

Daily Life

Each person is liable to have different needs, but the following issues may be relevant:

- ▶ You may have to take food in very small mouthfuls over a prolonged period of time that is much longer than a normal meal time.
- ▶ You may have to 'graze' on small amounts of food outside normal meal times and even during some lessons at school.
- ▶ You may have to visit the toilet unexpectedly and/or for long periods during lesson time at school to deal with regurgitation.
- ▶ If you are feeling anxious or stressed, it can make swallowing more difficult.
- ▶ Some food will not be appropriate because of its texture (eg grape or tomato skins; stringy beans or meat; potato or harder fruits) or because it may congeal before reaching the stomach (eg white bread, white rice)
- ▶ You may need to stand up, to walk around or to massage your chest during meal times.
- ▶ You may find that drinking water helps food to pass through into your stomach more easily.
- ▶ You may experience low levels of energy because of lack of normal nutrition, and this can be relevant for sports activities and playing games. A dietitian's advice will be helpful.
- ▶ Sometimes you may need to take special medication to deal with painful chest spasms.
- ▶ Eating out with friends and explaining your condition can be very awkward.

Treatment

- ▶ If you are under 16 years of age, it is likely that the best treatment will be from doctors at a specialist unit who have long-term experience and familiarity with achalasia.
- ▶ Pneumatic dilatation involves a doctor stretching the valve between the oesophagus and the stomach (*the lower oesophageal sphincter or LOS*). This can help food travel into the stomach more easily. Due to stretching the surrounding area, dilatation can alter the tissue in the oesophagus and/or the LOS, but it is often the first line of treatment.
- ▶ Heller's myotomy (*HM*) is surgery that cuts the muscles that hold the LOS tight shut so as to allow food to pass through into the stomach more easily. It is often combined with fundoplication where part of the top of the stomach is wrapped around the oesophagus to restore the valve function that prevents reflux. Sometimes reflux is combatted by medication.
- ▶ POEM (*per oral esophageal myotomy*) is a relatively new procedure that involves cutting the same muscles as the HM but by means of an endoscope inserted through the mouth. POEM does not include fundoplication.
- ▶ Surgery and medication doses are necessarily planned more carefully when children and young people are still growing and developing.
- ▶ Medical research has not yet found a real cure for achalasia but the treatments outlined above often reduce the symptoms. For many young people, the earlier that treatment can be given, the better. There may be some symptoms that persist to some extent after surgery or POEM, and you may have to be careful about how and what you eat afterwards.



www.achalasia-action.org

Reg Charity No: 1187367

Uniting for a rare swallowing condition

ACHALASIA in the YOUNG

Helpline 0300 772 7795

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What is Achalasia

Achalasia is a rare disorder of the oesophagus (*food pipe*) that causes a number of symptoms, including difficulty swallowing food and drink, vomiting or regurgitating undigested food, and chest pain. If not managed properly, these symptoms can prevent you from growing and putting on normal weight. It can affect nutrition, growth, development, mental health and quality of life. These symptoms will vary from person to person.

“When I eat, the food gets stuck and my throat feels restricted and tight. I find it difficult to breathe.

Because I cannot eat properly, I feel tired all the time and I have no energy. I find it difficult to keep up with my friends at school and in sports.

I would like to enjoy McDonald's like my friends can but I know that the food will just get stuck.

Living with Achalasia feels very lonely because it is very rare and hard for people to understand.

Leo (aged 11)

The NHS estimates that 6,000 people of all ages currently live with achalasia in the UK. This may be an underestimate, as not all receive a correct diagnosis. Achalasia can occur at any age and can affect perhaps 3 or 4 in a million children.



Achalasia occurs when the muscles controlling the movement of food down the oesophagus and into the stomach do not work properly. The ring of muscle between the oesophagus and stomach remains clamped shut rather than relaxing to allow the food to pass into the stomach. This can cause food to remain in the oesophagus for a long time, and/or be regurgitated, which can be very painful. Sometimes the muscles contract into a spasm that gives you pains in your chest.

“It's rubbish being sick all the time and not being able to eat like my friends. At Christmas I had a Xmas football party, all the boys ate pizza and chips, I couldn't eat the food as I know I wouldn't be able to swallow it properly and would need to vomit, so it was better for me to sit next to the boys without eating. I felt so uncomfortable and some of the parents noticed this.”

Guto (aged 8)

Achalasia Action

In January 2020, Achalasia Action was registered as a Charitable Incorporated Organisation by the Charity Commission of England & Wales (no 1187367)

We organise meetings where parents of children with achalasia can share experiences and produce a leaflet *Achalasia and Education* to help explain achalasia to schools and colleges.

The charity's aims include

To advance education about achalasia and associated conditions.

To preserve and protect the health of people with achalasia, including their friends and families.

To encourage and support research into achalasia

To make a donation to our charity, please visit

achalasia-action.org/donate-to-achalasia-action.html



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