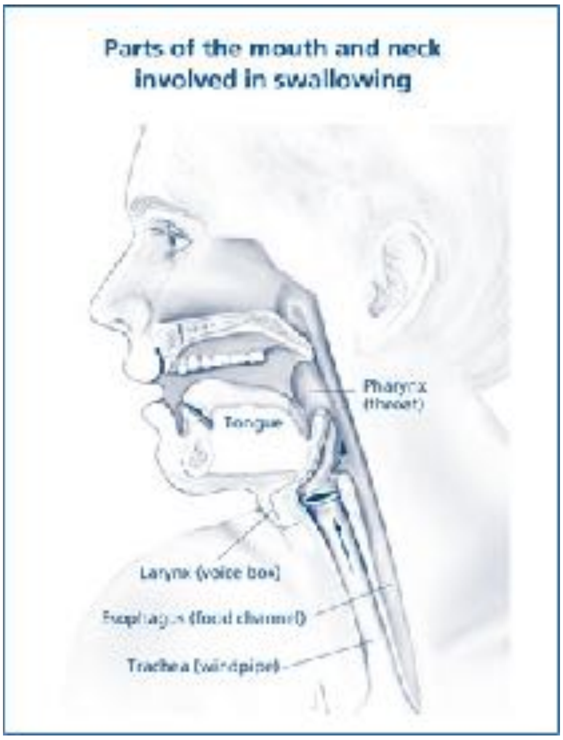
MND patient: “I have difficulty swallowing, what can I do?”

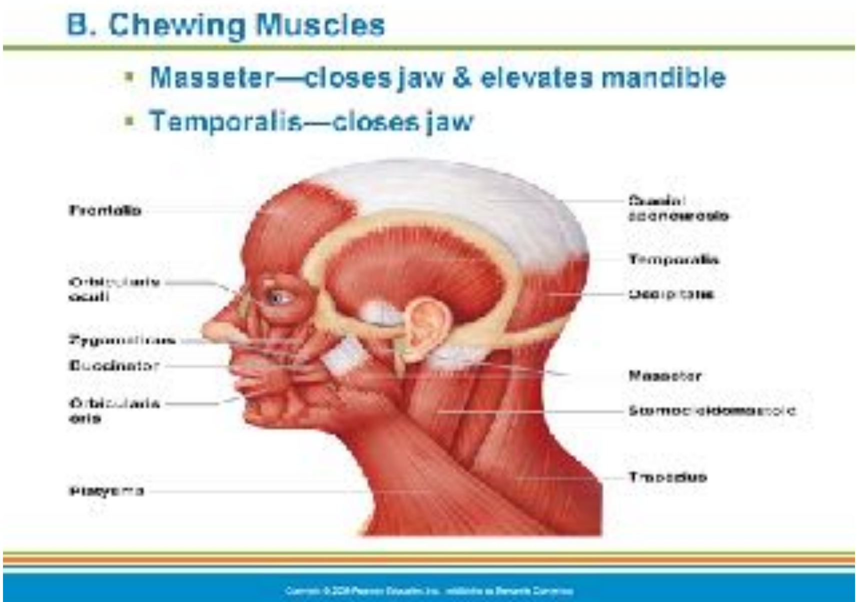


MND patients with bulbar involvement of the disease will have difficulty swallowing (dysphagia) and difficulty in articulate their speech (dysarthria). The problems of swallowing can affect any part of the swallowing mechanism illustrated in the picture above.

The normal mechanism of swallowing:

Video: https://youtu.be/eLvfzyZNnVw

The teeth grind the food and the saliva produced by the salivary glands in the mouth moisten the food with saliva. The food was chewed into a bolus by the movement of the jaw and the muscles involved then the tongue will help to push the food to the back of the throat to gulp down into the

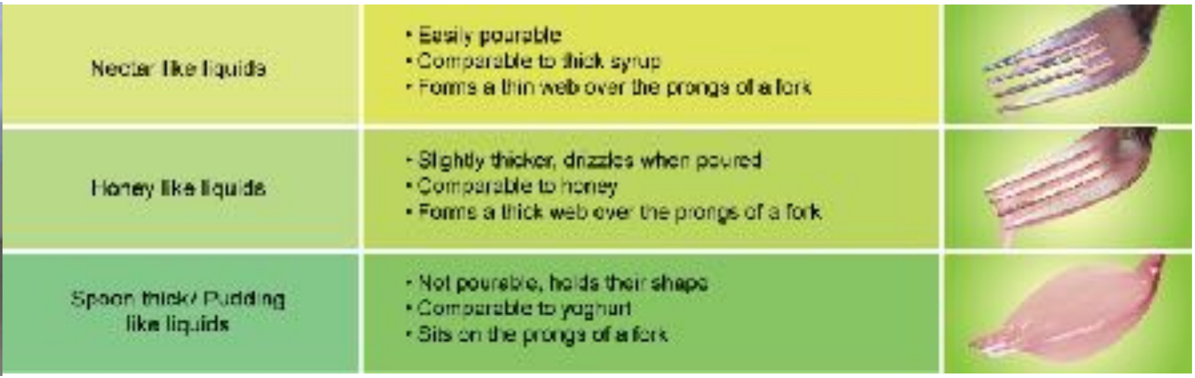


B. Chewing Muscles

- Masseter—closes jaw & elevates mandible
- Temporalis—closes jaw

oesophagus. The food is then sent down to the stomach in a passive propulsion process (peristalsis)

Common problems that the MND patients have in eating:	Suggestions to overcome:
• There is weakness of the muscle of chewing and unable to chew the food	• The consistency of the food need to change • Need to grind/blend the food or have liquid form of food that is easy to flow and feed
• Weakness of the lips to seal the food/fluids feeds into the mouth and constant drooling or dripping from the mouth • The tongue is weak and cannot push the bolus to the back of the throat	• If excessive salivation is the problem, may need medication to reduce the production of the saliva • The food/fluids on the small feeding spoon need to be brought to the back of the throat and let it flow down into the oesophagus (feeding tube)
• The tongue or the chewing muscles can become spastic (stiff and cannot move) and sometime it can be painful	• There is medication to relax the spastic muscles and to relieve the pain • The food/fluids on the small feeding spoon need to be brought to the back of the throat and let it flow down into the oesophagus (feeding tube)
• Some of the food stuck, just cannot flow down • Coughing or chocking observed during feeding	• The caretaker often need to do some” experiment” or “trial” to find the right consistency of the fluidity of the food/fluids for the particular patients • The right consistency meaning not too thick (difficulty to flow) and not too watery (too runny) • The choice of ingredients to thicken the consistency of the food includes add corn-starch, yogurt, honey, ice-cream or a pre-mix starch THiXER • Simply add water if want to make the consistency more watery
• There is loss of appetite and easily get tired during feeding • Patient continues to lose weight	• Consider substitute or supplement of feeding with the artificial feeding tube (PEG tube or NG tube) • If the patient choose not to have insertion of any artificial feeding tube, frequent feeding in small amount and lots of patience in feeding are needed • There is no diet restriction in MND, we advocate high calorie and even high fat diet to counteract the weight loss problem



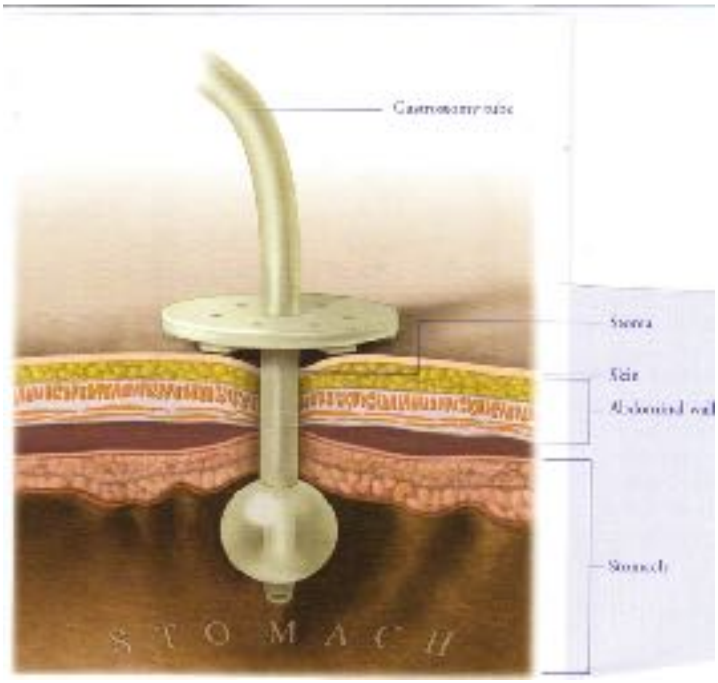
Nectar like liquids	• Easily pourable • Comparable to thick syrup • Forms a thin web over the prongs of a fork
Honey like liquids	• Slightly thicker, drizzles when poured • Comparable to honey • Forms a thick web over the prongs of a fork
Spoon thick/ Pudding like liquids	• Not pourable, holds their shape • Comparable to yoghurt • Sits on the prongs of a fork

Cannot eat = insertion of artificial tube?

Discuss with your doctor from Palliative team on decision of inserting an artificial feeding tube. We respect the right (autonomy) of the patient to choose to have or not to have an artificial feeding tube. Some patients still want to taste the food in the mouth and that is possible and can be done with or without the artificial feeding tube. Some patients feel very strongly of not having the artificial tube as they don't want to prolong their suffering with this incurable disease. Therefore, they state their will in advance care planning that they do not want any artificial feeding tube to be inserted onto their body when they are not able to swallow one day.

Types of artificial feeding tubes:

PEG (Percutaneous Endoscopic Gastrostomy) tube:



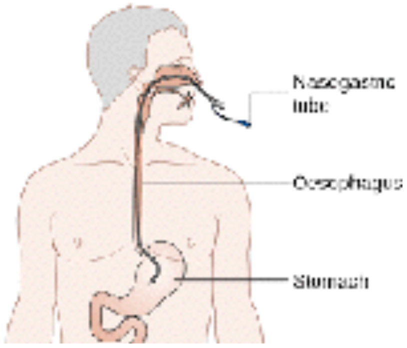
The PEG tube need to be insert by the expert doctor who have the expertise of endoscopic skill. The procedure is often perform at the scope room with the scope (camera) inserted to the patient stomach and an incision/cut is make at the patient’s stomach to insert the tube. The feeding tube can be use on the same day or next day if no complication of bleeding from the wound. Sedation may be given during the procedure and there is risk of breathing problems occur that the patient may need the help of ventilator to breath. The tube need no frequent change unless problems of infection with sever leakage or tube dysfunction.

Dietitian will advocate feeding of nutritional milk or with blended soup or liquid diet with the sieved liquid to prevent blockage of the tube with sediments. Some medication can also feed through the tube. In the long run, the tube may have fungal growth with blackish spots visible in the tube outside the body. Usually you don't need to change the tube. You can flush the tube with frizzy drink sometimes to prevent this problem.

Button Type PEG tube

PEG tube and the long tube outside

Nasogastric tube:



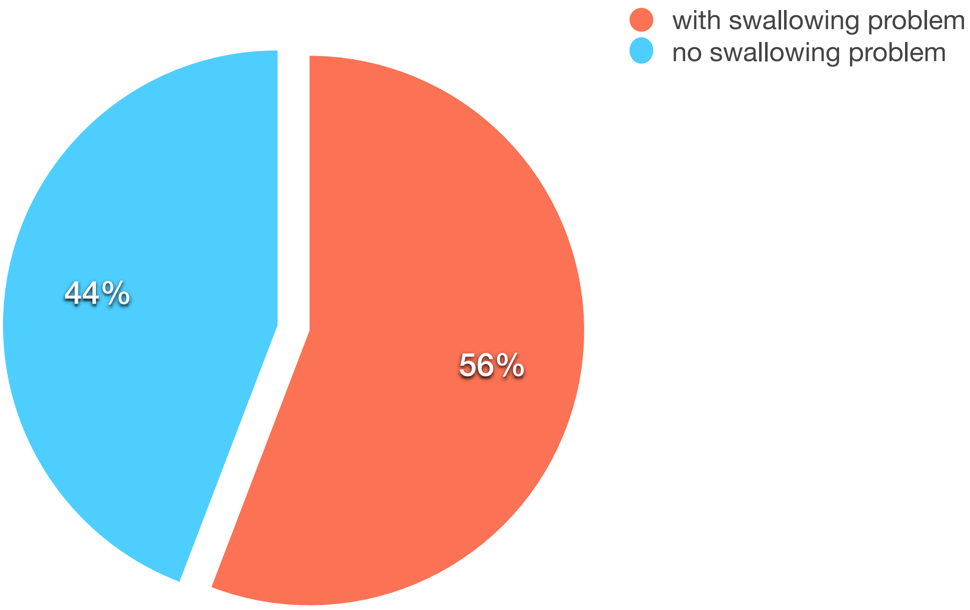
Nasogastric tube is a smaller tube which supplemental nutritional milk or medication can be fed through the tube. With proper care and flushing, the tube can last for weeks or months. But the NG tube may need more frequent change than the PEG tube and sometime it may cause discomfort to the patient.

More information on feeding and tubes:

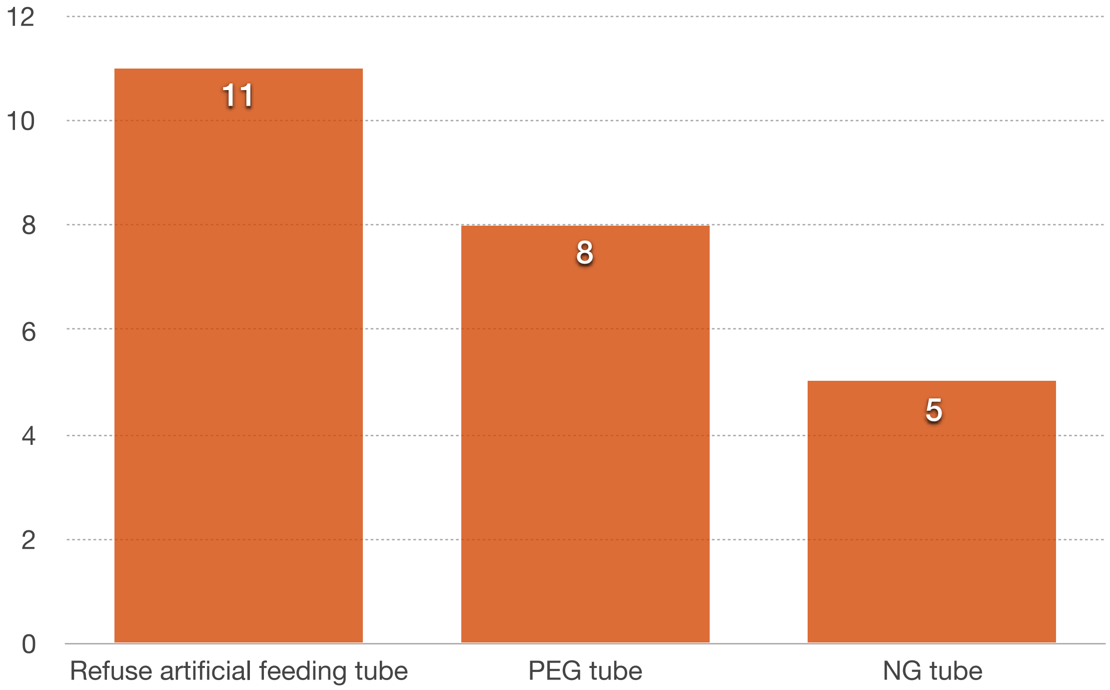
http://mytube.mymnd.org.uk

Our statistics in 2016:

Out of 43 MND patients under our follow up last year, 24 patients have problem with swallowing, 19 patients without swallowing problem.



Of the 24 patients, 11(45.8%) of them refused artificial feeding tube and fed through modified diet. 8 (33.3%) patients inserted PEG tube and 5 (20.8%) with supplemental feeding via the NG tube.



Some of the example of the feeding diet of the 19 patients who refused artificial feeding tube insertion:

- porridge with pumpkin
- ice-cream
- “Kuey teow” or rice noodle cut into small piece with soup
- Baby food/pureed
- chew and taste on small piece of fried chicken or lamb chop but not swallow
- candies or chocolate with the right consistency
- soup with blended fine veggie and beancurd
- pudding or jelly
- yogurt or smoothies
- half-boiled eggs
- mash potatoes with gravy