A PATIENT CHARTER FOR PEOPLE WHO LIVE WITH ALLERGIC DISEASE

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

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 allergy can be very far from this perception. The analysis we have gathered from our major research study is powerful in capturing the immense challenges of living with allergy:

- 61% 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 discriminates based on conditions and diseases

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 real lives of 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 allergy 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.

No-one should die from allergy

Our Vision

It’s time to take allergy seriously

Our Mission

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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 of a person’s life – it can be unexpected 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.

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The Vision of the Patient Charter

1. The Right to a Quality Standard of Care
2. The Right to Accurate Information and Education
3. The Right to Equality in Society

The Patient’s Responsibilities

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.

1. The Right to a Quality Standard of Care
- The right to health care systems which take allergy as a chronic long-term condition and provide 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 healthcare professionals who can recognise allergic disease and make a timely diagnosis.
- The right to timely access to the best available evidence-based treatment, if appropriate.
- The right to timely access to scientifically proven allergy testing and diagnostic tools.
- The right to be adequately trained and cared for in a person-centred approach.
- The right to timely transition care for those not young people as they move into adulthood.
- The right to holistic care and multi-disciplinary follow-up, as appropriate, that recognises the impact of allergic disease on mental health and well-being.
- The right to be involved in decision-making for the choice of treatment and care, with a person-centred approach.
- The right to be offered a referral to specialist care for the best possible evidence-based treatment, if appropriate.
- The right to a healthcare professional who can recognise allergic disease and make a timely diagnosis.
- The right to equitable access to care and treatment regardless of where I live in the UK.
- 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 be involved in decision-making for the choice of treatment and care, with a person-centred approach.
- The right to a referral to specialist care for the best possible evidence-based treatment, if appropriate.
- The right to a healthcare professional who can recognise allergic disease and make a timely diagnosis.
- The right to equitable access to care and treatment regardless of where I live in the UK.

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.
- The right to seek advice, support and training where needed.
- The right to be fully informed about managing their condition including understanding their triggers, and seek advice, support and training where needed.
- The right to carry the medication needed to respond to allergic reactions at all times.
- The right to timely access to the best available evidence-based treatment, if appropriate.
- The right to be involved in decision-making for the choice of treatment and care, with a person-centred approach.
- The right to a referral to specialist care for the best possible evidence-based treatment, if appropriate.
- The right to a healthcare professional who can recognise allergic disease and make a timely diagnosis.
- The right to equitable access to care and treatment regardless of where I live in the UK.

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 childhood provision that is informed, trained in allergy awareness, and can manage the healthcare needs of pupils living with allergic conditions.
- The right to a referral to specialist care for the best possible evidence-based treatment, if appropriate.
- The right to be involved in decision-making for the choice of treatment and care, with a person-centred approach.
- The right to a referral to specialist care for the best possible evidence-based treatment, if appropriate.
- The right to a healthcare professional who can recognise allergic disease and make a timely diagnosis.
- The right to equitable access to care and treatment regardless of where I live in the UK.

Allergy and related conditions are estimated to cost the NHS about £1 billion a year. Over 200,000 people require the prescription of emergency adrenaline due to their allergic condition.

About half a million people are admitted to NHS hospitals each year with a diagnostic 'label' of drug allergy.

In the UK, approximately 1-2% of adults and 5-8% of children have a food allergy. Cow’s milk allergy is responsible for 26% (17 of the 66) deaths of school aged children from 1998 to 2018. By 2025, asthma will represent the highest cause of all-cause anaphylaxis over the last 20 years.

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Allergic rhinitis affects more than 40% of patients with allergic rhinitis have asthma, and more than 80% of asthmatic patients suffer concomitant rhinitis.
Achievement of a quality standard of care for everyone with allergy throughout the UK

The Right to holistic care and multi-disciplinary follow ups, as appropriate, that recognises the impact of allergic disease.

The Right to timely access to scientifically proven allergy testing and diagnosis of allergic disease.

The Right to a healthcare system which recognises allergy as a chronic long-term condition and provides continuity of high 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 live without fear of discrimination, exclusion or prejudice.

The Right to clear and accurate information needed to make safe food choices to confidently eat in or out of the home.

The Right to accessible education and information about all allergic conditions.

The Right to carry the medication needed to respond to allergic reactions at all times.

The Right to be informed about new treatments, condition management and quality of life impacts.

Empowerment of patients with allergic conditions to understand and manage their condition with support from medical practitioners, friends, family, communities and organisations.

The Right to travel with confidence knowing that the needs of those living with allergy will be catered for.

The Right to education and training on allergic disease management, including medical devices.

The Right to timely transitional care for children and young people as they move into adulthood.

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.

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 Patient Charter

Allergy has been referenced as a 'global epidemic' by the World Health Organization. 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 skin, and how we live today.

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
- The Right to live in a society that takes allergy seriously
- The Right to live in a society that understands the lifelong impact of allergic disease
- The Right to access emergency medicines at all times and in all places
- The Right to carry the medication needed to respond to allergic reactions at all times
- The Right to travel with confidence knowing that the needs of those living with allergy will be catered for
- The Right to live without fear of discrimination, exclusion or prejudice
- The Right to education and training on allergic disease management, including medical devices
- The Right to clear and accurate information about living with an allergic condition
- The Right to be informed about new treatments, condition management and change of life impacts

1. The Right to a Quality Standard of Care
   - The Right to live with the diagnosis of 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 healthcare professionals who can recognise allergic disease and make a timely diagnosis
   - The Right to referral to specialist care and use of the best possible evidence-based treatment, if appropriate
   - The Right to timely access to specialist care (e.g. a respiratory specialist, diabetologist, allergist, or immunologist)
   - The Right to access to emergency treatment, including the prescription of emergency adrenaline
   - The Right to travel knowing that their needs will be catered for
   - The Right to carry adrenaline autoinjectors, keep them up to date and understand how to use them
   - The Right to access to the best possible evidence-based treatment, if appropriate
   - The Right to equitable access to care and treatment regardless of where I live in the UK

2. The Right to Accurate Information and Education
   - The Right to education and training on allergic disease management, including medical devices
   - The Right to be informed about and understand the evidence-based treatment of allergic disease
   - The Right to clear and accurate information about living with an allergic condition
   - The Right to be informed about new treatments, condition management and change of life impacts

3. The Right to Equality in Society
   - The Right to live without fear of discrimination, exclusion or prejudice
   - The Right to education and training on allergic disease management, including medical devices
   - The Right to clear and accurate information needed to make safe food choices to confidently eat out of the home without the fear of allergic reaction
   - The Right to be involved in decision-making regarding their health and care
   - The Right to time-limited transitional care for children not young people as they move into adulthood
   - The Right to access to allergy awareness training, including medical devices
   - The Right to travel with confidence knowing that the needs of those living with allergy will be catered for
   - The Right to carry adrenaline autoinjectors, keep them up to date and understand how to use them
   - The Right to access to the best possible evidence-based treatment, if appropriate
   - The Right to equitable access to care and treatment regardless of where I live in the UK

The Right to live in a society that takes allergy seriously.

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.

Empowerment of patients with allergic conditions to understand and manage their condition with support from informed healthcare professionals.

The Right to live in a society that understands the lifelong impact of allergic disease.

Achievement of a quality standard of care for everyone with allergy throughout the UK.

The Right to live without fear of discrimination, exclusion or prejudice.

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 allergy can be very far from this perception. The analysis we have gathered from our major research study is powerful in capturing the immense challenges of living with allergy:

- 61% 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 having equal rights in a society that discriminates on condition and discriminates on needs.

The Patient Charter represents the voices of our allergic community: people whose lives have been impacted by a disease that can be caused in 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. Participants who live with allergy and those who don’t. The surveys were carried out and the results were analysed by Campaign Collective and Sapios Research.

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 determination to improve the lives of people with this chronic health condition.

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