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## **BRIEFING NOTE ON ACHALASIA – January 2023**

### **Summary**

- Achalasia is a rare swallowing condition and counts as a chronic condition where support needs to be improved.
- Diagnosis is often late, due to a lack of awareness among primary care professionals. The experience of achalasia sufferers is inconsistent and often poor within the healthcare system.
- Research into the condition itself – including the causes of the condition and potential cures – is effectively non-existent.
- Achalasia Action calls on Government, policymakers and the wider health system to:
  - Promote earlier diagnosis by raising awareness among primary and specialist health professionals. Achalasia should be considered alongside other conditions, such as bulimia, at the earliest stage of diagnosis of patients with potential eating disorders.
  - Better consistency and standardisation for treatment by developing set processes, protocols and pathways for achalasia sufferers following diagnoses.
  - Support for a research programme into the causes and potential remedies to achalasia.
  - Greater awareness of achalasia among policymakers across the UK.

### **Background**

Achalasia Action has been a registered charity since 2020. Achalasia is a rare swallowing condition<sup>i</sup>. It counts as a rare condition because only 0.7 – 1.6 people are diagnosed per 100,000 in the UK each year (equating to 467-1069 diagnoses), but the prevalence (number of people continuing to be affected by the condition after diagnosis) may be around 10 in 100,000. About 6,000 in the UK are affected, within the criterion of 1 in 2,000 used by the UK Rare Diseases Framework Initiative<sup>ii</sup>.

#### **A serious problem affecting quality of life**

With achalasia, the normal process of peristalsis, where muscles propel food down into the stomach, is compromised by problems affecting the nerve endings that control those muscles. Food remains in the oesophagus and often must be regurgitated. This causes malnutrition, loss of energy, fatigue, anxiety, depression, painful chest spasms and a failure to thrive and develop properly, especially in children.

*“It's rubbish being sick all the time and not being able to eat like my friends. At Christmas I had a 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.*

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## **A chronic condition that is poorly managed**

There is no cure as such, and although treatments can improve the symptoms, achalasia counts as one of the chronic conditions where support needs to be improved. Achalasia shares, in common with many of these chronic conditions, treatment that is often badly managed. Chronic conditions affect the quality of life of around 10 million people in the UK, causing a lifetime, and millions of hours, of suffering. Even after surgical treatment, people will still need to be careful about what food they eat. Ultimately, end stage achalasia can involve very major and expensive surgery to remove the oesophagus (oesophagectomy).

## **Late Diagnosis**

Diagnosis is often delayed, sometimes by a number of years. Some people may be mis-diagnosed with reflux disease or, especially in young women, with an eating disorder like bulimia. This is, in part, due to the inevitable fact that GPs will not come across many cases of achalasia.

## **Lack of research**

Apart from surgical studies comparing techniques for cutting the peristaltic muscles to relax the lower oesophageal sphincter (the valve between the oesophagus and the stomach), there has been very little research conducted into achalasia. Some promising research into stem cell therapy in the digestive system has taken place but no recent research is in hand to develop this potential approach<sup>iii iv</sup>

## **Call to Action – key health system ‘asks’**

1. Earlier diagnosis by developing greater awareness among the medical profession of this condition, both at primary care and in specialist units. We call for achalasia to be incorporated into regular GP processes, alongside other conditions such as bulimia, when dealing with and diagnosing patients with potential eating disorders. This will help to lower the propensity for misdiagnosis and make it more likely that achalasia sufferers can be diagnosed early.
2. Better consistency and standardisation for treatment. Following diagnosis, the healthcare experience of achalasia sufferers varies widely – with patients dealing with inconsistent advice, limited or no aftercare and occasionally going years between check-ups. There are no set processes in the NHS for achalasia. We call for the NHS to develop set protocols and pathways for dealing with achalasia as a chronic condition, including referral to appropriate specialist consultants (even if said specialist does not operate within the patients Integrated Care System (ICS) area), regular scheduled meetings and examinations and clear guidance on treatment options for patients.
3. A progressive research programme funded by the National Institute for Health and Care Research, the Medical Research Council and others, looking into a potential cure for the condition.
4. The Secretary of State for Health and Social Care, Parliamentarians and policymakers to take a personal interest in ensuring that outcomes improve for people suffering from achalasia.
5. All home nations of the UK to support improvements in outcomes for achalasia.

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<sup>i</sup> [Achalasia - NHS \(www.nhs.uk\)](http://www.nhs.uk)

<sup>ii</sup> [The UK Rare Diseases Framework - GOV.UK \(www.gov.uk\)](http://www.gov.uk)

<sup>iii</sup> [Conor McCann's Research Group | UCL Great Ormond Street Institute of Child Health - UCL – University College London](http://www.conormccann.com)

<sup>iv</sup> [Dr Conor McCann - Guts UK \(gutscharity.org.uk\)](http://gutscharity.org.uk)