



# ACHALASIA ACTION

[www.achalasia-action.org](http://www.achalasia-action.org)  
Reg Charity no 1187367

*Uniting for a rare swallowing condition*

**Helpline: 0300 772 7795**

## **PRIVACY AND CONFIDENTIALITY POLICY – (Agreed by Trustees on 1 June 2021)**

Achalasia Action is a registered charity (Number 1187367 in England & Wales) that is operated by volunteers without paid employees or dedicated premises.

In offering support and information to those affected by achalasia we do not replace the advice of any medical practitioner and as a matter of policy recommend that an experienced specialist medical practitioner who has been examining and treating individuals is the best source of medical advice.

We regard all conversations that include personal experiences and symptoms as confidential and will not disclose details to others, including to their medical practitioners, without the consent of the individual concerned. This includes contact by telephone, internet, or in face-to-face meetings with people with achalasia and associated conditions. We therefore expect all those contributing to any group discussions to be governed by this principle and will remind contributors of this policy at appropriate intervals.

We may keep a brief record of those who have contacted us and generalised information to help us offer more helpful support in the future. We may ask those in contact with us if they are willing to be put into contact with others, by mutual consent, if it seems appropriate and beneficial to either or both parties. We may circulate newsletters to those with an interest in achalasia and details of research projects to enable people to take part in such projects should they so wish.

We may describe a person's medical condition on an anonymised and/or statistical basis in order to collate information about achalasia that may be helpful to understand the condition.

We may keep, subject to consent being given, names, addresses and contact details on a database of people with achalasia, medical practitioners, donors and those who otherwise have an interest in our charity, but will endeavour to check the accuracy and relevance of those details from time to time. We will not share personal details from the database with any other organisation except with consent, and respect our responsibilities to operate under the General Data Protection Regulations.

Should any dealings with children, young people or vulnerable adults arise, we are committed to respect, safeguard and protect the best interests of those individuals.

Should any incident occur that might give any reasonable cause for complaint, everybody within the charity has a duty to report the matter, initially to the Secretary or Chairperson of the charity.

**40 Orpington Road, Winchmore Hill, London, England N21 3PG**  
**Charitable Incorporated Organisation registered in England & Wales no 1187367**  
**Medical Chair & Trustee: Majid Hashemi FRCS Trustees: Amanda Ladell, Alan Moss,**  
**Andrew Williams, Neil Ham, Silvia Davey, Gavin Nash, David Holden.**