

Personal Statement for Sally Rose

My background

I have many years experience of being involved with children with asthma and their parents and carers. I ran asthma clinics for several years in primary care and have been an asthma nurse specialist on the Asthma UK Adviceline for the past year. At the Adviceline I receive telephone calls and emails from parents, carers, and sometimes children themselves on a daily basis.

Impact of asthma on children aged 12 and under

Parents/carers (P/C) say:

- ⌘ Worried their children will have it for life.
- ⌘ Affects the whole family, eg. a family pet may have to be re-homed.
- ⌘ Causes communication problems with school or nursery because their children can be marked out as different and the teachers don't understand about asthma. For example, children may need medication while at school or they may not always be able to do PE.
- ⌘ Can be difficult when need to take time off work to look after their child when their asthma is bad.
- ⌘ They hope their child will 'grow out of it'.

Children say:

- ⌘ They get bullied and called 'puffer boy/girl' (even when as young as six).
- ⌘ Teachers tell them off if they cough a lot in class.
- ⌘ Can cause family arguments. For example, if they ask a family member not to smoke around them, or if siblings blame them for not being able to have a pet in the home.
- ⌘ They wish they could be 'normal'.

What parents/carers say about inhaled corticosteroid medication (ICS):

- ⌘ It makes a big difference to their child's life because their asthma can be kept under better control, meaning they are well much more of the time and can join in with family and school life.
- ⌘ Better control means their child doesn't need to use as much reliever inhaler when at school or out and about, so they don't worry about their child as much.
- ⌘ They like the fact that ICS generally only has to be given morning & night when the child is at home and not at school or nursery.
- ⌘ But the main concern almost all P/C have is the possibility of long-term side effects of ICS on their children's growth and overall health. A few mention concerns about adrenal suppression. Worry over side effects tends to have several implications:
 - ⦿ P/C don't give ICS as prescribed, even when they see the benefits in their child's asthma.
 - ⦿ Because many children's main trigger is respiratory virus, P/C only give ICS at the start of a cold, then say it 'doesn't work' because child's asthma gets worse anyway.
 - ⦿ P/C try complementary therapies instead, such as homeopathy.
 - ⦿ P/C sometimes say they prefer fluticasone because they perceive the dose as being smaller than with beclometasone or budesonide.
 - ⦿ They prefer their child to have a long-acting B2 agonist (LABA) (or montelukast in the case of young children) added to ICS rather than a higher dose of ICS, although

more recently some have expressed concern about the safety of LABAs following press reports.

- ⌘ Some express concern about the local side effects of ICS in the mouth and throat and wish there was an ICS which didn't do this.
- ⌘ When their child is taking a LABA as well as ICS, they usually prefer giving it in a combination device - there is less chance of inhalers getting lost, they know the child has taken both medicines and there is less to nag/argue with their child about!
- ⌘ *But*, because some P/C are still advised to increase ICS at the first sign that their child has a cold, or have always done this, they just increase the combination inhaler dose meaning the child gets too much LABA, especially with the fluticasone/salmeterol devices.
- ⌘ Inhaler device is as important, and often more important, than the actual ICS chosen by the prescriber. Although I understand this is not within the remit of this appraisal, in my experience P/C feel it is not possible to separate the choice of drug from the choice of device. For example, P/C like devices with dose counters for older children so they can check that the child is taking it, so device choice may limit drug choice.
- ⌘ Many, many P/C express frustration at the lack of information about ICS and its effects (both good and bad) given to them by the prescriber, and complain of being fobbed off when they ask about side effects.
- ⌘ They want to be offered an informed choice of both ICS and device which is appropriate for their individual child. There is no 'one size fits all'. For example, they may ask if there is an ICS which doesn't cause their child to have a hoarse voice. They may prefer their child to have a dry powder device for portability, particularly if the child frequently spends time at different homes when parents live apart.

What children say about ICS:

- ⌘ Device is crucial - not really bothered about the actual medicine at this age unless they can tell it has side effects, such as a sore mouth. Even as young as seven they want a 'cool' device that's as much like a gadget as possible. For example, among older children, Accuhalers are popular.
- ⌘ If they need a LABA, they often prefer combination treatments because they can 'tell they are working'. Unlike with an ICS on its own, if they forget to take their combination inhaler, they are more likely to notice the difference in their asthma much sooner.

My own comments

Asthma has a clear impact on children and their families. It also has a big impact on a child's school life. Achieving good control of asthma symptoms reduces the effects of asthma on daily life, and so P/C generally see the benefits of using ICS and where appropriate, LABAs. But they want more informed choice of both the specific ICS and, often more importantly, the device. They want their children to be happy taking their medicine because it reduces conflict between P/C and child, and it also means the child is more likely to stick with their asthma medication. I also feel this can help establish good patterns of concordance throughout life.

P/C need a lot more information when their child is prescribed ICS. They hear the word steroid and immediately think of side effects, and often these are unnecessary concerns that can be addressed with good information, as well as a clear explanation of the benefits of achieving good asthma control on their child's health and development.

Inappropriate prescribing is a common issue that crops up when P/C contact the Adviceline. Some children are on high doses of ICS but no LABA (where it would be appropriate). Fluticasone is sometimes prescribed for very young children under four. More recently, as a

result of imminent changes to CFC-containing products, children are being prescribed Qvar. As an asthma nurse I have to alert P/C to these issues, although try to do it in a way which is reassuring. The problem is this can undermine the trust that P/C have in their child's doctor, as well as making them question the safety of ICS in general. I feel, therefore, that NICE needs to make its advice very clear around the issue of ICS prescribing and recommendations, especially in the light of the current CFC issues. There is potential for great confusion as prescribers could be overwhelmed with information and advice about changing patients to CFC-free ICS, as well as advice which may be contained in the final publication of this HTA currently under appraisal. Not being too prescriptive and allowing as much choice as possible would therefore probably be most helpful, so prescribers don't have to take too many factors and specific recommendations into account.

In the real world, P/C don't always supervise when or how their children take their asthma medicines, and I feel that NICE needs to take account of this. Device is crucial and can't easily be separated from drug. When children use a LABA as well as an ICS, combination inhalers may therefore be safer. Children are more likely to forget or miss out their ICS than their LABA when the two are taken separately, as they don't perceive a short term benefit with ICS. The disadvantage with a combination inhaler is that there is less flexibility in adjusting ICS doses when writing an asthma action plan of care for the child (though although for older children this may not be quite such a problem if they use Symbicort).

Listening to parents, carers and children, the most important thing they seem to want is the choice of a medicine and device which suits their individual lifestyle. It is not clinically or cost effective to prescribe asthma drugs which children won't take and P/C won't give. P/C want an ICS with as low a side effect profile as possible and want to use the lowest doses possible to keep good control of their child's asthma. Children want their asthma to be well controlled with a 'cool' device.