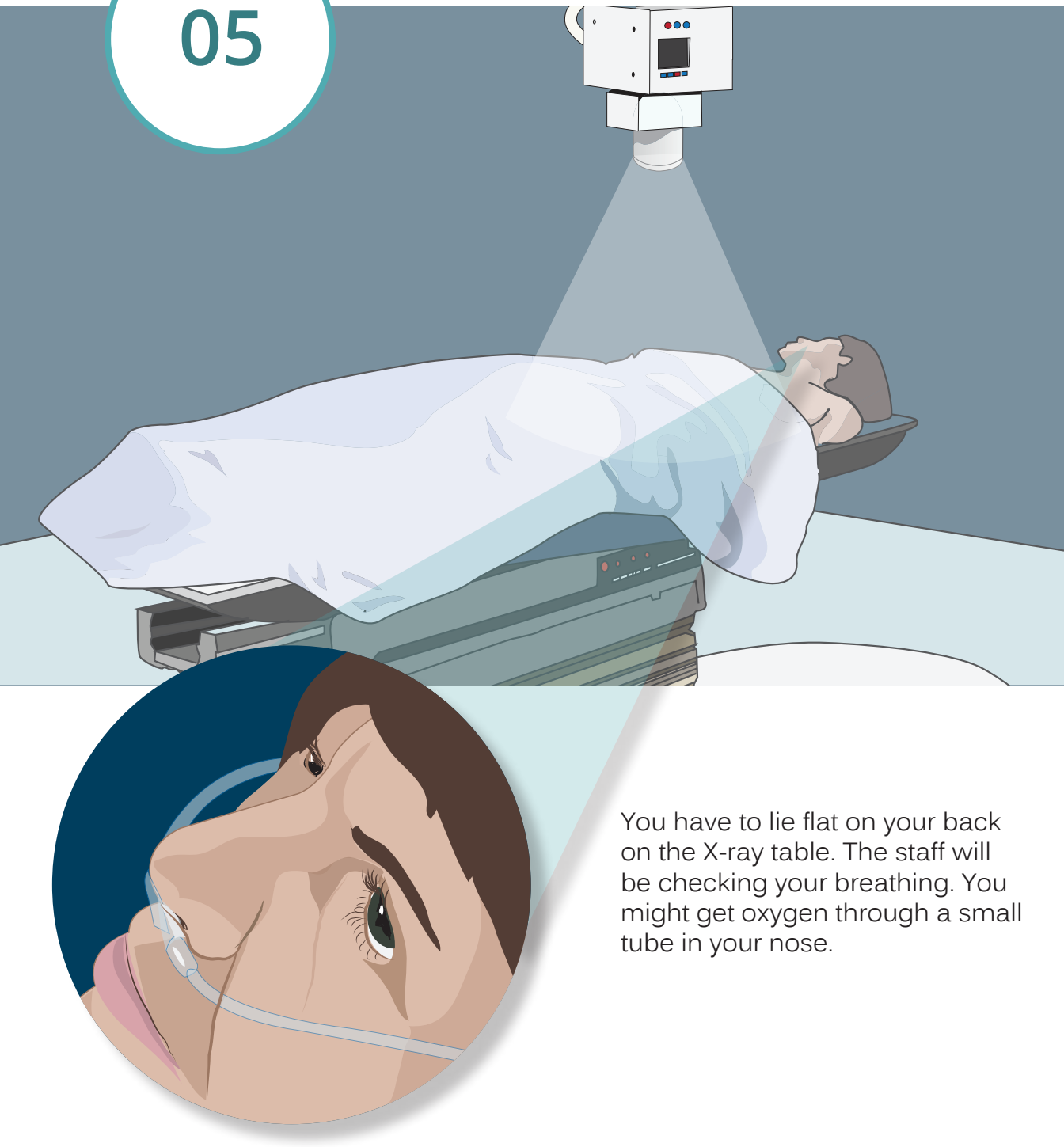




04

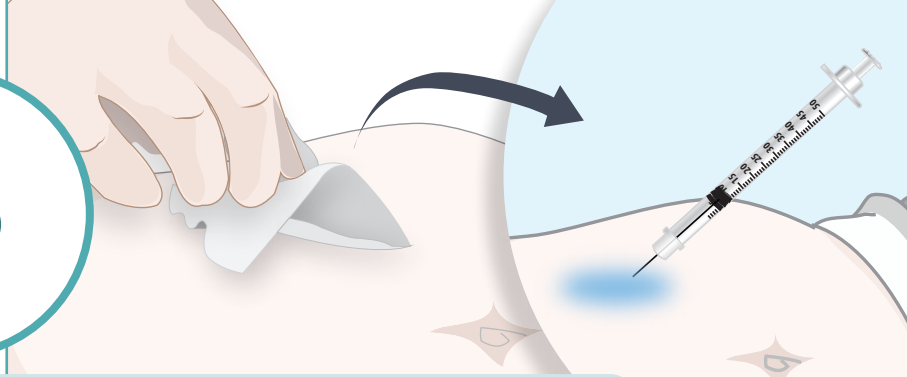
The RIG will be put in by a special doctor called an **“Interventional Radiologist”**. You do not need to be ‘put to sleep’ for this procedure. A medication may be used to help you relax and they may also give you some pain medication. These are given through the small tube in your hand or arm.

05



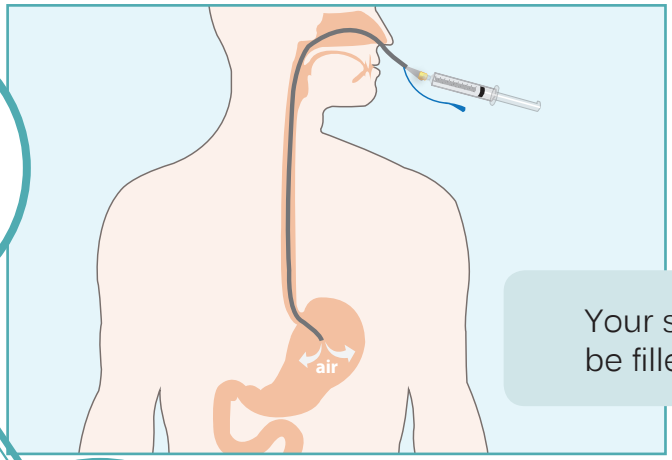
You have to lie flat on your back on the X-ray table. The staff will be checking your breathing. You might get oxygen through a small tube in your nose.

06



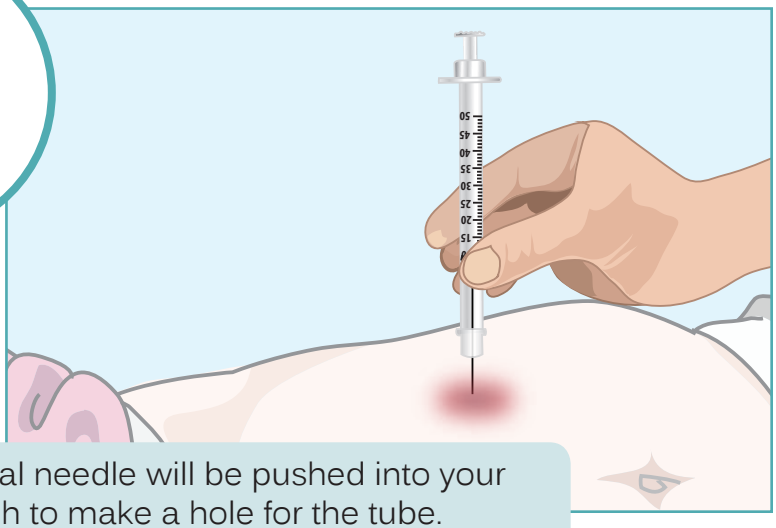
Your doctor will clean your skin, then freeze it with an injection.

07

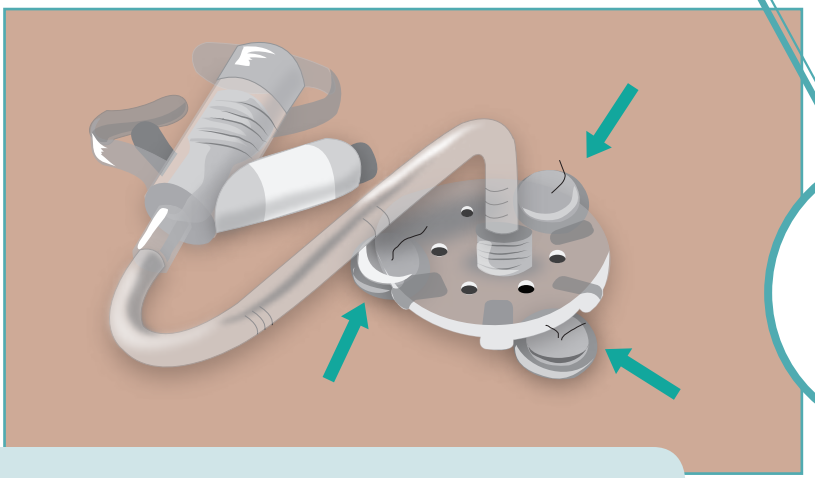


Your stomach will be filled with air.

08

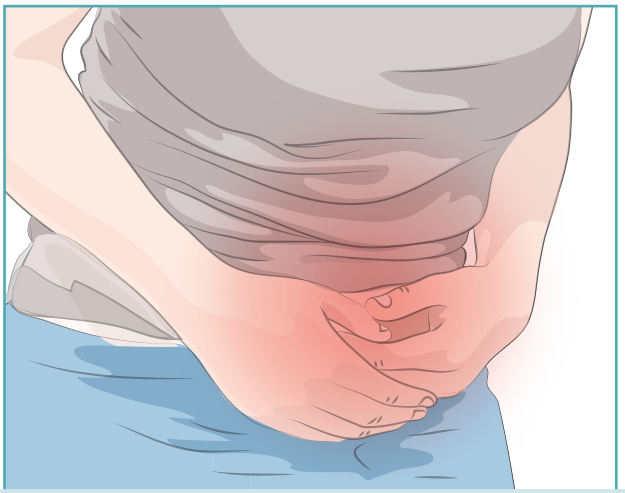


A special needle will be pushed into your stomach to make a hole for the tube.



09

2 or 3 anchors are stitched into place.

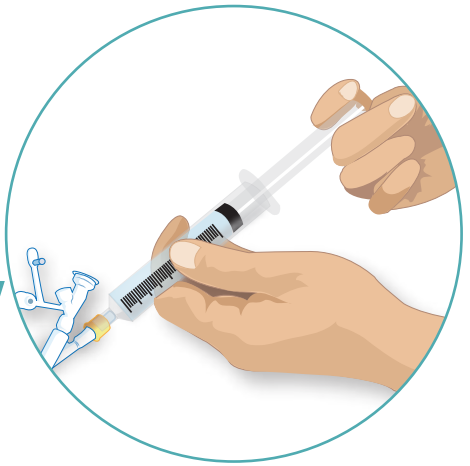


You might feel a pressure or pain, which will improve over time.

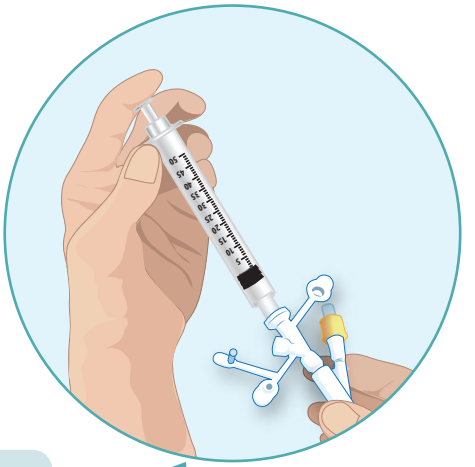
When the tube is first placed you may feel some mild pain around the area. This gets better with time and you can be given pain medication until it gets better.

The following days

Over the next few days you and your family will be shown how to care for your RIG tube by your healthcare team. The main things you will need to be shown are:

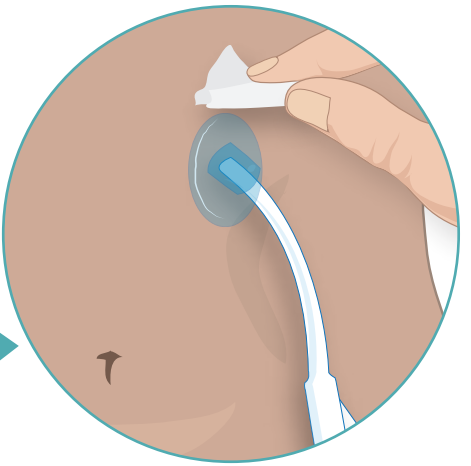


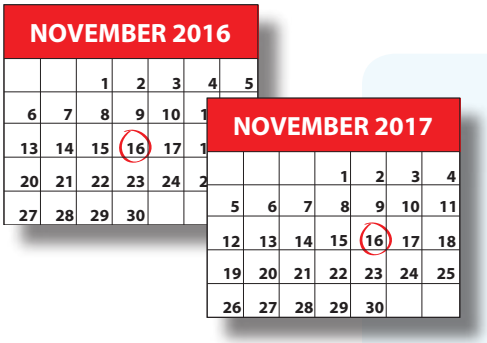
How to change the water in the balloon on your tube.



How to put liquids and medications through your tube.

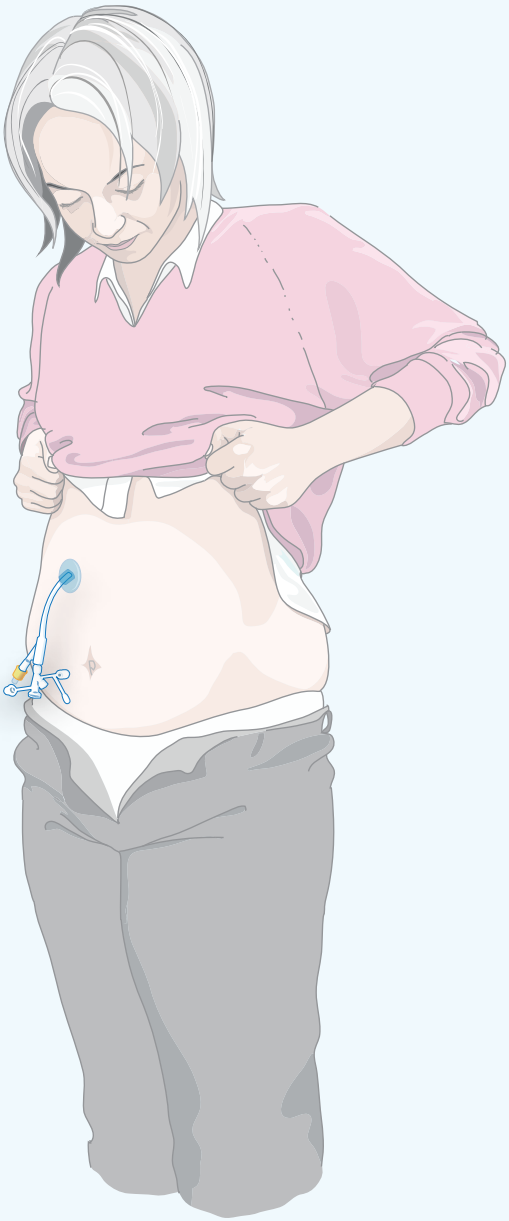
How to keep the skin around your tube clean.





The tube will need to be changed 6 months to 1 year after it is put in.

If you are going home after the procedure, your dietician will contact you to go over the home feeding guide.



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IMPORTANT: PLEASE READ

Information provided by this booklet is for educational purposes. It is not intended to replace the advice or instruction of a professional healthcare practitioner, or to substitute medical care. Contact a qualified healthcare practitioner if you have any questions concerning your care.

This pamphlet has been inspired by “Having a RIG tube inserted: Information for patients and carers”, by the Queen Elizabeth Hospital Birmingham, NHS Foundation Trust

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This material is also available through the MUHC Patient Education Office website www.muhcpatienteducation.ca

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Montreal Neurological Hospital
Room 354
Telephone: 514-398-5358

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La gastrostomie percutanée

installée en radiologie

VOTRE GUIDE D'ACCOMPAGNEMENT

CHUQ
CENTRE HOSPITALIER UNIVERSITAIRE DE QUÉBEC
L'HOTEL-DIEU DE QUEBEC

LA GASTROSTOMIE PERCUTANÉE INSTALLÉE EN RADIOLOGIE :
VOTRE GUIDE D'ACCOMPAGNEMENT

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CHUQ L'Hôtel-Dieu de Québec, mars 2006

Vous aurez bientôt une gastrostomie percutanée et il est normal que vous ayez des questions à ce sujet.

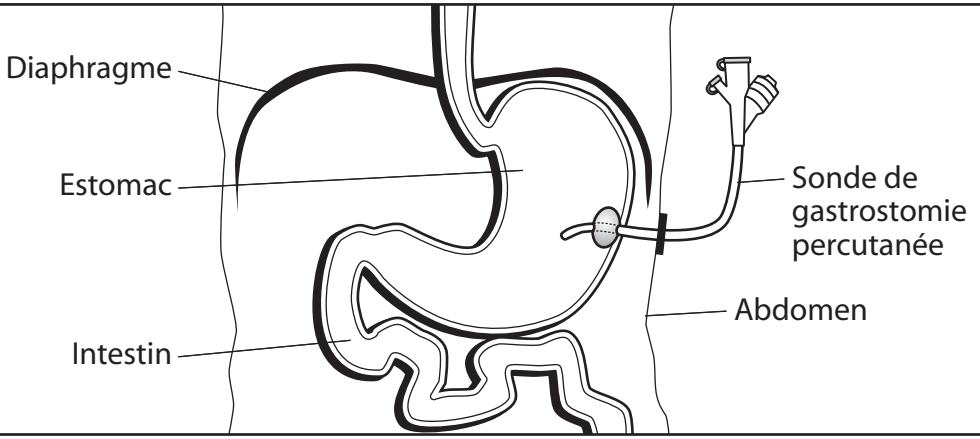
Ce guide répondra à plusieurs de vos interrogations. Il vous aidera à mieux vous préparer à cette intervention et à votre retour à la maison.

Nous vous invitons à le lire attentivement et à le consulter régulièrement.

QU'EST-CE QU'UNE GASTROSTOMIE PERCUTANÉE ?

La gastrostomie percutanée consiste à introduire un tube directement dans votre estomac à travers une petite incision de la peau.

Cette intervention est faite par un **radiologiste** dans une salle de radiologie.



QUE DEVEZ-VOUS FAIRE POUR VOUS PRÉPARER À L'INTERVENTION ?

La veille de l'intervention :

- Prévoir la présence d'un parent ou d'un ami le jour de l'intervention et les jours suivants si nécessaire, le temps de retrouver vos forces;
- À partir de minuit, arrêter de manger, boire ou recevoir une alimentation par sonde nasogastrique.

Le matin de l'intervention :

- Vérifier avec votre infirmière les médicaments que vous devez prendre (par la bouche avec de petites gorgées d'eau ou par la sonde nasogastrique);

  Médicaments à prendre :

- Mettre une jaquette d'hôpital et enlever vos sous-vêtements (soutien-gorge, camisole, culotte).

QUE VA-T-IL SE PASSER LE JOUR DE L'INTERVENTION ?

Avant l'intervention :

- S'il y a lieu, vous aurez une prise de sang;
- Une sonde (tube) nasogastrique sera installée par le nez jusque dans votre estomac;
- Si nécessaire, on rasera les poils de votre abdomen;
- Un cathéter (soluté) sera introduit dans une veine de votre bras pour vous administrer des médicaments pour relaxer (sédatifs), soulager la douleur (analgésiques) et prévenir les infections (antibiotiques);
- Vous serez amené à la salle de radiologie où vous serez accueilli par une équipe composée de **technologues**, d'une **infirmière** et du **radiologiste**.

Pendant l'intervention :

- Une échographie de l'estomac sera faite pour aider votre radiologiste à bien positionner le tube de gastrostomie installé habituellement sous les côtes;
- De l'air sera injecté par la sonde nasogastrique pour gonfler votre estomac;
- La peau de la région de l'estomac sera nettoyée avec une solution antiseptique et elle sera recouverte avec des draps stériles;
- Un anesthésique local sera injecté dans la peau pour engourdir la région où le tube sera installé;
- Le radiologiste attachera d'abord l'estomac à la paroi abdominale en insérant de petits dispositifs à travers la peau appelés « ancrages gastriques »;
- Par la suite, à l'aide de l'écran à Rayons X et d'un guide métallique, il introduira le tube dans l'estomac à travers une petite incision de la peau;
- Enfin, le tube de gastrostomie percutanée sera fixé à la peau à l'aide d'un point de suture.

Cette intervention dure habituellement moins d'une heure.

QUE VA-T-IL SE PASSER LE JOUR DE L'INTERVENTION ?

Après l'intervention :

- On vous ramènera à votre chambre sur une civière;
  Vous demeurerez au lit pendant au moins 4 heures.

Qui s'occupera de vous ?

- Une **infirmière** surveillera régulièrement votre pression artérielle, votre pouls, votre respiration et votre tube de gastrostomie;
  - Elle s'informera de votre état. N'hésitez pas à lui dire ce que vous ressentez, par exemple : douleur, nausée, étourdissement, difficulté à respirer;
  - Par la suite, elle vous montrera comment entretenir votre gastrostomie;

- Une **nutritionniste** vous rendra visite et, s'il y a lieu, elle vous enseignera comment vous alimenter par un tube de gastrostomie;
  - Elle vous indiquera les consignes à suivre à domicile et vous remettra la brochure « Guide d'alimentation par sonde à domicile »;
  - **La nutritionniste de votre CLSC** prendra la relève pour tout problème concernant votre alimentation;

- Vous rencontrerez **l'infirmière de liaison**. Elle fera les arrangements nécessaires pour qu'une **infirmière de votre CLSC** vous rende visite chez-vous dès le lendemain;
  - Elle vous remettra également un numéro de téléphone vous permettant de rejoindre en tout temps (24 heures sur 24 et 7 jours sur 7) une infirmière du CLSC en cas de problème.

Au sujet de la reprise de l'alimentation :

- Vous pourrez commencer à vous alimenter **24 heures** après l'intervention :
  Date : _____ Heure : _____

- Par contre, **12 heures** après son installation, vous pourrez prendre vos médicaments par le tube :
  Date : _____ Heure : _____

  Il est important de bien rincer le tube après le passage des médicaments.

AUREZ-VOUS DE LA DOULEUR ?

Habituellement, l'intervention n'est pas douloureuse car la peau est engourdie, mais vous pouvez ressentir un certain inconfort (douleur aux épaules et aux côtes) du fait de la présence d'air dans votre estomac. Ne vous inquiétez pas, vous recevrez une médication contre la douleur.

À votre retour à la maison, si nécessaire, vous pourrez prendre de l'Acétaminophène (Tylénol) sous forme liquide. N'oubliez pas de bien rincer votre tube.

QUE DEVREZ-VOUS FAIRE POUR ENTRETENIR VOTRE GASTROSTOMIE PERCUTANÉE ?

Actions	Pourquoi ?
Lorsque la peau autour du tube est bien cicatrisée (habituellement 7 jours après l'installation du tube) :	
1 fois par jour :	
• Nettoyer la peau autour du tube ainsi que la collerette à l'eau tiède savonneuse.	
• Utiliser une débarbouillette ou un coton-tige (Q-Tips).	*L'usage d'un coton-tige facilite l'accès sous la collerette.*
• Soulever légèrement la collerette.	
• Bien rincer et assécher la peau sous la collerette avec une débarbouillette sèche ou un coton-tige (Q-Tips).	*Prévient l'infection de la peau.*
• Laisser un espace entre la peau et la collerette.	*Permet la circulation d'air entre la peau et la collerette.*
Avant chaque repas :	
• Vérifier la longueur du tube à l'aide du chiffre le plus près de la collerette.	*Permet de s'assurer que le tube est dans l'estomac.*
Si présence d'un écoulement autour du tube :	
• Pratiquer une fente au centre d'une gaze 2X2.	
• Nettoyer et assécher la peau.	
• Appliquer sur la peau une barrière cutanée (onguent de Zinc, vaseline etc.)	*Prévient l'irritation causée par le contact de la peau avec le liquide gastrique.*
• Introduire seulement une épaisseur de gaze sous la collerette.	
• Remplacer le pansement dès qu'il est souillé.	

QUELS PROBLÈMES PEUVENT ARRIVER APRÈS VOTRE RETOUR À LA MAISON ?

Même si toutes les mesures sont prises pour éviter les complications, il peut arriver que vous présentiez les problèmes suivants :

Problèmes	Ce que vous devez faire
Péritonite **Signes** : fièvre (plus de 38,5 °C ou 101 °F), douleur, distension et rigidité de l'abdomen (abdomen gros et dur)	Présentez-vous à l'urgence dans le plus bref délai
Hémorragie digestive **Signes** : sang dans le tube et /ou dans les selles	Présentez-vous à l'urgence dans le plus bref délai
Retrait accidentel du tube	Présentez-vous à l'urgence dans le plus bref délai
Présence de liquide gastrique autour du tube	***Écoulement léger :*** Avisez l'infirmière de votre CLSC : Téléphone : _____ ***Écoulement important :*** Avisez votre médecin traitant: Téléphone : _____ ou l'infirmière stomothérapeute : téléphone : 418 691-5047
Obstruction du tube (tube bloqué)	Avisez votre CLSC: Téléphone : _____ ou l'infirmière stomothérapeute : téléphone : 418 691-5047
Lésions de la peau	Avisez l'infirmière de votre CLSC: Téléphone : _____ ou l'infirmière stomothérapeute : téléphone : 418 691-5047

AUTRES CONSEILS PRATIQUES :

- Pour prévenir le blocage de votre tube, vous devez :
    - Rincer le tube après chaque utilisation ou aux 4 heures si la solution alimentaire est administrée en continue;
    - Privilégier la médication sous forme liquide;
    - Écraser les comprimés en une fine poudre et dissoudre la poudre dans un demi-verre d'eau tiède si la médication n'est pas disponible sous forme liquide;
    - Ne pas mélanger les médicaments avec la solution alimentaire.

- Vous pourrez prendre une **douche** lorsque la peau autour du tube de gastrostomie sera cicatrisée soit **environ 7 jours** après l'installation du tube.

- Pour prendre un **bain**, vous devez attendre que les points aient été enlevés soit **environ 16 jours** après la mise en place du tube.

- La **baignade** est permise **4 semaines** après l'installation du tube.

- **IMPORTANT** :
  Le tube de gastrostomie percutanée doit être changé **aux 3 mois**.
  Assurez-vous que les arrangements sont pris avec votre médecin traitant ou l'infirmière stomothérapeute pour le changement du tube.

NOTES :

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Le centre hospitalier universitaire mère-enfant
Pour l'amour des enfants
Université de Montréal

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-(LONG TERM) CLIENTS-
(FOR A PERIOD OF MORE THAN 2 YEARS)

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ADMINISTRATIVE OFFICERS

JULY 2018

3175 Côte Sainte-Catherine Road
Montréal, QC
H3T 1C5

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CHU Sainte-Justine
Le centre hospitalier universitaire mère-enfant
Pour l'amour des enfants
Université de Montréal

3175 Côte Sainte-Catherine Road
Montréal, QC
H3T 1C5

This is to confirm your registration in the Quebec Enteral Feeding Program managed by CHU Sainte-Justine. This request for financial and/or technical assistance to meet your nutritional needs was completed by your healthcare worker and signed by you, or your respondent, as the case may be. Your healthcare worker should have explained to you what the program involves, the basis for this assistance and how the program works.

This quick and easy guide contains all the information to help answer any questions you might still have since registering in this program. We hope you find it useful. Please read the information carefully and refer to it as often as necessary. This guide is an indispensable tool, so we suggest that you keep it in an easily accessible place.

PATIENT WITHOUT PRIVATE INSURANCE □

You are receiving financial assistance in the form of supplies required to meet your nutritional needs.

The first order, based to the needs assessment done by the healthcare worker who registered you in the program, will be sent directly to your home. In the future, you will have to order new supplies yourself as needed either by e-mail, by fax or mail. You will find the maximum allotted quotas to which you are entitled for one year, from the date of your enrolment in the program or your first receipt of supplies, on page 3. You must order supplies for your tube feeding only. You may be asked to justify certain orders.

In planning your inventory, allow enough time for shipping and handling of your order and receipt of your supplies by mail.

To request an adjustment in supplies or for any other request, contact your main healthcare worker (p. 19). Any additional supplies you wish to use will be at your own expense. Supplies are available in pharmacies. We will not reimburse any purchases you make on your own.

Should you become insured during the course of treatment, please follow the procedure on page 7.

ALLOTTED QUOTAS* **

You will be reimbursed the same amount if you become insured privately.

ePump Supplies	**Max. Annual Quantity**
Open System: #773656 (1000ml soft bag)	120
Closed System: #775659	365 (or as per treatment)
Joey Pump Supplies	
Open System: #763656 (1000ml soft bag)	120
Closed System: #765559	365 (or as per treatment)
Gravity feeding supplies	
Open System: #8884702500 (1000ml soft bag)	120
Open System: #702505 (1000ml heavy flow soft bag)	120
Skin Level Balloon Gastrostomy (button) and Foley probes	
Nutriport, Entristar, Bard, Mickey	on request
Extensions for feeding system (button extensions)	
Nutriport, Entristar, Bard, Mickey	6 (8 if going to school)
Syringes	
10cc	100
60cc or 60cc catheter plugs	120 (240 if bolus syringes)
Syringe adapters	12
Nasogastric tubes	
8FR x 42 in. (radiopaque)	52
Corpak/Corflo	6
Pedi-Tube	12
Other supplies	
Hypafix (5cm x 10m, 10cm x 10m, 15cm x 10m)	as per assessment
Transpore (transparent tape)	as per assessment
Micropore (paper tape)	as per assessment
Elastoplast (pink tape)	as per assessment
Tegaderm	as per assessment
Duoderm	as per assessment
Compresses (2x2 and/or 4x4 non-sterile)	as per assessment
Drain attachment (Hollister drain #9781 or #9782)	52 units
Y connector (adapter) for PEG	6

*All additional supplies will be at your own expense.

**For all unlisted supplies, contact your healthcare worker to place an order. Your request will be assessed and added to your file, if accepted.

Supplies not covered without exception

- Tracheostomy compresses (pre-cut compresses)
- Sterile compresses and woven compresses
- Mounted swabs (cotton swabs)
- NACL.9 , sterile water
- Sterile and non-sterile gloves
- Needles for syringes
- Suction catheter
- Masks
- Quilted pads (mattress protectors)

Important notes

*Supplies may come in different shipments and by different carriers. Only one shipping address is permitted. Please allow 3 to 5 business days for delivery.

*Any change in the initial request must be made by your healthcare worker.

*Only one system (open or closed) is allocated. Alternating between the two systems will be at your own expense.

Renewal of supplies

Procedures for the renewal of supplies:

1- by e-mail: include the name, contact information (address and phone number) and a detailed description of the supplies you would like and send your request to: programme.ministeriel.hsj@ssss.gouv.qc.ca which can be found on our website : https://www.chusj.org/soins-services/A/Alimentation-enterale

Or

2- by mail: fill out the order form (see page 5). Mail your order form to:

CHU Sainte-Justine
Quebec Enteral Feeding Program-Order
3175 Côte Sainte-Catherine
Étage 7, Bloc 6
Montréal, QC H3T 1C5

Or

3- by fax: fill out the order form (see page 5). Send it to 514-345-4983

* If you order by mail, please notify us if order forms are needed.

** Available quantities of each item differ per order and will be added, based on the information in your file, within the annual quotas. Each item will be added separately. The date of the annual quotas will be different from the application date. Please manage your supplies accordingly.

Order form for : Patient's name : _____

Phone Number : _____ Date : _____

Supplies			Desired quantity	Maximum annual quantity
ePump supplies (3 months)				
Open System: #773656 (1000ml soft bag)		- 1 box of 30 units	_____	120 units
Closed System: #775659		- 3 boxes of 30 units	_____	365 units
Joey Pump supplies (3 months)				
Open System: #763656 (1000ml soft bag)		- 1 box of 30 units	_____	120 units
Closed System: #765559		- 3 boxes of 30 units	_____	365 units
Gravity feeding supplies (3 months)				
Open System: #8884702500 (1000ml soft bag)		- 1 box of 30 units	____	120 units
Open System: #702505 (1000ml heavy flow soft bag)		- 1 box of 30 units	____	120 units
Skin Level Balloon Gastrostomy (button) and Foley probes				
	o Nutriport _____FR x ____CM	o Mickey _____FR x ____CM	____	On request
	o Entristar _____FR x ____CM	o Bard _____FR x ____CM		
Feeding system extensions (button extensions)				
	o Nutriport continue ___ bolus ___	o Mickey □12'' □24'' continue ___ bolus ___	____	6 (8 if going to school)
	o Entristar continue ___ bolus ___	o Bard ___FR continue ___ bolus ___		
Syringes				
10cc			____	100 units
60cc luer-lok tip (4 months = 40 (80 if bolus))			____	120 (240) units
60cc catheter plugs (4 months = 40 (80 if bolus))			____	120 (240) units
Syringe adapters			____	12
Nasogastric tubes				
8FR x 42 in. (radiopaque)			____	52
Corpak/Corflo ____FR x ____ CM			____	6
Peditube ____FR x____ CM			____	12
Other supplies (check format if necessary)				
Hypafix : 5cm x 10m : ___ 10cm x 10m : ___ 15cm x 10m : ___			____	As per assessment
Transpore (transparent tape)			____	As per assessment
Micropore (paper tap)			____	As per assessment
Elastoplast (pink tape)			____	As per assessment
Tegarderm			____	As per assessment
Duo-derm			____	As per assessment
Compresses non stériles : 2x2 : ____ et/ou 4x4 : ____			____	As per assessment
Drain attachment Hollister : Drain #9781 : ____ Drain #9782 : _____			____	52
"Y" connector (adapter) for PEG: 16FR : ___ 20FR : ___ 24FR : ___			____	6
Lubricating jelly			____	As per assessment

PATIENT WITH PRIVATE INSURANCE □

The financial assistance you are receiving is to cover the non-refundable portion of those supplies purchased for your tube feeding, which are not covered under your private insurance plan.

You must arrange to purchase the feeding supplies you require (an extensive list of suppliers appears on p. 13). To receive a refund, you will need to follow the procedure on page 8. This procedure applies only if your insurance plan covers this type of supplies.

Any supplies that are non-refundable or not covered under your insurance plan will be provided to you free of charge through our Program. Order the supplies you require but keep in mind that they must not be covered by your insurance plan. You will be asked to provide proof that your claim has been rejected.

You can also request reimbursement for the non-refundable difference in the cost of purchasing your tube feeding solution, not covered by your insurance plan. The procedure is the same as for supplies. You are entitled to a refund even if your insurer does cover the cost of supplies.

For more information, contact your main healthcare worker listed on page 19.

This financial assistance is valid for as long as you are being treated. Please notify us via your social worker when your treatment ends. If no refund is claimed for four consecutive periods, the file will be closed after a final check with the healthcare worker listed.

IMPORTANT POINTS FOR PATIENTS WITH PRIVATE INSURANCE

- If you are currently insured or become insured during your treatment, your healthcare worker must submit a claim first to your insurance company for payment of the supplies.

- You will need to have a needs assessment done, obtain a quote from a private supplier and submit it to your insurance company. Be sure to get a letter as soon as possible confirming or reversing the insurer's decision. In the event of a negative response (verbal or written), do not make any purchases as they will not be reimbursed by the Program.

- Under Bill 33 of the Quebec government's drug insurance plan, insurers are required to provide the minimum RAMQ coverage (tube feeding solutions). Employees insured with the Government of Canada may encounter problems with payment. For all other problems or outstanding issues with your insurer or to learn what recourse you may have, go to www.accap.ca

- Regarding supplies, insurance company contracts take precedence and are not regulated by any law nor carry any obligation on the part of the insurer.

- If the insurer refuses to pay for supplies, the Program will provide them to you.

- If the insurer accepts to pay for supplies, the non-refundable difference can be covered by the Program.

- To obtain a refund, submit a claims form with the following information::

    1. original invoices or duplicates of purchases made (no photocopy or fax);

    2. a copy of the insurance statement (photocopy accepted) detailing the expenses incurred. Not required if the amount to be refunded or paid is clearly indicated on the purchase invoice.

- If your insurance coverage ends during treatment, the Program will provide the supplies to you.

- If your insurance coverage changes during treatment, you will need to begin the above procedure over again, without the presumption that coverage will remain the same.

- In the case of a patient who reaches the age of 18 and is covered by parents' or another person's insurance policy, verify that the insurance coverage is still valid. In many cases, insurance ends at age 18, and the patient now becomes eligible to receive tube feeding supplies through the MSSS Enteral Feeding Program. This is not a firm rule, however, so it is important to verify the circumstances. Remember to advise the Program of any change to your insurance coverage.

REQUIRED DOCUMENTS TO FILE A CLAIM

Failure to comply with the requirements and/or any variance between the claims form and the documents received will result in your claim being refused and all documents will be returned to you.

Please allow 30 business days for your claim to be processed.

- Your original purchase invoices or duplicates.
    - Photocopies are inadmissible and will be returned to you. Your pharmacy or supplier can provide you with these documents. Simply ask at the time of purchase.

- A copy of the statement from your insurer (photocopy acceptable) listing your expenses and explaining clearly the amounts reimbursed by them
    - This is not required if your pharmacy or supplier indicates on the invoices the amounts to be reimbursed or paid.

- Claims forms duly filled in (see page 9)
    - This guide contains four detachable claims forms with pre-set dates. Once you have used up these forms, please notify us in the comments section of your final claim and we will send you a new set. In order to receive a refund, you must comply with the dates written on the forms. No refund will be made for expenses submitted after the claim period is past.

- If the dates suggested on the forms do not suit you, please advise us in writing, explaining the reasons why. New dates will be proposed.

- Forward the above documents to the following address:

Insurance - Refunds
MSSS Enteral Feeding Program
3175 Côte Sainte-Catherine
Étage 7, Bloc 6
Montréal, QC.
H3T 1C5

CLAIMS FORM 1
(Detachable)
PERIOD FROM APRIL 1 TO JUNE 30

Patient's Name: _____

Name and phone number of the person to whom the cheque should be made out:

_____

Mailing address for the cheque: _____

_____

_____

_____

Number of invoices included with this mailing: _____

Total amount claimed (if possible): $_____

Comments or explanations:

_____

_____

_____

REMINDER: Failure to comply with the requirements and/or any variance between the claims form and the documents received will result in your claim being refused and all documents will be returned to you.

INCLUDE: Your original invoices, insurance statement and this form, and mail to:

Insurance – Refunds
Quebec Enteral Feeding Program
3175 Côte Sainte-Catherine
Étage 7, Bloc 6
Montréal, QC
H3T 1C5

CLAIMS FORM 2
(Detachable)
PERIOD FROM JULY 1 TO SEPTEMBER 30

Patient's Name: _____

Name and phone number of the person to whom the cheque should be made out:

_____

Mailing address for the cheque: _____

_____

_____

_____

Number of invoices included with this mailing: _____

Total amount claimed (if possible): $_____

Comments or explanations:

_____

_____

_____

REMINDER: Failure to comply with the requirements and/or any variance between the claims form and the documents received will result in your claim being refused and all documents will be returned to you.

INCLUDE: Your original invoices, insurance statement and this form, and mail to:

Insurance – Refunds
Quebec Enteral Feeding Program
3175 Côte Sainte-Catherine
Étage 7, Bloc 6
Montréal, QC
H3T 1C5

CLAIMS FORM 3
(Detachable)
PERIOD FROM OCTOBER 1 TO DECEMBER 31

Patient's Name: _____

Name and phone number of the person to whom the cheque should be made out:

_____

Mailing address for the cheque: _____

_____

_____

_____

Number of invoices included with this mailing: _____

Total amount claimed (if possible): $_____

Comments or explanations:

_____

_____

_____

REMINDER: Failure to comply with the requirements and/or any variance between the claims form and the documents received will result in your claim being refused and all documents will be returned to you.

INCLUDE: Your original invoices, insurance statement and this form, and mail to:

Insurance – Refunds
Quebec Enteral Feeding Program
3175 Côte Sainte-Catherine
Étage 7, Bloc 6
Montréal, QC
H3T 1C5

CLAIMS FORM 4
(Detachable)
PERIOD FROM JANUARY 1 TO MARCH 31

Patient's Name: _____

Name and phone number of the person to whom the cheque should be made out:

_____

Mailing address for the cheque: _____

_____

_____

_____

Number of invoices included with this mailing: _____

Total amount claimed (if possible): $_____

Comments or explanations:

_____

_____

_____

REMINDER: Failure to comply with the requirements and/or any variance between the claims form and the documents received will result in your claim being refused and all documents will be returned to you.

INCLUDE: Your original invoices, insurance statement and this form, and mail to:

Insurance – Refunds
Quebec Enteral Feeding Program
3175 Côte Sainte-Catherine
Étage 7, Bloc 6
Montréal, QC
H3T 1C5

Medical Suppliers

Below are some suggested names of medical suppliers for patients who have private insurance or who wish to purchase additional supplies. Most of the pharmacies, ostomy centre and specialized medical supplies centre can also provide these kinds of supplies. This list is a comprehensive list and is not sponsored in any way.

RÉGION DU BAS ST-LAURENT		
Maison André Viger	619 boul. Wilfrid-Hamel, Québec, Qc. G1M 2T4	418-914-1213
RÉGION DU SAGUENAY LAC-ST-JEAN		
Maison André Viger	619 boul. Wilfrid-Hamel, Québec, Qc. G1M 2T4	418-914-1213
Distribution Médical Saguenay	1657 boul. St-Paul, Chicoutimi, Qc. G7J 3Y3	418-602-0662
RÉGION DE LA CAPITALE-NATIONALE		
ProAssist (Centre de Stomie du Qc)	355, rue du Marais Local 130, Québec, Qc. G1M 3N8	418-522-1268
Maison André Viger	619 boul. Wilfrid-Hamel, Québec, Qc. G1M 2T4	418-914-1213
Médico Concept	390 boul. Père-Lelièvre, Québec, Qc. G1M 1M8	418-686-6688
Médi-Sélect Ltée	670 rue Bouvier, Québec, Qc. G2J 1A7	418-623-3353
RÉGION DE LA MAURICIE ET DU CENTRE-DU-QUÉBEC		
Centre de Stomie de la Mauricie Inc	226 boul. Thibeau, Trois-Rivières, Qc. G8T 6Y1	819-378-4204
Le Groupe Medicus	3000 boul. Saint-Jean, Trois-Rivières, Qc. G9B 2M9	888-833-6381
RÉGION DE L'ESTRIE		
Centre Orthopédique CDD	126 rue Hériot, Drummondville, Qc. J2C 1J8	819-472-5417
Oxybec Médical Inc	981 rue King O, Sherbrooke, Qc. J1H 1S3	819-346-0555
Pharmacie Grondin Duval	10 rue Bruno-Dandeneault, Sherbrooke, Qc. J1G 2J1	819-563-4401

Medical Suppliers (continued)

RÉGION DE MONTRÉAL		
Caléa	4847 rue Levy, Saint-Laurent, Qc. H4R 2P9	514-335-3500
Maison André Viger Inc	6700 rue St-Denis, Montréal, Qc. H2S 2S2	514-274-7560
Mediquip	163- 175 av. Stillview, Pointe-Claire, Qc. H9R 4S3	514-697-8868
Premier Ostomy Center	6607 ch. Côte-des-Neiges, Montréal, Qc. H3S 2B3	514-940-9666
Dufort & Lavigne	8581 Place Marien, Montréal-Est, Qc. H1B 5W	514-528-2339 1-800-361-0655
RÉGION DE L'OUTAOUAIS		
Les Entreprises Médicales de L'Outaouais	131 boul. Gréber, Gatineau, Qc. J8T 6G6	819-205-9111
RÉGION DE L'ABITIBI-TÉMISCAMINGUE		
Maison André Viger Inc	6700 rue St-Denis, Montréal, Qc. H2S 2S2	514-274-7560
RÉGION DE LA CÔTE-NORD		
Maison André Viger	619 boul. Wilfrid-Hamel, Québec, Qc. G1M 2T4	418-914-1213
RÉGION DE LA GASPÉSIE-ÎLES-DE-LA MADELEINE		
Jean-Coutu- Daniel Larendeau #138	79 rue Jacques Cartier, Gaspé, Qc. G4X 1M5	418-368-5501
RÉGION DE CHAUDIÈRE-APPALACHES		
Ultra Médic	1000 127^{e} Rue, local 103, St-Georges, QC. G5Y 2W7	418-227-6900
RÉGION DE LAVAL		
Michel Cullen Médical Inc	1040 boul. Michèle Bohec, Blainville, Qc. J7C 5E2	450-434-1920
Stomo Médical Laval	3241 Av. Jean-Béraud, Laval, Qc. H7T 2L2	450-786-0786
RÉGION DE LANAUDIÈRE		
Maison André Viger Inc	3340 boul. Taschereau, Greenfield Park, QC. J4V 2H6	450-465-7560
Michel Cullen Médical Inc	1040 boul. Michèle Bohec, Blainville, Qc. J7C 5E2	450-434-1920

Medical Suppliers (continued)

RÉGION DES LAURENTIDES		
Michel Cullen Médical Inc	1040 boul. Michèle Bohec, Blainville, Qc. J7C 5E2	450-434-1920
RÉGION DE LA MONTÉRÉGIE		
Centre d'Équipement orthopédiques et de Stomisés de Sorel	265 boul. Fiset, Sorel, Qc. J3P 3P9	450-780-2825
Centre de Stomothérapie du Québec Inc	3180 ch. de Chambly, Longueuil, Qc. J4L 1N6	450-670-0600
Stomo Médical Longueuil	157 rue Saint-Charles O, Longueuil, Qc. J4H 1C7	450-928-4848
Pharmacie Bergeron, Jutras, Ménard	145 rue St-Charles O. Longueuil, Qc. J1G 2J1	819-563-4401

IV Pole

You are entitled to receive an IV pole when you register with our Program.

If you wish to purchase one, please refer to the list of suppliers on the previous page or any other medical equipment supplier.

The inventory number of the product we suggest is AMG775751.

- Purchase the IV pole and send the original invoice for refund to the address below.
- The maximum refundable amount is $100 (excluding taxes and transport fees).
- Refunds are made through the accounting department of our hospital.
- Anticipate approximately one month from the time your invoice is received by us for your refund to arrive.

Important: Adapting or modifying the IV pole is at the patient's expense.

Address for refunds:

IV Pole – Refunds
Quebec Enteral Feeding Program
3175 Côte Sainte-Catherine
Étage 7, Bloc 6
Montréal, QC
H3T 1C5

USEFUL LIFE OF SUPPLIES*

Bags with integrated tube	3 days
Tube with piercing pin or *Spikeright*	1 day or 1 per bottle/bag
Syringes	1 week for hydration 3 days if bolus /gavage by syringe
Syringe adapters	1 month
Extensions for gastrostomy button	2 months
Nutriport or Mickey type gastrostomy button	1 year and on request in case of breakage
Bard or Entristar-type gastrostomy button	On request/as needed
Y connectors	2 months
N/G 8fr 42 in. radiopaque tubes	1 week
Nasogastric tubes	Peditube:1 month Corpak: 3 months
Compresses, tape, drain attachments (Hollister drain)	Based on clinical assessment
Urinary probes (Foley)	1 per month if no button 1 per year in case of a broken button

*Note that these useful lives are based on study standards and may vary depending on the patient's treatment regimen. They may need to be justified, where necessary.

MAINTAINING SUPPLIES

- General Information

  - After each tube feeding, rinse the bag and tube, extensions and syringes with warm water until the water runs clear.
  - **Soapy water**: 1 tbsp of dishwashing powder diluted in 125 ml of boiling water. Be sure to let the mixture cool before using.

- Open System

  - **Major cleaning once every 24 hours:**
    - Rinse the bag and tube thoroughly in warm water until the water runs clear.
    - Place 250 ml of warm water and 1 tbsp of soapy water in the bag and force down the tubing.
    - Rinse thoroughly again with warm water until the water runs clear (no soapy residue). Repeat as necessary.

- Closed System

  - Do not rinse the piercing pin or *Spikeright*.
  - Do not touch the piercing pin or *Spikeright* with your fingers to avoid contamination.
  - Use only one tube per bottle. Discard the bottle and do not reuse in the place of another bottle. Follow the written instructions on the bottle for suspension times.

- Syringes and Extensions

  - To clean the syringes and gastrostomy extensions thoroughly, follow the same procedure as the tube feeding bags (See Open System). To clean the gastrostomy extensions, place soapy water in a 60 ml syringe diluted with warm water and roll the tube between your fingers to dislodge any residue that remains stuck. Rinse with warm water for as long as necessary to ensure that no soapy residue remains.
  - Always use warm water to clean and rinse, since hot water will make the plastic rigid, melt away the numbers on the syringes and make the plunger sticky.

- Gavage Pumps

  - Be sure to clean your gavage pump to minimize the risk of breakage, poor operation, contamination and incorrect dosage. Refer to the user's guide for proper maintenance.

VERIFICATION PROCEDURE FOR THE KANGAROO ePump ENTERAL FEEDING PUMP

1. **Cleaning Procedure**

Attention: Disconnect the pump from the electrical outlet before cleaning. Once the pump is clean, do not reconnect it until the pump and power cord is completely dry.

√ Cleaning the outside of the pump

- Use a gentle cleanser. If necessary, the pump can be cleaned with a 1:10 solution of bleach and water. 70% isopropyl alcohol can also be used.
- Gently clean the blue door both outside and inside. **(Figure 1)**

Figure 1

√ Cleaning the power cord

- Clean the power cord with a cloth dampened with a cleaning solution, starting at the plug and working up to the end of the cord.

√ Cleaning the drip detectors **(Figure 2)**

- Use a cotton swab dampened with a cleaning solution to clean the drip detectors.

A dirty sensor can cause a "FEED ERROR" alarm.

√ Cleaning the rotor **(Figure 3)**

- Clean each roller, as well as the centre of the rotor, using a well dampened cotton swab.
- Thoroughly wipe the rollers and rotor before turning the pump back on.

Figure 2

Figure 3

VERIFICATION PROCEDURE FOR THE KANGAROO JOEY ENTERAL FEEDING PUMP

1. **Cleaning Procedure**

Attention: Disconnect the pump from the electrical outlet before cleaning. Once the pump is clean, do not reconnect it until the pump and power cord is completely dry.

√ Cleaning the outside of the pump and charger

- Remove the pump from the charger. (**Figure 1**)
- Use a gentle cleanser. If necessary, the pump can be cleaned with a 1:10 solution of bleach and water. 70% isopropyl alcohol can also be used.
- Gently clean the blue door both outside and inside. (**Figure 1**)

Figure 1

√ Cleaning the power cord

- Clean the power cord with a cloth dampened with a cleaning solution, starting at the plug and working up to the end of the cord.

√ Cleaning the drip detectors (**Figure 2**)

- Use a cotton swab dampened with a cleaning solution to clean the drip detectors.

A dirty sensor can cause a "FEED ERROR" alarm.

(Note du traducteur : message d'erreur anglais du fabriquant)

√ Cleaning the rotor (**Figure 3**)

- Clean each roller, as well as the centre of the rotor, using a well dampened cotton swab.
- Thoroughly wipe the rollers and rotor before turning the pump back on.

Figure 2

Figure 3

Telephone contacts

You should contact your primary caregiver if you have any questions regarding the Quebec Enteral Feeding Program or an update of your file. It can be any health professional who knows your current health status. Make sure you have a contact person on your file.

Broken Pump*

In the event of a defect or other problem with your pump, please call the following number and mention that you are enrolled in the Quebec Enteral Feeding Program:

Cardinal Health : 1-800-268-7916 (Parts and Service)

***Make sure that you put an emergency procedure in place with your therapist in the event that your pump breaks.**

Inactive File

Please read the following information carefully to ensure that your file remains active and in good standing. If you fail to comply with any of these conditions, your file will be closed. A final check with your last known healthcare worker will be done before any definitive action is taken.

- If you do not order supplies for a long period of time (1 year), your file will be closed. We will, however, take into account the specific requirements of each case. We will check with you or your healthcare worker before closing a file permanently.
- If you have private insurance, be sure to make a claim at least once a year. If there are no claims in a full year, your file will be closed. Also make sure that you comply with the dates of the fiscal year (April 1 to March 31 of the following year.) No refunds can be made once a fiscal year has ended.
- You must advise us of any change of address. You can e-mail us at programme.ministeriel.hsj@ssss.gouv.qc.ca or mail us the form for this purpose on page 20 or notify us through your healthcare worker. If mail or supplies are returned because you failed to let us know that you had moved, your file will be closed after a final check with your last known healthcare worker.
- If you return material to us without a stated reason, we will assume that your treatments have ended and your file will be closed.

Returning Supplies

Points to remember

- You must notify your patient navigator so that he / she can inform us of the end of the treatment.
- Do not return the feeding solutions because they are not reusable on our part.
- **Provide the name of the patient with the shipment and the reason for the return on a sheet that you will integrate with your shipment.**
- Keep the confirmation # of your return. You may be asked if there is a problem or no reception of the return.

RETURNING PUMP

You must request an Authorized Return Number (RGA) from Customer Service at Cardinal Health: 1-800-268-7916,

E-mail: NTSC-SC@cardinalhealth.ca

Adress: NTSC

6201 Vipond Drive Door 5. Mississauga, Ontario. L5T 2B2

RETURNING NON-OPEN TUBING BOXES

- If you are able to come in person, please return the material to:

Service liaison/ Consultation réseau
CHU Sainte-Justine
3175 Ch. De La Côte-Ste-Catherine
Étage 7 Bloc 6
Montréal, QC
H3T 1C5

- If you are unable to come in person, use the **free return** service and give the address above.

Purolator: 1-888-744-7123

Account number: 4805832

- The supplies must be returned in good working order since they will be used by other patients who need the same service you benefited from. Do not return opened or used material.

Moving

In the event of a change of address please send us an e-mail with the necessary information to the following address:

programme.ministeriel.hsj@ssss.gouv.qc.ca

Use these forms to notify us of your new address.

Return to: **Moving/Change of Address**
Quebec Enteral Feeding Program
3175 Côte Sainte-Catherine
Étage 7, Bloc 6
Montréal, QC
H3T 1C5

- -

First and last names of patient: ______________________________

New address: ______________________________

____

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Phone: ______________________________

Email: ______________________________

- -

First and last names of patient: ______________________________

New address: ______________________________

____

____

Phone: ______________________________

Email: ______________________________

- -

First and last names of patient: ______________________________

New address: ______________________________

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Phone: ______________________________

Email: ______________________________

PERSONAL NOTES AND UPDATES

Use this page to jot down any information that seems important to you.
You will be advised of any updates to procedures as soon as they come into effect. Use this page to note any discrepancies with the procedures described in this guide.

Conclusion

We hope that you find this practical guide helpful.
Refer to it as often as necessary.
If you have questions and can't find the answers in this guide, contact your healthcare worker first, who will be able to answer them for you.

If you still need answers, you can send us your questions by e-mail at the following address: programme.ministeriel.hsj@ssss.gouv.qc.ca

Or via the mail at:

Correspondence- Questions- Comments
Quebec Enteral Feeding Program
3175 Côte Sainte-Catherine
Étage 7, Bloc 6
Montréal, QC
H3T 1C5

Or via the fax number 514-345-4983

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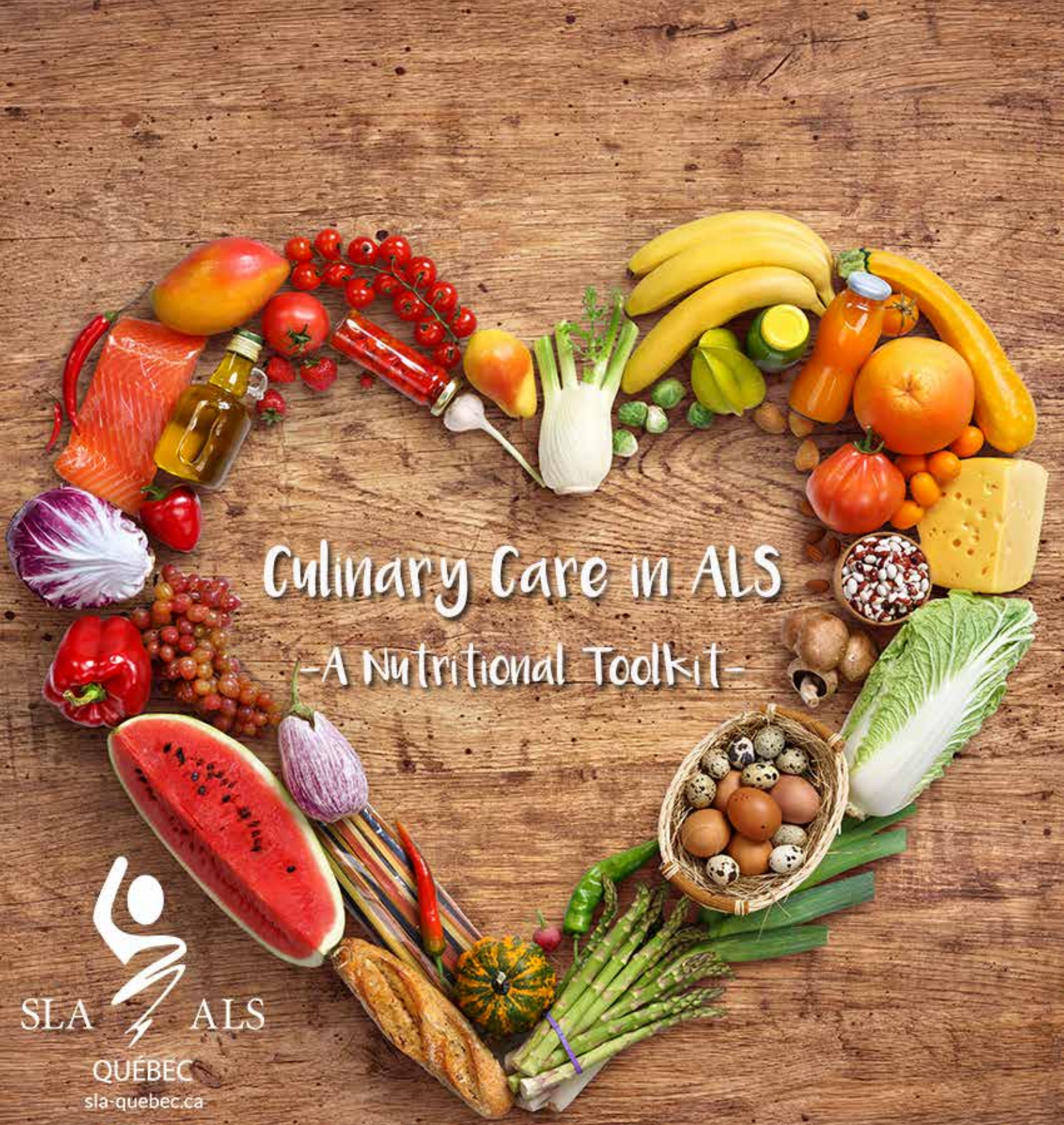

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This resource is also available in French.