# Information for staff to support children young people and their carers in the management of their asthma

**London asthma standards**

11. CYP and their families receive **sufficient information, education and support** to encourage and enable them to participate actively in all aspects of their care and decision making. This means information is tailored to their needs in an accessible format (eg written information may use pictures, symbols, large print, Braille and different languages) throughout the care pathway extending into schools and community settings.

12. CYP and their families have **access to self-management support packages** which may include peer support.

**Introduction**

This guide is for clinicians working with children and young people to help you support your patients in the management of their condition

**What is self-care?**

Self-care is defined as an active partnership between the patient and the system it’s about both long and short term conditions and not just about medical care.

The child and parent/carer needs to understand their condition and the medicines they are prescribed so they can manage their condition and make any necessary changes to their lifestyle. Education is essential but we need to sign post patients to the right support/resources to help

The NHS can support people to self-care at any point along the way.

<http://www.selfcareforum.org/about-us/what-do-we-mean-by-self-care-and-why-is-good-for-people/>

We hope children and young people who self-manage their condition will adhere to treatment, have fewer symptoms and therefore fewer emergencies and need fewer urgent consultations. Clinicians have a key role to play in supporting children and young people to become key decision makers in managing their condition as soon as they are old enough to do so. This should be done through regular yearly reviews, provision of appropriate structured education and information and access to clinical expertise.

***Low numbers of children with an asthma plan***

The *British Thoracic Society / Scottish Intercollegiate Guidelines Network (BTS/SIGN) guideline*[[1]](#footnote-1) and recent *National Review of Asthma Deaths* (NRAD)[[2]](#footnote-2) suggest that every child with asthma should have a personal asthma action plan

However, NRAD found only 14% of those who died had a PAAP and a 2014 Asthma UK survey found implementation and uptake of these asthma management plans is slow with London being the worst in England.[[3]](#footnote-3) Work is needed to implement this recommendation as only 19% (n= 133/637) of the children in London said they had an asthma plan compared with 22% (n=1,109) nationally, 75% said their inhaler technique had been checked and 68% said they had had an asthma review compared to 76% nationally*.* Patients without a PAAP are 4 times more likely to need hospital treatment for their asthma.[[4]](#footnote-4) There is a need to look at innovative ways to increase the provision and uptake of asthma action plans. On a more positive note a recent London public heath pharmacy campaign found that 48% (out of 9860 surveryed) stated that they had a plan, although they were not asked if this was a written one.

Seventy five per cent of children’s admissions could be prevented through better primary care, rigorous pre-discharge assessment with optimization of treatment by hospital specialists and the use of Personal Asthma Action Plans, hand held records and regular reviews. Two thirds of hospital admissions could be averted, with improved preventative care, incorporating these asthma plans, education and risk reduction and better disease control .[[5]](#footnote-5) Provision of written asthma action plans will help patients to self-manage and self-monitor. [[6]](#footnote-6)

**Collaborative Care planning**

Children, young people and their families should be supported to manage their asthma. We aim to do this by setting goals identifying and agreeing support needs and developing a documented personalised asthma action plan (PAAP) that they understand. Access to culturally appropriate educational packages should be available for the child and family.

*‘As care planning for people with long term conditions (LTCs) becomes the default, there is great potential for care plans to become a ‘patient passport’ which directs them to the right source of advice, professional or service in the event of an exacerbation of their condition . If they have a named keyworker, then they will be the point of first contact, otherwise most people with an LTC will be directed to contact their GP surgery who provide continuity of care through a ‘named responsible clinician’. Some people with complex or unusual needs and most children with LTCs will be signposted via their care plan directly to a specialist’ [[7]](#footnote-7)*

**Asthma action plans**

All children and young people should have a personalized asthma action plan which can help them recognize when their symptoms are worsening and know what to do about this.

This plan should include information on:

* Triggers
* What the treatment does (prevents/relieves)
* How and when to take treatment
* Current treatment
* How to spot asthma getting worse (symptoms and peak expiratory flow)
* What treatment to take in an emergency; how and when to call for help

## [Example Asthma Action plans](http://www.patient.co.uk/doctor/asthma-action-plans) (as recommended by NICE in 2013)

* See basic PAAP link to
* [Asthma UK](http://www.asthma.org.uk/advice-asthma-and-me)
* *If you would like a Monkey wellbeing asthma action plan, click* [*here*](https://www.monkeywellbeing.com/wp-content/uploads/2014/09/asthma-plan-v3.pdf)*(under 7s) or* [*here*](https://www.asthma.org.uk/globalassets/health-advice/child-asthma-action-plan.pdf) *(over 7s).*

Link to other example asthma plans NCL, UCLP etc

It is important to explore children and parents concerns and expectations and provide them with the information they need to support decision making..

Aim to implement consistent improvements in education around self- management using tailored education packages or existing online resources such as *itchy wheezy sneezy* <http://www.itchysneezywheezy.co.uk/>

**Ability to recognise asthma deteriorating**

Allergies and asthma often co-exist therefore, recognition and avoidance of environmental exposure to allergens and smoke is important. Children need to learn to recognize what triggers their asthma and how to minimize these risks any deterioration –

* Are they using their reliever medication more than twice a week?
* Is their asthma waking them at night?
* Are they less able to do their regular activities such as sport?

## Asthma Inhalers

It is essential children and young people use their inhalers correctly and as prescribed. Inhaler techniques should be assessed at every contact (link to inhalers)

**Prevention and public awareness**

* I will grow up in an **environment** that has **clean air that is smoke free**.
* I will have access to an **environment** that is **rich with opportunities to exercise**.

**London asthma standards**

Consultations **routinely promote healthy lifestyles**, including assessment of long term health needs, such as:

- Systematic approach to obesity (eg growth measurement, calculation of BMI)

- Assessment of CYP and family for living conditions and housing freed from damp and mould, alcohol, drugs and smoking.

Every **child and their family are assessed** at health or social care encounters for their **exposure to smoking** either actively or passively (this includes e-cigarettes). They should be provided with brief advice and referred to smoking cessation clinics.

There is **access to smoking cessation clinics** and other support services for families, Fraser competent CYP and carers that address issues of smoking and monitor outcomes.

Children’s asthma services need to be commissioned in a seamless integrated fashion across the entire pathway from prevention and self-management to in hospital and out of hospital care. It should be managed and evaluated against national [London asthma standards for children and young people](https://www.myhealth.london.nhs.uk/healthy-london/children-and-young-people/resources) and local standards.

**Triggers**

* I will grow up in an **environment** that has **clean air that is smoke free**.

**London asthma standards**

Every child has an **assessment of the triggers** for their wheeze and is educated about how to deal with this.

Children with asthma should be screened for other atopic comorbidities, in particular allergic rhinitis and food allergy.

There is **access to a paediatric allergy service** for assessment and appropriate management, including adrenaline auto injector device prescription and training if required.

Many things can make a child’s asthma worse, these may different for individuals and it is important to identify what triggers a child’s asthma

Further information available on [NHS Choices](http://www.nhs.uk/Livewell/asthma/Pages/Asthmatriggers.aspx)

**Air quality and asthma**

A [recent Royal College of Physicians and Royal College of Child Health report](https://www.rcplondon.ac.uk/projects/outputs/every-breath-we-take-lifelong-impact-air-pollution)[[8]](#footnote-8) found air pollution is linked to 40,000 deaths every year. There is mounting evidence air pollution may cause asthma, as well as triggering symptoms. The report also highlighted the issue of indoor air quality as well which includes kitchen products, faulty boilers, open fires, use of spray deodorants, air freshener and scented candles.

Further information on [pollution](http://asthma.us2.list-manage.com/track/click?u=63ea995e3f7f9de3e68718a61&id=112a8c2388&e=559cbe2767) and [indoor environment](http://asthma.us2.list-manage.com/track/click?u=63ea995e3f7f9de3e68718a61&id=0334cf0703&e=559cbe2767) available from Asthma UK

Regular updates are available via a number of apps available on the app store:

**Allergens**

House dust mites, pets, mould and pollen can be a trigger for people with asthma. Pollen comes from trees, grasses and weeds and is spread by the wind and insects.

Local health economies could consider regular [air quality alerts](http://www.airtext.info/), [weather](http://www.metoffice.gov.uk/public/weather/forecast/gcpvj0v07) and [pollen count](http://www.worcester.ac.uk/discover/pollen-forecast.html)[[9]](#footnote-9) updates and advice. Whilst a job for government, local authorities or business to make legislative changes, parents and young people can take a part to reduce pollutant exposure and triggers to help protect themselves

**Psychosocial**

Psychosocial aspects of care are as important as physical aspects and therefore a full assessment of the child and family should be undertaken

Build resilience of families by working with local communities and optimising neighbourhood resources for the benefit of raising awareness, education and concordance

1. Psychological intervention for children with asthma (review) <http://www.thecochranelibrary.com/userfiles/ccoch/file/CD003272.pdf>
2. Difficult to control asthma in children
3. <http://www.medscape.com/viewarticle/554049_5>

Link to article: The impact and influence of pschocial factors on asthma Fran Beresford, Clinical psychologist, Royal Brompton Hospital (Appendix A)

**Smoking**

Exposure to tobacco smoke may trigger symptoms and can significantly increase the severity and frequency of attacks. Therefore, healthcare professionals should make every contact count and encourage children and young people to avoid exposure to tobacco smoke. Parents/ carers or children themselves may need help and referral to smoking cessation services

The recent pharmacy public health campaign reinforced the case for children and young people and their parents/carers in smoking cessation

**23%** children and young people lived with a smoker

**10%** 15 years old with asthma were self-reported smokers

**16-18%** of 16 and 17 year olds were self-reported **smokers**

Support to give up smoking is available [here](https://www.nhs.uk/oneyou/smoking#K85hghRaWfJfdJC2.97)

* find [stop smoking services in England](http://www.nhs.uk/smokefree/help-and-advice/local-support-services-helplines)
* call the free Smokefree National Helpline on 0300 123 1044

**Links to free online training aimed at all staff**

Very brief advice on smoking: Short Training (1 hour) Module Freely available. CPD accredited <http://www.ncsct.co.uk/publication_very-brief-advice.php>

[Advice available on local smoking services](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216927/9193-TSO-2900254-NHS-Stop-Smoking_Accessible.pdf)

[NICE guidance: Preventing the uptake of smoking by children and young people](http://www.nice.org.uk/guidance/ph14/resources/guidance-preventing-the-uptake-of-smoking-by-children-and-young-people-pdf)

[**National referral system**](http://www.ncsct.co.uk/publication_national-referral-system.php)

There is now a National Referral System for smoking cessation referral It has already processed over 10,000 referrals to local stop smoking services across England. The system results in a significantly greater number of staff being trained in delivery of very brief advice on smoking, and the routine identification of hospital patients who smoke

* Trial monitoring all teenage children (Gillick competent) at point of care – carbon monoxide monitors or urinary cotinine levels. Counsel children as appropriate
* Lobby to Improve regulation of e-cigarettes as in Queensland where they are treated the same as regular cigarettes

**Exercise**

Exercise can trigger shortness of breath, coughing, wheezing or chest tightness in some people but this should not stop children from taking part in PE (link to PE and exercise section in schools). Many athletes have exercise induced bronchoconstriction (see Paula Radclife and exercise: [**http://www.nhs.uk/Livewell/asthma/Pages/PaulaRadcliffe.aspx**](http://www.nhs.uk/Livewell/asthma/Pages/PaulaRadcliffe.aspx)

**Viral infections**. A cold, flu or other respiratory infections can make asthma worse. Therefore children and staff should be encouraged to have a flu injection each year.



Monkey well being Flu fighter resources available here <https://www.monkeywellbeing.com/new-monkey-flu-fighter-poster/>

link to flu in pharmcy document

Insert prevention here including flu for staff

**Technology**

Alternative technology should be considered ie apps, access to medical records via health portals websites i.e.

Microsoft health vaults <https://www.healthvault.com/gb/en>

My health locker <https://www.myhealthlockerlondon.nhs.uk/>

**Useful reading**

The health Foundation (2015) A practicalguide to self-management check this out <http://www.health.org.uk/publication/practical-guide-self-management-support>

Evaluating self-help for CYP with long term conditions <http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1715-162_V01.pdf>

Asthma UK Self management plans <http://www.asthma.org.uk/Sites/healthcare-professionals/pages/self-management-materials>

Asthma UK: Asthma and me & Asthma and my child booklets

<http://www.asthma.org.uk/Sites/healthcare-professionals/pages/point-of-diagnosis>

*If you would like information on managing your asthma better visit the Asthma-UK website* [*here*](http://www.asthma.org.uk/advice-manage-children)*.*

*Or you could look at the Wessex Academic Health Science Network website* Owning My Asthma (14-19 year olds) – enhanced self-management

[*http://wessexahsn.org.uk/projects/43/owning-my-asthma-14-19-year-olds-enhanced-self-management*](http://wessexahsn.org.uk/projects/43/owning-my-asthma-14-19-year-olds-enhanced-self-management)

***Videos***

* Department of Health <http://www.dh.gov.uk/en/Healthcare/Qualityandproductivity/QIPPworkstreams/index.htm>
* Asthma UK: <http://www.asthma.org.uk/>
* Asthma4children <http://www.youtube.com/user/Asthma4children/videos>
* My Asthma Log: <https://play.google.com/store/apps/details?id=com.solarsoftware.myasthmalog&hl=en>

**Multifaceted intervention for asthma** (MIA)

* A link to the full report is below:
* <http://www.journalslibrary.nihr.ac.uk/hsdr/volume-2/issue-28>
* The MIA research team also developed a video to highlight the research findings:
* <http://vimeo.com/105418355>
* <http://www.asthma.org.uk/Blog/research-south-asian-families-need-more-help>
* NECLES HIEC Asthma site: <http://www.necles.org.uk/whatwedo/Asthma/index.html>

**Inhaler techniques**

Wessex Academic Health Science Network

<http://wires.wessexhiecpartnership.org.uk/video-series/inhaler-technique/>

You can view some of the podcasts here:

* [**Inhaler project poor technique**](http://psnc.jellyha.us/manchester/wp-content/uploads/sites/10/2013/07/Inhaler-project-poor-technique.pdf)[**Inhaler project good technique**](http://psnc.jellyha.us/manchester/wp-content/uploads/sites/10/2013/07/Inhaler-project-good-technique.pdf)[**inhaler project mixed technique**](http://psnc.jellyha.us/manchester/wp-content/uploads/sites/10/2013/07/inhaler-project-mixed-technique.pdf)[**Inhaler project hints and tips**](http://psnc.jellyha.us/manchester/wp-content/uploads/sites/10/2013/07/Inhaler-project-hints-and-tips.pdf)

**Help me manage my asthma at school:** <http://www.wellatschool.org/index.php?option=com_content&view=article&id=96&Itemid=262&gclid=Cj0KEQiAypGjBRCPme6jmqu3gZsBEiQA8NAiINQcaQtGO_EjzZVC3z-EwRmiF8AJhJ0NP6rMmZa_FZ8aAph_8P8HAQ>

<http://wessexahsn.org.uk/projects/43/owning-my-asthma-14-19-year-olds-enhanced-self-management>

**European Respiratory Society Monograph**, (2012) Vol. 56. <http://www.ers-education.org/publications/ers-monograph/archive/paediatric-asthma.aspx> Paediaric medicine

<http://www.realfirstaid.co.uk/understanding-asthma/>

Paediatric asthma remains a health problem on a global scale, for the individuals, their families and the children,. most children with asthma are able to have a "healthy" life, and participate in physical activities on an equal level with their healthy peers, with a normal development into adolescence and adulthood.

**Asthma UK**

Stay up to date with the latest developments in asthma and receive updates on how Asthma UK is working with healthcare professionals to improve asthma care.<http://www.asthma.org.uk/Sites/healthcare-professionals/pages/available-training>

### Appendix A

# The Impact and Influence of Psychosocial Factors on Asthma

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In order to deliver effective asthma management both **psychosocial** and physical factors need to be considered; they are inextricably linked to all health issues but have been noted to be particularly pertinent in some chronic illnesses, one of which is asthma. The impact can be either positive or negative. For instance, the beliefs children and families have about asthma, prescribed medication and/or the disease will impact on how they perceive the child’s symptoms, their willingness to engage with health advice, any prescribed treatments and/or suggested life changes. Evaluation of mental health symptoms and psychosocial factors that are known to be associated with asthma leads to informing more effective and comprehensive interventions resulting in better asthma control, improved child and family quality of life, reduced mortality and health care cost savings. It is not useful to try and determine causality, whether asthma caused psychosocial issues or the other way round, if both are present, both need addressing on their individual merits.

**The Psychosocial Issues and the Impact they have on asthma**

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**Mental Health and Coping in the Primary Care Giver**

It is widely reported that there is a higher incidence of anxiety and depression in parents of children with asthma, particularly mothers (Easter et al 2015). The impact of depression can be profound. Mothers’ level of depression was associated with beliefs and attitudes that directly influence adherence, such as less belief in the efficacy of asthma medication and poorer understanding of how to use medication (Bartlett et al., 2004). Parents’ mental health can have an unfavourable impact on the course of asthma in their children (Tibosh, Verhaak & Merkus, 2010).

Taking the time with caregivers and families to assess, listen, discuss and provide education about asthma and asthma management helps build confidence and trust between the medical team and family, which will promote collaboration in goal setting and aid adherence to the child’s asthma medication regimen (Bender, 2002). Written instructions and materials given to caregivers and their families aim to reinforce the education/instructions that are provided during visits.

Asthma Action Plans should be regularly updated and given to all caregivers, including school (e.g. updated at every clinic visit). Providing good asthma education to parents and carers builds on self-efficacy and confidence, leading to reduced asthma-related hospitalisations in children (Flores, Abreu, Tomany-Korman, & Meurer, 2005), this will include assessment of inhaler technique, understanding of medications, knowing how to identify when asthma is deteriorating and knowing what to do. The assessment and addressing of parents mental health needs, identifying the issues, referring to appropriate agencies and offering regular reviews is equally as important.

**Mental Health and Coping in the Child Patient**

The challenges of coping with a chronic disease, such as asthma, requires a child (and parents) to manage an additional level of stress. Managing this stress can require adaptation cognitively, emotionally, behaviourally and socially. The child and their family’s coping style has been shown to have significant associations with clinical outcomes, such as physical functioning, disease control, morbidity, mortality and quality of life (Braido et al 2012). An adaptive style of coping might include acceptance of the illness, actively addressing challenges presented by the disease and acknowledgement of the emotions associated with this. Maladaptive coping styles can include passive, avoidant or emotion focussed coping styles. Once coping styles are identified, children and their families can be offered training and educational interventions to strengthen their coping strategies, improving asthma management, self-confidence and reducing anxiety and make positive changes where appropriate.

Empirical evidence consistently reports higher rates of anxiety, depression and stress in children with asthma (Katon et al 2004). Parental coping styles directly influence the coping style of their child, this is particularly pertinent to anxiety. Anxiety (also referred to as ‘worry’, ‘fear’ or ‘stress’) can be causal and/or a consequence of asthma. The impact is variable and dependent on many contributing factors. A helpful impact of anxiety is that it will heighten awareness of symptoms and can help children to avoid allergens, use medication and/or to seek adult help. Conversely a negative impact can be hyper-vigilance of symptoms, avoidance of activities and/or misinterpretation of anxiety and panic symptoms. Physical manifestations of anxiety include hyperventilation and other dysfunctional breathing patterns (which may themselves be mistaken for uncontrolled asthma and managed by inappropriate escalation of medication), palpitations, breathlessness, sweating and shakiness. Thoughts connected with this state of arousal can include ‘I can’t breathe’, ‘I’m going to die’, which in turn fuels the anxiety response. These consequences of anxiety can complicate the clinical picture and lead to escalation of medical interventions that could be avoided by recognition and treatment of the anxiety. The literature suggests that children reporting high levels of anxiety access healthcare more frequently and children who report a significant level of anxiety and/or depression symptoms also report a much higher asthma symptom burden (Richardson et al 2006). This has implications on their and their main care givers’ quality of life and the cost of health care services.

By screening for anxiety symptoms, exploring children’s thoughts and beliefs and assessing their breathing pattern, any reported worries and fears can be identified and then addressed by the multi-disciplinary team, including clinical nurse specialists, physiotherapists and psychologists. This can be through psycho-education of anxiety, breathing techniques, relaxation and cognitive behavioural therapy.

Below is a link to an example of a toolkit for teenagers and young people living with asthma:

<http://www.paintoolkit.org/downloads/My_Asthma_Toolkit_April_2015.pdf>

The diagram below gives an example of various systems, and as such possible influences, which may surround the child and/or their family. At the Royal Brompton Hospital we have found that by involving wider systems around the child and family we have improved the understanding of the individual needs of a child and family, resulting in improved concordance of the child and their family to the management of asthma.

In summary, both from the literature and anecdotally, psychosocial factors have been found to play a significant role in gaining a clear understanding of childhood asthma and without this understanding the management can be compromised. Through a thoughtful assessment the level of complexity can be clarified and interventions offered according to need. This is a relatively new area and further research is needed to build a model of what works for whom.

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