

# A PATIENT CHARTER FOR PEOPLE WHO LIVE WITH ALLERGIC DISEASE

Developed by Allergy UK, in collaboration with patients, parents and leading clinical experts



#itstimetotakeallergyseriously

TAKE ALLERGY SERIOUSLY AllergyUK



### The Patient Charter

#### Allergy has been referenced as a 'global epidemic' by the World Health Organisation.

Our research has shown that an estimated 41 million people in the UK have one or more allergic conditions. It affects all ages and can develop at any stage in a person's life - it can be unpredictable and sometimes fatal.

Allergic disease is influenced by a number of complex issues such as globalisation, climate change, how foods we eat have changed and are manufactured, the pollution in the air we breathe, the products we are using in our homes and on our skins, and how we live today.



**615% increase** in hospital admissions related to all-cause anaphylaxis over the last 20 years

Allergy and related conditions are estimated to cost the NHS about £1 billion a year



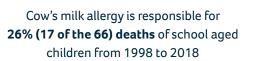
By 2025, asthma will represent the most prevalent chronic childhood disease and result in one of the highest causes of health care costs

About **half a million people** admitted to NHS hospitals each year have a diagnostic 'label' of drug allergy



Over **200,000 people** require the prescription of emergency adrenaline due to their allergic condition

Approximately 1-2% of adults and 5-8% of children have a food allergy



Allergic rhinitis affects **26% of adults** in the UK



500% increase in food allergy related hospital admissions since 1990



Cow's milk allergy affects 2-3% of babies and young children



More than **40% of patients** with allergic rhinitis have asthma, and more than **80% of asthmatic patients** suffer concomitant rhinitis

### The Charter

#### The Vision of the Patient Charter

- Achievement of a quality standard of care for everyone with allergy throughout the UK
- Empowerment of patients with allergic conditions to understand and manage their condition with support from informed healthcare professionals
- Promotion of a better awareness and understanding of allergy so that people with allergic conditions are not discriminated against in any aspect of their daily lives.

#### **1. THE RIGHT TO A QUALITY STANDARD OF CARE**

- The Right to a healthcare system which recognises allergy as a chronic long-term condition and provides continuity of quality care for all allergic diseases.
- The Right to equitable access to care and treatment regardless of where I live in the UK .
- The Right to a healthcare professional who can recognise allergic disease and make a timely diagnosis.
- The Right to a referral to specialist care for the best possible evidence-based treatment, if appropriate.
- The Right to timely access to scientifically proven allergy testing and diagnosis of allergic disease.
- The Right to be involved in decision-making for the choice of treatment and care, with a person-centred approach.
- The Right to timely transitional care for children and young people as they move into adulthood.
- The Right to holistic care and multi-disciplinary follow ups, as appropriate, that recognises the impact of allergic disease on mental health and well-being.

#### 2. THE RIGHT TO ACCURATE INFORMATION AND EDUCATION

- The Right to education and training on allergic disease management, including medical devices.
- The Right to accessible education and information about all allergic conditions.
- The Right to clear and accurate information about living with an allergic condition.
- The Right to be informed about new treatments, condition management and quality of life impacts.

#### **3. THE RIGHT TO EQUALITY IN SOCIETY**

- The Right to live without fear of discrimination, exclusion or prejudice.
- The Right to an education system and childcare provision that is informed, trained in allergy awareness, and can manage the healthcare needs of pupils living with allergic conditions.
- The Right to clear and accurate information needed to make safe food choices to confidently eat in or out of the home without the fear of allergic reaction.
- The Right to travel with confidence knowing that the needs of those living with allergy will be catered for.
- The Right to carry the medication needed to respond to allergic reactions at all times.
- The Right to access emergency medicines at all times and in all places.
- The Right to live in a society that understands the lifelong impact of allergic disease.
- The Right to live in a society that takes allergy seriously.



### The Patient's Responsibilities

People living with allergic disease have a responsibility to:

- Seek medical help when their symptoms are impacting on their quality of life.
- Share information with their healthcare professional so that validated testing can help to make an accurate diagnosis and determine appropriate treatment.
- Ensure that they are fully informed about managing their condition including understanding their triggers, and seek advice, support and training where needed.
- Adhere to their allergy management plan.
- Where prescribed, carry adrenaline autoinjectors, keep them up to date and understand how to use them.
- Consider their allergic disease when making life choices to reduce their risks and improve self-management.
- Disclose their allergy where relevant, so that service industries and others can provide relevant care and support, for example schools, employers, airlines and other health providers such as dentists.
- Show consideration and respect for the rights of everyone living with allergic disease, regardless of the type of allergy and symptom severity.

We urge patients, clinicians, and policy makers to endorse this Charter as a commitment to improving the lives of people with allergy in the UK and to acknowledge this as a 'Gold Standard' of patients' rights.



## The facts

For people who do not experience allergy in their lives it can be viewed as a trivial and insignificant condition. However, the realities of living with an allergy can be very far from this perception. The evidence we have gathered from our major research study is powerful in capturing the immense challenges of living with allergy:

- 6/1% would like government to do more to help people with allergies
- 65% of parents wanted specialist allergy nurses in GP surgeries
- 63% of parents wanted quick tests to identify allergy
- 65% say their child has felt discriminated against in a restaurant, because there was nothing they could safely eat
- 72% of parents feel that sometimes their children's allergies are not taken seriously
- 76% feel people should take allergies seriously

As the leading charity for people living with allergy, we have developed this Patient's Charter which reflects the challenges that patients face in every single aspect of their lives – from accessing high quality care, wherever they live in the UK, to feeling equal in a society that dismisses their condition and disregards their needs.

The Patient Charter represents the voices of our allergic community; people whose lives have been impacted by a disease that has no cure; parents fearful for the safety of their children; the children themselves who experience isolation and bullying; and the people with allergy and asthma who are the first to suffer because of poor air quality.

It confronts the realities of living with allergy and demands equal rights in healthcare provision and in society in general. It also recognises the responsibilities of this community – responsibilities that are willingly acknowledged in a more enlightened society where allergy is taken seriously.

The statistics mentioned above come from the national survey undertaken by Allergy UK in 2021. This is the largest ever national attitudinal survey towards allergies and involved over 7,000 people from all over the UK including people who live with allergy and those who don't. The surveys were carried out and the results were analysed by Campaign Collective and Sapio Research.



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# Our Vision

### No-one should die from allergy

# Our Mission

### It's time to take allergy seriously

Our mission reflects everything that we have learnt about the lives of people living with allergy, from our research, from calls to our Helpline, from focus groups and from meeting members of our allergic community. It captures the lack of awareness and understanding of allergy that our community faces, and it encapsulates our commitment to improving the lives of people with this chronic health condition.



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