

## TIPS AND TRICKS ON FEEDING TUBES

ALS patients often need to make use of feeding tubes. The most popular version is the PEG probe. But what exactly are the advantages and disadvantages of these probes? Two patients talk about their lives with a PEG feeding tube.

A probe is a catheter (a thin tube) to dose liquid food to people who can't eat or drink in an independent manner. Such a probe can be placed through the nose and through the stomach.

ALS patients usually use so-called PEG feeding tubes. PEG stands for "Percutaneous endoscopic gastrostomy probe. This refers to the procedure in which the probe is inserted: through the skin (percutaneous) through the gastrointestinal tract (endoscopic) an opening is made in the abdomen (gastrostomy).

The placement of a PEG probe is done under (local) anesthesia. Usually required a short hospitalization. The whole operation takes about 30 to 45 minutes. A so-called gastro scope makes it possible to look into the stomach through the throat. Then an opening is made in the abdominal wall. From there, the PEG-probe can be brought from the stomach to the outside (on the abdomen). The tube of the PEG probe consists of flexible material, typically polyurethane or silicone, with a diameter of about 0.6 centimeters.

### Benefits

A PEG probe can increase the quality of life of ALS patients. Yet there may also be complications. Therefore we give briefly some advantages and disadvantages.

First the benefits :

- A better social acceptance: compared to nasogastric tubes the PEG probes are clearly less stigmatizing.
- No potential irritation of the nose, throat or esophagus, which can be the case with nasogastric probes.
- Reduced risk of displacement or failure of the probe.
- The catheter (tube) of the PEG probe is slightly thicker than nasogastric tubes, thus reducing the risk of clogging.

Some doctors quickly recommend ALS patients, therefore, to have a PEG probe placed. It's better to get a PEG probe in advance before the patient really needs it. For example at the time a patient still has more than half of its vital capacities. The sooner such a PEG probe is placed, the faster the patient will recover of the surgery, the argument goes.

Following signals according to these doctors shows it's time to place a PEG probe: difficulty swallowing and chewing; remarkable weight loss; fatigue caused by eating; meals that take an hour or longer; choking or gagging happens frequently during the meal; recurrent respiratory infections.

### Disadvantages

Nevertheless not everything is rosy. PEG-probes can also have some disadvantages:

- As has been cited the placement of the probe requires a (small) surgery;
- There is a risk of complications (abdominal pain, inflammation around the probe);
- An ethical objections may occur. It's always possible to dose moisture, food or medication through a PEG tube, even when life extension is no longer in the best interest of the patient. It's therefore important for ALS patients to discuss this in advance with the treating physician.

## "DEVELOPED OUR OWN WAY"



The Flemish ALS patient Timmy Putzeys has found its own way to deal with feeding tubes. Since Timmy was diagnosed with ALS, it all went very fast. Independent breathe, speak or eat doesn't work anymore for Timmy.

*"Like being bon vivant it was very hard that I could not enjoy all kinds of delicious things," Timmy starts off. "But I wouldn't give up. Especially I wouldn't give up against the ALS monster."*

Early 2012 therefore a PEG probe was placed with Timmy. From then Timmy began with standard probe feeding. "But my body didn't respond that well to the tube feeding," he remembers. "My bowel couldn't adapt to feeding tubes. I suffered a lot of constipation. I also had a bloated feeling. Also for my family, the feeding tube was a big adaptation. They felt always guilty eating something I previously like to eat. "

One day, Timmy saw his sister eat a sandwich with cheese. He couldn't take his eyes off the sandwich. His family could not stand it anymore and decided a different approach. His relatives made then a sandwich with cheese, put it in the mixer of the food processor and lengthen it with lots of water. Then the substance was thrown in the sieve, so only the liquid remained.

Timmy: "The idea that I could eat with them again, gave me a lot of satisfaction. Even I don't taste what I eat. What matters is the feeling that I can join the meal. That I also could enjoy all those good things. "

From that moment Timmy eats everything again. "I even eat chips, cookies, meat and even enjoy a drink," he says proudly. "All this is just given via the PEG probe. All foods are first properly diluted with liquid, mixed and then sifted. So the thick mass is certainly thin enough to get injected into the PEG probe. After this is given, we flush the PEG tube each time with water. "

Timmy experience some benefits. "Since we do this, I have a lot less problems with constipation," said the Flemish ALS patient. "I also never had a shortage of vitamins, because I receive all the vitamins and fiber. And very important for me is : I can just join the others. Again eat what I like and my family should no longer feel guilty if they eat something delicious. Even though I don't taste: the feeling I can participate, is worth so much to me! "

Even financially Timmy is doing a good thing. "The standard tube feeding is usually not cheap. Because my partner just can cook it for me too, we save a tidy sum."

## “BEST TO GET A PEG PROBE AS SOON AS POSSIBLE”



Brian Epp, a 45-year-old American from Battle Ground (Washington State), confirms that the placement of the PEG probe drastically increased his quality of life in all areas. In 2010 he received the terrible diagnosis of ALS. Less than a year later Brian Epp decided already for the placing of a feeding probe. At the time he still could chew and swallow.

It was a feeding probe with a long tube 'sticking out his abdomen. "I wasn't exactly enthusiastic about the idea that something hung out my belly that prevented a lot of activity," said Brian. Barely six months later, he decided to switch to a PEG probe.

This inexhaustible urge to keep moving, has everything to do with "his earlier decision to place a PEG feeding tube sooner rather than later ", he explains."

Also what food is concerned, Brian sees great advantages of the EPP probe. He uses his feeding tube for an increased intake of water and vegetable juice. This vegetable juice has a high nutritional value, but according to Brian Epp would also have a terrible taste. "The advantage of a feeding tube I can save my taste buds the bad taste of vegetable juice. I use the probe when it suits me well."