

Guide to

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# Good asthma care for adults and children with asthma

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**This guide sets out Asthma UK’s vision for what people with asthma should expect in helping and supporting them to manage their asthma. In developing this document, we have drawn on local, regional, national and international evidence.**

**The guide is written for all people with asthma – this covers adults and children and young people with asthma and their carers/families.**

**It is based on an understanding that healthcare professionals who provide asthma care should have received recognised training in asthma management, and those working with children and young people to have specific knowledge, skills and training in children’s asthma.**

**All clinical aspects of the guide reflect the 2009 version of the *British Guideline on the Management of Asthma*.<sup>i</sup>**

**Medical terms printed in bold are explained in Appendix A on pages 14–16.**

**A short checklist is also provided in Appendix B on page 17.**

### **Aims**

To improve the quality of life for people with asthma and ensure they reach their full potential by:

- informing people with asthma about what a high quality asthma service should look like
- improving their access to services and reducing health inequalities
- ensuring a high standard of care and treatment for all people with asthma.

### **Key objectives**

- To inform people with asthma what they can expect from health, social, education, employers and community services.
- To empower people with asthma and their families to manage their condition.
- To encourage people with asthma, their families and **healthcare professionals** to develop a partnership approach.

**You may find it helpful to take this guide with you when discussing your asthma with your healthcare professional or to call our Adviceline on 0800 121 62 44 and speak to one of our asthma nurse specialists.**

# Standard of care people with asthma should expect

## 1. Diagnosis

People with suspected asthma should expect:

- to be offered a **holistic** assessment and tests to get a prompt and accurate **diagnosis**
- to receive tests as outlined in the **BTS/SIGN** guideline including structured questionnaires which may include the **Royal College of Physicians (RCP) Three Questions** on asthma control
- to be given information which is relevant, easy to understand and in an accessible format
- to discuss the possibility of allergy adding to their symptoms (including allergic **rhinitis**)
- to be referred for further investigation in specialist care if diagnosis is unclear or symptoms are severe (this means step 4 or above of the **BTS/SIGN** guideline).

## 2. Self-management

People with asthma should expect:

- to have a full discussion on a regular basis with their **healthcare professional** about medicine, side effects and inhaler technique
- to discuss and to agree a written **personal asthma action plan**
- all information provided to be in a language and a format they can access and understand
- to be offered regular asthma **reviews**; face-to-face consultations can be supported by use of other technologies including telephone, online, mobile phone and **telemonitoring**
- to be supported in understanding their **triggers** and monitoring their asthma symptoms
- to be confident in knowing how to respond when their asthma gets worse
- to be confident in knowing what to do if they have an asthma attack
- opportunities to receive support from other people with asthma.

Children and young people with asthma, and their parents/carers, should also expect:

- to be offered ongoing, accurate and timely information about their condition through a variety of ways suitable for their age, stage of development and understanding, and reflecting their ability to manage their own condition
- to receive guidance and support as to how to use and record their **peak flow** if appropriate
- to be given the opportunity to practice their inhaler technique with an age-appropriate inhaler device
- to hold a full discussion with their healthcare professional about:
  - medicine and potential side-effects
  - how asthma affects their life
  - the management of **triggers** at home and at school
  - risk taking behaviours if appropriate
- opportunities to receive support from other young people with asthma and offer it
- to be supported to take more responsibility for managing their asthma as they get older
- health services to use new and creative methods, that fit in with the lives of young people, including the use of text messages and social networking websites to encourage **self-management** of their asthma
- to be given information in an appropriate format that details their current treatment and what to do in an emergency in order to inform teachers, school and pre-school staff about their asthma.

### **3. Regular structured review**

People with asthma should expect:

- regular (at least yearly for adults, three to six monthly for children) face-to-face meetings with their **healthcare professional**
- a complete assessment of their asthma control. This includes:
  - use of a validated **asthma control questionnaire**
  - review of **reliever** and **preventer** medicine
  - review of the number of asthma attacks they have had
  - use of oral **steroids** (if appropriate)
  - side-effects of medicine
  - checking correct use of their inhaler and selection of an inhaler device that they can easily use
  - age appropriate **lung function** tests such as **spirometry** or peak flow
  - monitoring of height and weight in children

- an opportunity to discuss concerns regarding asthma and its treatment options
- the development and review of their **personal asthma action plan**
- a discussion of symptoms and **triggers** and any associated allergies and conditions
- to be given asthma education according to their needs and understanding of asthma
- to be offered health education on diet, exercise and smoking cessation where appropriate
- to be offered psychological support when required (such as counselling, access to a psychologist etc)
- a review of their family and social circumstances where appropriate
- a review of days missed from work or school owing to asthma-related illness and any urgent (unplanned) visits to the doctor/emergency visits to the hospital
- an assessment of ability to undertake normal daily activities (such as exercising, socialising, participating in work or study)
- **referral to specialist teams** if required
- to receive up-to-date information on asthma and relevant support groups
- a review of other related conditions including allergic rhinitis that will lead to improved asthma control and quality of life
- community pharmacists to support them to manage their medicines and improve their self management of asthma making use of pharmacist-led medicine reviews (called **Medicines Use Review** in England and Wales) and to refer them for further support/review if required
- to receive an explanation and reassurance from community pharmacists regarding the use of **generic drugs**
- to be referred for a review with specialist respiratory physician (if on step 4 or above of the **BTS/SIGN guideline**) if asthma becomes difficult to control, or if the person with asthma asks for a second opinion.

#### **4. Management of acute exacerbations**

People with asthma should expect:

- to receive adequate education and information so that they know when their asthma is worsening and when and who to call for help
- to receive prompt and accurate assessment of their condition across **primary care, A&E/Urgent Care** and Walk-in centres, pharmacies and out-of-hours services

- ambulance services to be aware of local arrangements for getting people with asthma into hospital quickly and safely
- to be treated by **healthcare professionals** according to the severity of their condition according to BTS/SIGN guidelines
- to have a full asthma assessment and discussion covering factors which may have led to an attack, possible changes in medicine, checking correct use of inhaler and to be given asthma education and an interim **personal asthma action plan**
- clear lines of communication between out-of-hours services, GP and specialist care
- to be reviewed by their GP or asthma nurse within two working days after discharge from hospital. This includes being offered an updated personal asthma action plan
- support services to be in place for families of people with asthma who have been in Intensive Care Unit
- to have an agreed plan for quick access to emergency care if they have severe or life-threatening asthma.

In addition, children with asthma and their parents, and young people with asthma should expect:

- to be treated in an age-appropriate ward if admitted
- to be transferred, if necessary, to **Paediatric Intensive Care Unit/High Dependency Unit** under the supervision of appropriately trained staff.

## **5. Management of severe asthma**

People with severe asthma should expect:

- to have access to a specialist respiratory **multidisciplinary** team and unit with appropriate equipment
- to be referred to this team if asthma becomes difficult to control, or the person with asthma asks for a second opinion
- to receive a holistic approach to their care with further referrals for assessment, treatment and services from health specialists and social and educational services if required
- to be offered support in order to maintain connections with social networks and community life
- assistance with personal care and household activities when they need it
- to be signposted to a local self-help group and self-management courses

- to be actively assessed for anxiety and depression and offered appropriate support
- health and social care staff to work together along with leisure and community services and employers to support people with severe asthma
- to have a case manager, if required, to assess and monitor their asthma and other conditions.

## **6. Management of severe asthma in children and young people**

Children with severe asthma and their parents, and young people with severe asthma should expect:

- to be referred to, and be seen by, a specialist paediatric respiratory multidisciplinary team in a timely fashion, if receiving high doses of corticosteroids or if there is uncertainty about their diagnosis or if they have numerous emergency visits
- to be treated on the lowest dose of medicine appropriate for the severity of their asthma to gain control of their symptoms
- healthcare professionals based at different locations to have clear communication pathways to and from **specialist teams**
- referrals to be timely and straightforward. This includes referrals from GPs to specialists and from children's services to adults' services.

## **7. Asthma, allergy and anaphylaxis**

People with asthma and allergy related problems including **anaphylaxis** should expect:

- to receive an accurate assessment, a detailed history taken, appropriate investigations and treatment of allergic conditions by **healthcare professionals** trained in the management of allergy
- to be given education about indoor and outdoor **allergens** and discussion concerning the usefulness of allergen avoidance measures
- to be referred to specialist allergy service if required
- to be given a written action plan for **anaphylaxis** which is easy to understand and tailored to them
- to be given training and yearly checks on how to use their epinephrine auto-injector (**epipen**).

In addition, children and young people with asthma and allergy related problems including **anaphylaxis** and their parents should expect:

- to have one **multidisciplinary** team of specialists responsible for both asthma and **anaphylaxis**

- to be seen within two weeks of a severe acute episode (emergency) or new allergic response by an asthma/allergy team that includes:
  - a **paediatrician**
  - a dietician
  - a nurse with a special interest in allergy and asthma
- local authorities and school nurses to support schools and pre-schools to develop and implement policies which support children with asthma, allergy and **anaphylaxis**
- pre-school and school children to receive an action plan to use during school or pre-school.

## **8. Care of the child and the family**

Families of children with suspected asthma or diagnosed with asthma should expect:

- to be at the centre of their child's care and involved as partners in all decisions about their treatment
- to be supported by a range of local clinicians across community, primary, hospital and specialist care including community nurses and health visitors who provide care in the home
- a designated **paediatrician** who has fulfilled the training requirements of the **RCPC**H with special interest in respiratory paediatrics to maintain standards of asthma care in the paediatric unit and the emergency unit
- clinical staff in hospital to offer adequate information about diagnosis in a timely fashion to colleagues in primary care
- rapid access to hospital between the emergency and outpatients department
- timely access to services for scheduled and unscheduled appointments
- timely access to specialist support for children with difficult-to-diagnose or complex respiratory problems.

## **9. Partnerships with schools/pre-school establishments**

Children, young people and their families should expect:

- the **NHS** and local authorities to work together to ensure asthma policies are implemented in every primary, secondary and nursery school in their area
- school asthma policies to be regularly reviewed, evaluated and updated
- school nursing service to support schools to develop and implement action plans for asthma and anaphylaxis
- all schools to maintain an up to date asthma register

- all school staff to be provided with asthma education including training on what to do in an asthma attack and **anaphylaxis**
- to work with school staff and health and social care professionals to create a supportive environment for pupils with asthma to enable them to fully participate in educational activities
- every pupil to have an action plan to communicate vital information to school staff about their asthma
- pupils to be encouraged to look after their own reliever inhaler where appropriate.

## **10. Transitional care**

Young people with asthma should expect:

- health services to be designed to cater for the specific needs of young people
- to be fully involved in their asthma management including the development of their personal asthma action plans
- health services to have in place a clear pathway for transition from paediatric to adult services
- to be consulted about how and when they are transferred from paediatric to adult services
- to be offered the opportunity to attend a transition clinic in the paediatric department
- to be supported by primary care in developing increasing independence to self manage their asthma
- to be offered the opportunity to make their own appointments for asthma reviews with their doctor or asthma nurse and to order/collect their prescriptions.

## **11. Occupational asthma**

Employees should expect:

- their employer to offer necessary protection from the possible causes of **occupational asthma** such as exposure to chemicals
- their employer to offer protection from those conditions that **trigger** symptoms of pre-existing asthma
- their employer to provide up-to-date information on preventing, reducing the risk of and managing **occupational asthma**
- people who develop symptoms suggestive of **occupational asthma** to be referred by their employer for immediate investigation and prompt diagnosis

- if diagnosed with occupational asthma, for their employer to ensure management of their condition and ongoing protection
- their employer to ensure that all employees know what to do if a colleague experiences an asthma attack
- their **healthcare professional** to consider their occupation at time of diagnosis and regular review.

## **12. Bereavement through asthma**

People including families, carers and communities, bereaved through asthma should expect to be proactively offered support from relevant organisations.

Families and carers should expect:

- effective systems to exist which ensure that lessons learnt can be shared and practice improved where necessary
- to be invited by their GP and practice to review the death in a supportive, open and transparent manner and to offer support during their bereavement
- to be directed to relevant support organisations including Asthma UK Adviceline nurses, **CRUSE** and child bereavement charities
- confidential death enquiries to occur annually and to be supported by the relevant government departments.

Where there is concern over the death, to be actively referred to:

- relevant **Clinical Governance** team and a request for a review of the death to be conducted
- relevant local patient support services.

Communities affected by bereavement (including schools and workplaces) should expect:

- to be directed to Asthma UK for support and advice
- a risk assessment to be performed to identify gaps in care.

## **13. Health and social care professional education and training**

People with asthma should expect:

- information and advice on managing asthma to be an essential part of training and education of all members of the healthcare team including ambulance staff

- healthcare managers to regularly assess knowledge of asthma in the healthcare team and implement appropriate asthma training and education programmes in their organisation
- appropriate members of the healthcare team to have protected time to offer asthma education.

#### **14. User involvement, communication and information**

People with asthma, regardless of age or background should expect:

- to be equal and expert partners with their **healthcare professional** at each stage of their treatment and care
- to be asked about the quality of local asthma services
- to be invited by health, education and social organisations to plan, develop and monitor asthma services in their area
- to be consulted and/or invited to become members of **managed clinical networks**/respiratory working groups to improve local asthma services
- good communication between primary, secondary, specialist and community services
- healthcare professionals to point them to:
  - relevant helplines
  - self management courses
  - local self-support groups
  - other community support resources, including local physical activity groups
  - voluntary sector organisations
  - other sources of information about asthma
- information to be made available in a variety of accessible formats including written, web based, face-to-face, via the telephone, translated into their first language
- information on possible treatments and the services available locally, regionally and nationally
- a discussion about complementary medicines and therapies with their GP or asthma nurse.

#### **15. Support for carers**

Carers of people with asthma should expect:

- to be treated as partners in care and involved in all aspects of care planning
- to be involved in supporting self-management of the person they care for
- support from health and social care staff working together along with leisure and community services

- appropriate members of the healthcare team to have protected time to offer them asthma education
- health and social care professionals to point them to relevant helplines and other community support resources and voluntary sector organisations
- information to be made available in a variety of accessible formats including written, web based, face-to-face, translated into their first language
- information on types and quality of services and carer support available locally, regionally and nationally
- to be offered assessment and support when required.

## **16. Prevention**

People with asthma should expect:

- to be offered a discussion about their smoking history and to be given information on the effects of smoking and passive smoking on asthma control
- health, social, education, community and voluntary agencies to work together in order to educate everyone about tobacco (especially pregnant women) in order to minimise harm to themselves and others. This includes offering a smoking cessation service
- schools and community groups to provide tobacco information in their curricula
- to be asked about how to design smoking cessation services suitable for their needs – particularly young people.

Pregnant women with or without asthma should expect:

- up-to-date information about the benefits of breast feeding from their **healthcare professional**
- health and social care agencies to work with their communities to support breast feeding.

## **17. Targeting inequalities**

People with asthma should expect:

- to receive high quality asthma services and information regardless of age, gender, sexuality, ethnicity and culture, religion, disabilities, co-morbidities and socio-economic status from the agencies/organisations involved in their asthma care
- access to high quality asthma services wherever they live in the UK – whether urban, rural or remote.

# Glossary of terms (Appendix A)

**A&E** – accident and emergency department

**Acute** – describes a disease or condition that develops quickly with severe symptoms

**Allergen** – a substance capable of producing an allergic response in the body

**Anaphylaxis** – a severe allergic response to an allergen leading to a severe or life threatening reaction

**Asthma control questionnaire** – a tool to help patients assess their asthma control

**BTS** – British Thoracic Society. The aim of the organisation is to improve the care of people with respiratory and associated disorders

**Case manager** – the professional who is responsible for coordinating services provided to a person with a complex long-term condition

**Clinical governance** – term describing key activities needed to maintain high standards of patient care

**Clinical guidelines** – statements drawn together by specialists to help make decisions about how to treat a particular condition

**CRUSE** – organisation which helps support those who have had a bereavement

**Diagnosis** – identification of an illness or health problem by its signs and symptoms. This involves ruling out other illnesses and possible causes for the symptoms

**Epipen** – trademark for a commonly used autoinjector of epinephrine (adrenaline) which can be used by anyone (ie not just doctors). It provides a rapid, single dose of adrenaline to individuals experiencing potentially life threatening anaphylaxis

**Exacerbation** – an increase in the severity of a disease or in any of its signs or symptoms, a ‘worsening’

**Generic drug** – a drug produced and distributed without patent protection (ie it is cheaper)

**Health inequalities** – differences in health outcomes, access to, and uptake of health services between groups in society

**Healthcare professional** – a person qualified in a health profession (eg doctor, asthma nurse)

**Holistic** – an approach that considers physical, psychological, social and spiritual well-being

**Lung function** – lung function is a term that is used to describe how well the lungs are working. It usually refers to how much air you can breathe in and out, how fast you can breathe air in or out, and how well your lungs deliver oxygen to your blood

# Glossary of terms continued

**Managed Clinical Network** – a network of a variety of health staff and organisations from primary, secondary and regional health care working together to make sure that high quality clinically effective services are fairly distributed

**Medicines Use Review** – an appointment with a pharmacist to focus on how a person is getting on with their regular medicines

**Morbidity** – the incidence or commonness of a condition/disease in a population (ie the number of people with the condition/disease)

**Multidisciplinary** – an approach combining the knowledge, skills and expertise of a range of organisations and professionals

**NHS** – National Health Service

**Occupational asthma** – asthma that is caused by some substances that you might come across in the workplace

**Paediatric** – the care and medical treatment of children and young people

**Paediatrician** – a doctor who deals with children and young people and the medical treatment of their condition

**Peak flow** – peak flow rate is a measure of how fast a person can blow air out of their lungs. It is measured by something called a peak flow meter

**Personal asthma action plan** – a plan that contains the information you need to keep control of your asthma. It includes details about your asthma medicines, how to tell when your symptoms are getting worse and what you should do about it, and emergency information on what to do if you have an asthma attack. It is agreed by you and your healthcare professional

**Preventer** – medicine taken regularly which stops inflammation in the lungs and reduces the symptoms of asthma

**Primary care** – care delivered to patients outside hospitals and includes general practices as well as dentists and pharmacists

**Referral** – when a patient is referred from one professional to another, usually for specialist advice and treatment

**Reliever** – a medicine that acts quickly to relax and open up the airways making it easier to breathe

**Review** – an assessment with the possibility of changing or confirming a current treatment plan (ie current medicines)

**Rhinitis** – irritation and inflammation of internal areas of the nose

# Glossary of terms continued

**RCPCH** – Royal College of Paediatrics and Child Health

**Royal College of Physicians (RCP) Three Questions** – questions asked to patients to assess their asthma control concerning the symptoms experienced during the night, during the day and during their usual activities

**Self-management** – gaining the skills and knowledge that are required to cope with the physical, social and emotional aspects of a medical condition and improve one's quality of life

**SIGN** – Scottish Intercollegiate Guidelines Network – SIGN develops national clinical guidelines to help improve the quality of healthcare in Scotland

**Specialist team** – in addition to respiratory specialist doctors this includes asthma nurse specialists, dieticians, mental health workers and physiotherapists

**Spirometry** – a test used to determine how well the lungs are functioning. It involves blowing into a device called a spirometer which can then record the amount of air that can be blown into and out of the lungs and how fast

**Steroid** – a medicine given in asthma to reduce inflammation, swelling and excess secretions within the airways. It can be given as either an inhaler, tablet or sometimes as an injection

**Telemonitoring** – a system where home based monitoring equipment is set up and linked to either a call centre or respiratory team to help in the monitoring of respiratory conditions in the home

**Transition** – moving or preparing to move from one service to another, for example, children to adult services

**Triggers** – something that irritates the airways and leads to the symptoms of asthma

# Good asthma care checklist

## (Appendix B)

A good asthma service means that a person with asthma:

- ✓ receives a quick and accurate diagnosis of asthma, through the most appropriate methods, with referral to a respiratory specialist if required
- ✓ has a Personal Asthma Action Plan, in an appropriate format, that they have discussed and agreed through a face-to-face consultation with their healthcare professional
- ✓ has access to appropriately trained healthcare professionals who follow the British Guideline on Management of Asthma and who work across organisational boundaries
- ✓ has access to effective emergency and out-of-hours services when experiencing an asthma attack or worsening of their condition with follow up appointments arranged prior to discharge
- ✓ has access to specialist healthcare professionals and services that meet individual needs, including specialist wards and centres
- ✓ has their condition managed in an appropriate manner, with particular recognition given if they are a young person moving into adulthood
- ✓ and their parent/carer has access to a range of local services including education, social care and housing that also meet their social, emotional and psychological needs
- ✓ and their parent/carer is empowered to be actively involved in the local planning, delivery, development and evaluation of services to meet the diverse needs of all people with asthma
- ✓ has access to easy-to-understand high quality asthma information in a format and language they can understand as part of an effective health inequalities strategy
- ✓ benefits from an integrated approach between local government and health services to tackle the wider social and economic factors of health inequalities with an emphasis on targeting 'seldom heard' groups.