



Royal Hospital for Neuro-disability

A national medical charity



Swallowing problems and feeding tubes in Huntington's disease

Huntington's disease can change your ability to swallow food and drink.

This makes eating and drinking more difficult.

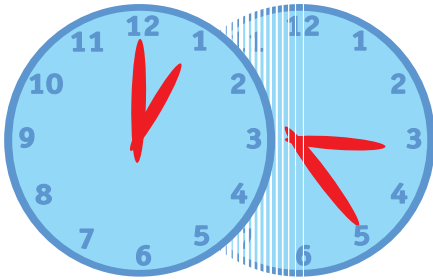
You will notice this when you ...



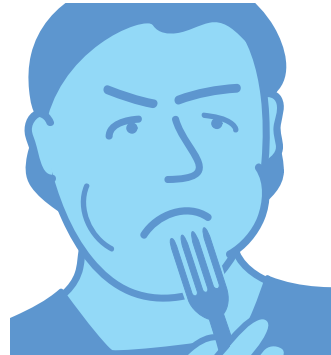
cough more
when you eat
or drink



become tired really
quickly at meal
times



take a **long time**
to finish your
food or drink



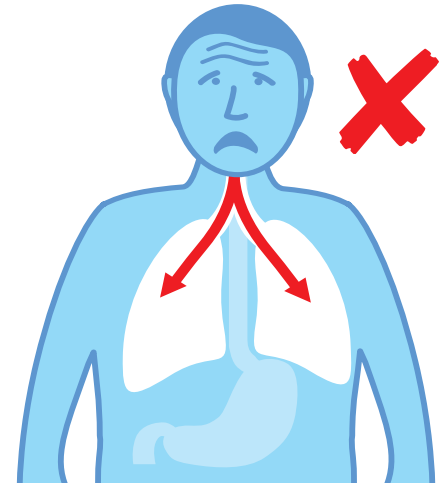
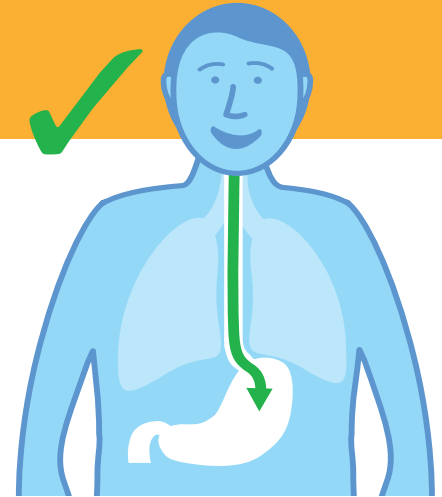
find that
eating is a
real **struggle**



are **put off**
your food

Huntington's disease can also make eating and drinking unsafe.

- Normally food goes into your stomach.
- When your swallowing gets worse, food can go into your lungs instead.
- You could choke or become seriously ill with a chest infection.



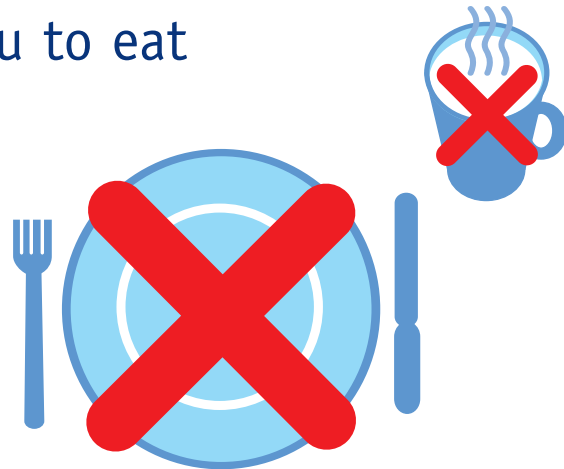
What is a feeding tube?

- It's a small tube which is put into your stomach to give you food, drink and medication.
- You may hear this called a Percutaneous Endoscopic Gastrostomy (PEG) tube and it might look like this.



Will I still be able to eat and drink?

- It may **not be safe** for you to eat and drink at all.
- You might take in all food, drink and medication through your feeding tube.

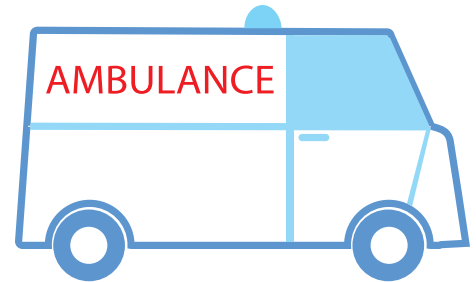


- Or you may still have **certain things to eat and drink.**
- You won't have to struggle to eat and drink the large amounts your body needs.



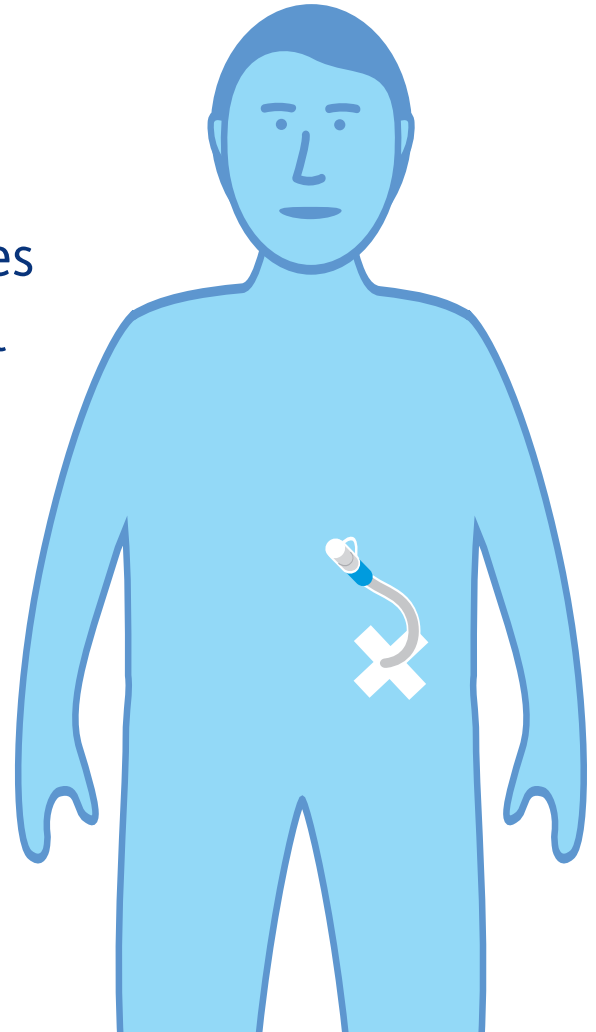
Where will the procedure happen?

- It will take place at a hospital.
- Transport to the hospital and back is likely to be in an ambulance with a nurse.
- You are usually back the same day.



How is the PEG placed?

- It's a small operation that takes about 20 minutes, with a local anaesthetic and sedation.
- It may be a little sore and tender for a day.
- You will be given something to help the pain.

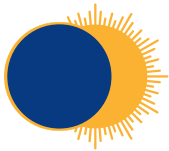


There are choices for you to make ...

- If you have a feeding tube, it may prolong your life so you will live longer with the effects of Huntington's disease
- If you are unable to swallow and you choose not to have the feeding tube, you may become seriously unwell and there is a possibility of your life being shortened
- If you have chosen not to have a feeding tube, we will respect your wishes and keep you comfortable

SOME IMPORTANT POINTS TO NOTE

- Whatever choice you make, we will do everything possible to enable you to eat and drink small amounts of food for pleasure
- Our team of Specialists is on hand to support you and provide information so that you can make your decision



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Registered charity number 205907

The Royal Hospital for Neuro-disability (RHN) is a national medical charity providing assessment, rehabilitation treatment and care for people who have profound and complex disabilities caused by disease or damage to the brain or other parts of the nervous system.



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– reviewed by the Huntington's Disease Association

2009