

## Daily Life

- Each person is liable to have different needs, but the following issues may be relevant
- Food may have to be taken in very small mouthfuls over a prolonged period of time that is much longer than a normal meal break.
- It may therefore be necessary to 'graze' on small amounts of food outside normal meal times and even during some lessons.
- Visits to the toilet might need to be made on an unexpected and/or prolonged basis during lesson time to deal with regurgitation.
- Swallowing may not be possible if the person is feeling anxious or stressed.
- Some food will not be appropriate because of its texture (eg grape or tomato skins; stringy beans or meat) or because it may congeal before reaching the stomach (eg white bread, white rice)
- It may be necessary for them to stand up, to walk around or to massage their chest during meal times. Drinking water (room temperature) with meals can be important.
- Low levels of energy might be experienced because of lack of normal nutrition, and this can be relevant for sports activities.
- Sometimes they may need to take special medication to deal with painful chest spasms.

## Student/Pupil Profile

Name

Form/Year/Class

Age (D.O.B)

Teacher/Tutor

How Achalasia effects me (key issues)

The Strengths I use to help myself (relating to my issues)

How teachers/staff can help my friends to support me

When will we review my plan (date)



**ACHALASIA ACTION**

*Uniting for a rare swallowing condition*

# Achalasia & Education

Helpline 0300 772 7795

NOVEMBER 2021

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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, and chest pain. If not managed properly, these symptoms can prevent people from maintaining a healthy weight and can affect nutrition, wellbeing, mental health and quality of life. These symptoms will vary from person to person.

**“I began feeling that food was getting stuck when eating things such as almonds and oat biscuits.”**

Verina, person with achalasia

The NHS estimates that 6,000 people currently live with the condition in the UK. This may be an underestimate, given how difficult it is for people to readily receive a correct diagnosis.

Achalasia occurs when the muscles controlling the movement of food down the oesophagus and into the stomach do not work properly. As a result, a 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 to be regurgitated, which can be very painful. Sometimes the muscles contract into a spasm that makes patients feel as if they might be suffering from a heart attack.

## Issues with Achalasia

It can take people with achalasia many years to receive a correct diagnosis. This is because achalasia symptoms can include weight loss, regurgitation and reluctance to eat certain types of food, which can be confused with eating disorders such as anorexia and bulimia. However, people with achalasia genuinely desire to eat well.

People with achalasia will often have to spend a long time over meals because they will not be able to eat at a normal speed.

Sometimes food that is swallowed will simply build up in their oesophagus and cause chest pain.

If the food cannot travel into the stomach it will sometimes have to be regurgitated, a long and distressing process.

**“When I first went to the GP and explained that I found it painful to swallow food, I was told this was down to stress and anxiety.**

**The GP warned my mum it could also be an eating disorder, a plausible diagnosis given that I was 17 at the time. I only received a correct diagnosis following a private consultation with a gastroenterologist, who was familiar with achalasia.”**

Silvia, person with achalasia

## Achalasia Action

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

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



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To make a donation to our charity, please visit [www.achalasia-action.org/donate-to-achalasia-action.html](http://www.achalasia-action.org/donate-to-achalasia-action.html)

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