FOR HEALTHCARE LEADERS

HSJ ANAPHYLAXIS

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STUNG INTO ACTION

IS IT TIME TO RETHINK YOUR APPROACH TO ANAPHYLAXIS?

SENSITIVE SUBJECT

Smarter prescribing and better training are key to cutting costs and improving care for anaphylaxis – a topic too often overlooked by commissioners. By Claire Read

Adrenaline on hand: sufferers are given auto-injectors such as these

Steve Ogram, key account manager at pharmaceutical firm ALK-Abelló, spends his working days trying to get the issue of severe allergy on to the agendas of commissioners. It is, he reports, far from an easy task.

"Unfortunately allergy is just not perceived as a serious illness," he explains. "Commissioners aren't always quite aware of the debilitating nature of what allergy can bring to someone's life. Research has shown that the quality of life of a child with a peanut allergy can be worse than that of a child with insulin-dependent diabetes."

The likelihood of that is increased when an individual suffers from severe allergies. Anaphylaxis – an extreme allergic reaction to an antigen – affects the whole body, generally happens within minutes of exposure, and can be fatal.

According to the National Institute for Health and Care Excellence, 20 people die each year in the UK due to anaphylaxis. To call allergy a non-serious condition is thus clearly a misnomer. And yet Mr Ogram is far from the only one to report a lack of focus on the issue.

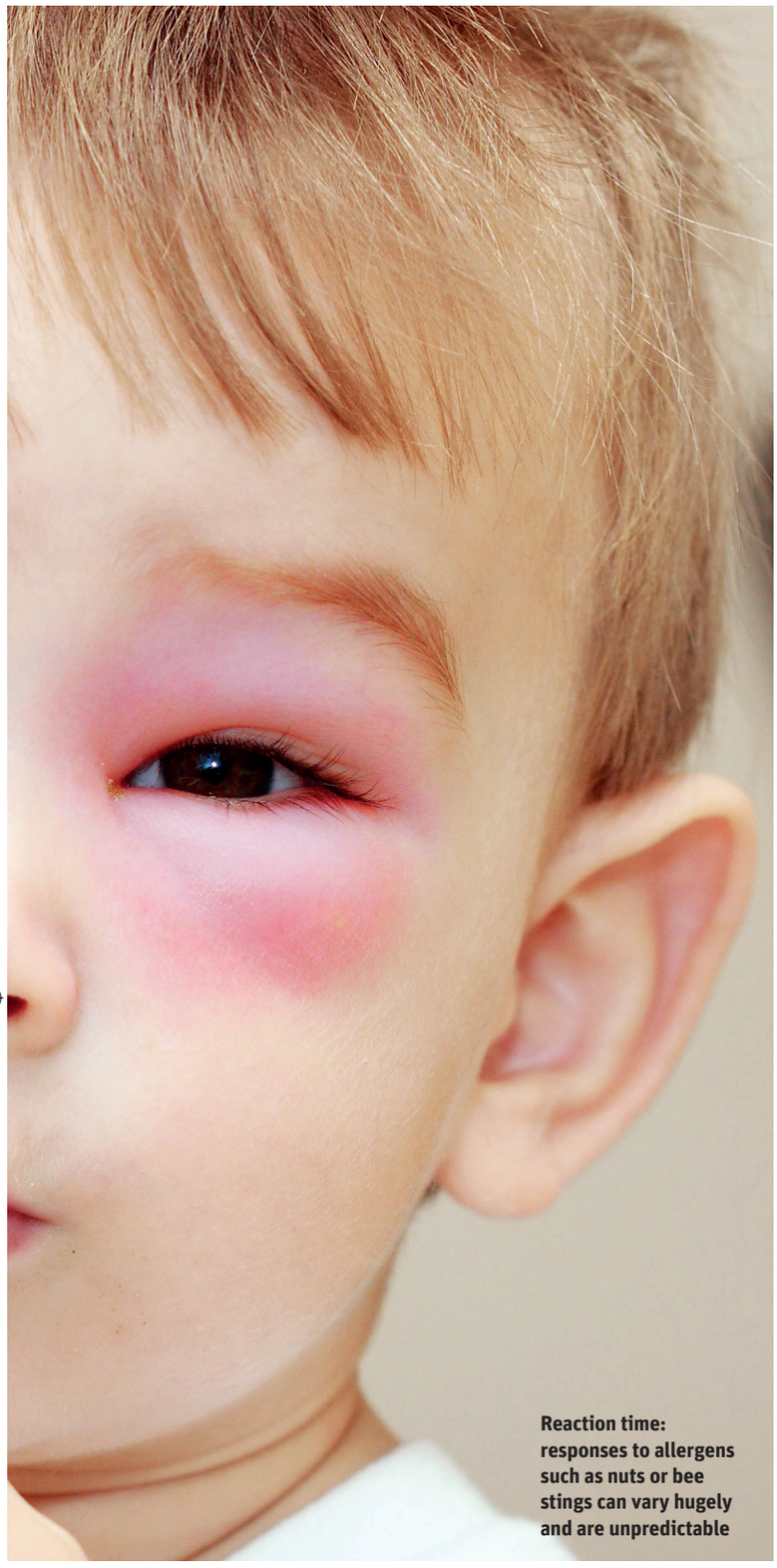
"One of our key challenges is just getting recognition of the seriousness of the condition," admits Lynne Regent, chief executive of charitable organisation the Anaphylaxis Campaign. "It's a challenge just to get people to understand what the issues are."

It is undeniable that those issues are multiple. A severe allergy is not always a straightforward condition to handle – for sufferer, carer, or healthcare provider. For a start, identifying those with the potential for a future, very severe allergic reaction is not simple.

"There isn't a test where you can say you've got this result and therefore we know you've got this condition," points out Sarah Crotty, interface pharmacist at Aylesbury Vale and Chiltern CCGs. "The diagnosis is generated from taking a history. A clinically severe allergic reaction is generally an unexpected event which is not commonly witnessed by a healthcare professional. It is therefore not something which you can easily define as a 'disease', in the way you can with heart failure or asthma."

The challenges do not end with a diagnosis. While adrenaline can be a highly effective first aid treatment prior to attention in hospital, it too has complexities. It must be administered quickly, and the unexpected nature of anaphylaxis means that adrenaline typically needs to be self-administered, or given by a non-healthcare professional known to the sufferer. That in turn means that the sufferer needs to carry an auto-injector device at all times – sometimes easier said than done given that many of those with known severe allergies are youngsters. Add to that the relatively short shelf life of adrenaline and the need for sufferers to regularly replace their devices and you immediately have several challenges with which providers need to grapple.

Yet as Mr Ogram and Ms Regent report, it seems many commissioners may not be doing so. The explanation may not only be the common concept that allergy is not a serious issue, it may also be the relatively small scale of anaphylaxis. While precise figures do not exist,



Reaction time: responses to allergens such as nuts or bee stings can vary hugely and are unpredictable

estimates suggest that one in 1,333 of England's population has experienced an anaphylactic reaction at some point in their life. The prevalence of severe allergies may be significantly on the rise but it remains a rare condition when compared to, for example, the more than one in three people in the UK who will be diagnosed with cancer at some point in their lives.

All that means that the cost of providing adrenaline auto-injectors to sufferers is a fairly small chunk of a commissioner's budget. It seems that a belief that anaphylaxis is not an area in which significant quality or cost improvements can be made is combining with the relatively low frequency of deaths to make anaphylaxis a lower priority condition for commissioners.

'We didn't really feel there were proper criteria for who should be offered adrenaline injectors'

It is, argues Mr Ogram, a significant oversight. "A short, determined effort can bring about a quantum shift in terms of the management of the patient, and potential for cost savings," he reports.

It is something which Ms Crotty has seen first hand. Last October, NHS Buckinghamshire changed their recommended auto-injector product from EpiPen to Jext, manufactured by ALK-Abelló. It was a decision initially driven by the desire to increase the likelihood patients had an in-date device – Jext has a maximum shelf life of 24 months from date of manufacture – without any significant effect on the budget for adrenaline auto-injectors.

"When we took on Jext, we did think it was going to cost us a little more money because it was a more expensive product than the brand leader," Ms Crotty explains. "But it has a longer maximum shelf life, so we thought we would spend a bit more in the first year and save a small amount in the second."

The reality has been different – Ms Crotty says the potential for some cost savings has been seen almost immediately. She suggests this is because a more general opportunity to review anaphylaxis provision was enthusiastically seized. "We dovetailed the switch with giving guidance to GPs about how many auto-injectors to prescribe and who would qualify for one," she explains. "So we have already seen a reduction in the volume of devices prescribed."

"When we talk about savings, there are several potential savings above and beyond the longer maximum shelf life of Jext compared to EpiPen," explains Mr Ogram. "They all link in with the management of the patient. If you improve the prescribing, you improve the costing, because there's less wastage."

The chances are that many organisations could make such improvements. Since no national guidance exists on how many auto-injectors should be prescribed, and to whom, local guidance is often varying or absent. That was certainly the case in Buckinghamshire prior to the switch to Jext.

"We didn't really feel there were proper criteria for who should be offered adrenaline injectors," reports Ms Crotty. "We wanted it to be a bit clearer which cohorts we thought should have an adrenaline injector, and so we developed some local criteria.

"We weren't intending to restrict availability, just make it a bit more consistent. It appeared to me that some GP practices were offering the auto-injectors

to lots of patients and other practices seemed to be prescribing far fewer."

It was a similar story when it came to the number of devices. "We didn't really have an agreement on the number of auto-injectors that was appropriate. I think there was some historic PCT guidance and there was some hospital guidance, but they didn't give consistent advice about quantities."

In Buckinghamshire, the two CCGs and the local hospital came together at the joint formulary management group and area prescribing committees to discuss how many devices should be issued. This included discussion with the local allergy lead. The ultimate decision was to recommend two devices, with a third in some exceptional instances – when the sufferer is a young child, for example, who cannot and should not be depended on to carry the device. It is a decision which mirrors the advice given by the Anaphylaxis Campaign.

"We feel that every patient should be prescribed two auto-injectors and that those devices should be with them at all times. But we are increasingly finding that patients are being prescribed only one auto-injector," says Ms Regent. "There's always the danger that the first device is used inappropriately – there are cases where people accidentally inject their thumbs, including among clinical professionals."

At the other end of the spectrum are requests for multiple devices. "There's a small but significant group of patients that has way, way, way more pens than necessary – 10, 12, 14 sometimes," explains Mr Ogram. "We had anecdotal reports of two for granny, two for mum, two for dad, two for school and one for my pocket," Ms Crotty says.

Interestingly both the too-few and too-many scenarios point to an area for improvement in anaphylaxis provision: education and training. Patients, carers and health professionals all need to be confident in how to administer the device, reducing the risk the treatment is given incorrectly. Sufferers and carers also need to understand that the risk of an allergic reaction does not cease during the time it takes to move between home and school – devices must be carried at all times.

Funded entirely by charitable donation, the Anaphylaxis Campaign is a major provider of training. Ms Regent reports that some organisations have block bought the campaign's e-learning modules but expresses concerns about education elsewhere.

"We're concerned that some of the training that is being offered to healthcare professionals, to school nurses and to nursery nurses, is inadequate. And it's absolutely vital that they are completely up to speed so that they can train other staff on how to deal with children who have severe allergies."

Unfortunately, commissioners can find it difficult to reach such groups. It is thus unsurprising that some cite the training offered by ALK as an important reason for moving to Jext.

"We didn't really have the staff locally to do this type of training," reports Ms Crotty. "So the training was a key reason we switched. They provided packs for every GP practice and every community pharmacy. Having all these tools has been really helpful for us."

In Buckinghamshire, there has been a focus on patient education too. GPs are asked to ensure at annual reviews that patients know how to use devices and understand the importance of replacing them when the expiry date arrives. Pharmacists are also involved.

"We engaged with the local pharmaceutical committee to make sure the pharmacists were asked to check that patients had been counselled when they changed over to the new device," says Ms Crotty. "Since patients are not changing this product every month, when a new device is issued that's a good time to say: 'You haven't had one of these for a long time, can I show you how to use it?'"

The experience in Buckinghamshire suggests that both patient and commissioner can benefit from a review of anaphylaxis provision, including auto-injectors. But for now Mr Ogram reports that it is still a daily battle to get organisations talking about allergies and understanding the potential cost and quality benefits of looking at auto-injectors. He wonders if this is another area in which the NHS is failing to share best practice and learn from the experiences of others.

"If it was commercial industry, the drive would be to learn from other people but we haven't really seen that with the NHS," he says. "There are easy wins here," he says. "It's not as though there's a huge amount of work to do to make savings and improve the management of the patient. And at the end of the day, these are potentially life-saving medicines." ●

ANAPHYLAXIS FACTS

- A severe allergic reaction which can affect the entire body and which often occurs within minutes of exposure to an allergen
- Symptoms may include a rash, swelling of the face, a narrowing of the airways which can cause breathing difficulties, and a drop in blood pressure which can cause unconsciousness
- The most common allergens involved in anaphylaxis are food-related but other possible causes include medicines, insect stings and latex
- Precise figures as to the number of people with severe allergies do not exist but it believed that around one in 1,333 people in England have experienced an anaphylactic reaction at some point in their life
- The prevalence of severe allergies is on the increase
- It is estimated that 20 people die each year in the UK as a result of an anaphylactic reaction. Many are children, adolescents, or young adults.
- Intramuscular adrenaline injection is the first line treatment for anaphylaxis
- Those with a known history of severe allergy, or considered to be at risk of such a reaction, should be prescribed an adrenaline auto-injector. Given correctly, this treatment can be life-saving
- Self-injectable adrenaline should be considered first aid treatment and the user should call 999 for an ambulance immediately after injection

'Both patient and commissioner can benefit from a review of anaphylaxis provision'

CASE STUDY

NEEDLE CRAFT

Providing healthcare professionals with refresher training and advice on the use of auto-injectors has been key to improving care in Norfolk and Buckinghamshire

Ian Small, formerly pharmacy adviser for NHS Norfolk and now at the commissioning support unit, admits that he had not really been aware there were any issues with anaphylaxis provision in his area.

"It has just gone along as a normal thing," he remembers. "There haven't been any incidents in the past that I can recall, and adrenaline auto-injectors had been quite a small cost as well. So anaphylaxis hadn't come up as an issue and therefore when I saw a representative who talked about Jext, the question for me was: what can you do for me that's not there already?"

The answer quickly became clear. "Once we'd talked it through, I realised that there were issues that hadn't been addressed; that had kind of been hidden under a stone for a long time. And the main one was refresher training.

"We sent out letters saying we intended to change auto-injector device and that training is on offer," he explains. "Interestingly, when that letter went out, some prescribers admitted it was years since they had last been trained in this area."

It was a gap which the PCT and ALK-Abelló, manufacturers of Jext, worked together to fill.

"The letter said to contact the person from ALK about the training, and many practices did phone up and e-mail and said: actually, I would like some training," explains Mr Small. "In addition, the Jext representative went along to the local pharmaceutical committee and demonstrated the device to them as well, so the pharmacists who dispense it were involved too.

"Every single pharmacy in Norfolk has now been visited by somebody from the company, to give a dummy injector and to show the training pack," he continues. "So when a pharmacist gives out a new device and the patient says it is different from the last one, the pharmacist is able to reassure the patient. They can feel confident that they know what they're talking about and can demonstrate it to the patient, show that this is what you do to administer it."

While the choice in Norfolk was to focus on GPs and pharmacies, over in Buckinghamshire ALK-Abelló has trained an even wider group.

'Ask your nurses and GPs if they are confident in demonstrating the usage of an auto-injector'

"If you were to draw a flowchart or map of the people who needed training in Buckinghamshire, there were a few key job roles who impact on a patient from diagnosis to chronic management," explains key account manager Steve Ogram. "That includes various people in secondary care – A&E, paediatrics, adult allergy, respiratory, dermatology and so on. All of those needed some sort of training.

"Then GPs and practice nurses were another group. And school nurses – we trained school nurses on every site in Buckinghamshire."

Sarah Crotty, the PCT pharmacy advisor who recommended the switch and worked with Mr Ogram on it, says that having properly trained professionals leads to reassured and well informed patients and carers. "If you were a mum or a carer of somebody who might need an auto-injector, just the fact that people have taken the time and effort to make sure you know how to use it makes people feel safer and feel looked after, I think."

Mr Small, meanwhile, has simple advice for anyone who considering whether they should review anaphylaxis provision in their local area.

"I would say: ask your nurses and GPs if they are confident in demonstrating the usage of an auto-injector. Just ask the question – how confident are you with the governance of somebody using adrenaline?

"Or even ask when did you last have training. I think most people will say, 'actually, I can't remember'." ●

CASE STUDY

Moving to a new type of auto-injector device gave Fiona Garnett the chance to address an area of anaphylaxis provision which had worried her.

"I get concerned because parents and carers request a number of auto-injectors. A typical example is: 'I need eight injectors, please – two at Grandma's, two at home, two at school, and two at the childminder'," reports Ms Garnett, pharmaceutical adviser at Bedfordshire Clinical Commissioning Group.

"I always want to point out that your child doesn't stop having an allergy when not at one of those places. We shouldn't be prescribing people eight injectors and then encouraging them to leave them lying around. People need to understand the importance of carrying the devices. Not everyone takes anaphylaxis seriously and actually carries the auto-injectors. And it worries me."

Personal experience means that Ms Garnett has never underestimated the seriousness of severe allergies. She still vividly remembers a time, many years ago, when she was confronted with the reality of anaphylactic shock.

"I was living in the north of England at the time and walking around the walls in Berwick-upon-Tweed and a gentleman came up to me gasping for breath – he'd had a bee sting," she says. "He had the auto-injector in his hand but he was in such a state he couldn't use it. So I've actually administered one. And imagine where Berwick-upon-Tweed is – the time waiting for the ambulance to arrive. It's a very scary thing."

Bedfordshire may not be quite as isolated as Berwick, but it does have some rural areas where it would be difficult for an ambulance to reach a patient within five to 10 minutes. It is one of the many reasons that Bedfordshire has now issued guidance saying that all patients should be given just two devices.

"Effectively the policy is that the minimum and maximum number of injectors a patient should have is two," Ms Garnett says. "We recommend one to be given immediately in the event of an anaphylactic reaction, and one five to 20 minutes later if there fails to be a response."

There are some exceptions. "If somebody is very obese, they may need more devices, and the same if somebody is in a very rural area. And obviously there may be certain exceptions such as young children. It would be inappropriate to give a three-year-old a pen to take to nursery – clearly the nursery has to have their own.

"But our main aim is to really underline the importance of patients carrying them."

In so doing, requests for multiple devices should decrease – or not be honoured when they are made – which should mean reduced wastage and lower costs. Getting across the importance of carrying the devices will also mean less risk for sufferers of severe allergy.

Of course the real hope is the treatment will never be needed. "We're spending taxpayers' money on something we hope is going to go in the drugs bin," says Ms Garnett. "We don't want to waste excessive money. But equally we want to protect patients."

"Bizarrely, quite often the message we're delivering is how to avoid having to use the Jext auto-injectors," explains Steve Ogram, key account manager at ALK-Abelló. ●

Jext®: Instructions For Use

1, Grasp the Jext® injector in your dominant hand (the one you use to write with) with your thumb closest to the yellow cap.

2, Pull off the yellow cap with your other hand.

3, Place the black injector tip against your outer thigh, holding the injector at a right angle (approx 90°) to the thigh.

4, Push the black tip firmly into your outer thigh until you hear a 'click' confirming the injection has started, then keep it pushed in. Hold the injector firmly in place against the thigh for 10 seconds (a slow count to 10) then remove. The black tip will extend automatically and hide the needle.

5, Massage the injection area for 10 seconds. Seek immediate medical help.

'We shouldn't prescribe people eight injectors and encourage them to leave them lying around'

How should healthcare professionals respond to patient and carer requests for multiple auto-injectors? Bedfordshire CCG has thought hard about its answer

TWO IS THE MAGIC NUMBER

STEPS TO BETTER CARE

Few organisations will have clear and consistent guidelines on anaphylaxis – and even fewer will have recently reviewed practice in the area. Yet considering a few key areas can quickly and easily lead to better anaphylaxis guidance, potentially improving quality and cutting costs

Agree on a recommended number of devices

The number of auto-injector devices prescribed for individuals varies significantly, not just from local area to local area but also from GP practice to GP practice and sometimes even from GP to GP. Issuing guidance on the number of devices which should be given can be a quick and easy way to reduce wastage. It is important to engage with local specialists when creating such advice, not least because ensuring local hospitals follow the same recommendations will lead to even greater consistency of care.

Agree on who should receive devices

As it is hard to define which patients are at risk of future anaphylactic reactions, issuing clear guidance on exactly who should be offered a device can also help to significantly reduce waste.

Look at staff education...

"If I had to emphasise one thing, it would be training," says Lynne Regent, chief executive of the Anaphylaxis Campaign. The charity provides 'AllergyWise' e-learning, with separate modules for patients/carers, GPs/practice nurses, and school nurses/other healthcare professionals.

Sarah Crotty, interface pharmacist at Aylesbury Vale and Chiltern CCGs, says that the training support and materials offered by ALK-Abelló was an important reason for moving to the Jext device. "ALK provide very good guides and they have a five minute web-based video that I think is really helpful."

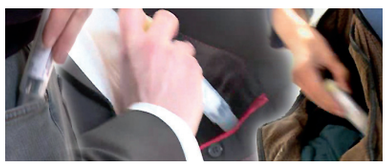
...and patient and carer education too

Consider writing into any policy that GPs and pharmacists must offer counselling before prescribing or issuing an auto-injector. Reviews can offer an opportunity to check whether the patient is in fact still allergic. Moving the devices from repeat to acute prescriptions can provide greater opportunity for such conversations.

"Patients with a specific allergy trigger sometimes have these auto-injectors and don't use them for 10 years at a time," points out Sarah Crotty, interface pharmacist at Aylesbury Vale and Chiltern CCGs. "If they were trained 10 years ago, they might have forgotten by the time they actually need to use it." It is also helpful to ensure they know the symptoms of anaphylaxis and the action to take when they appear – to use the auto-injector and then immediately call 999 for an ambulance.

Since adrenaline has a limited shelf life, the expiry date also needs to be part of education. Lynne Regent explains: "We've done a couple of campaigns about this in the last few years because we know that about a third of the auto-injectors being carried out there have exceeded their expiry date." That means that, if used, the injectors may be less effective than an in-date device. ALK-Abelló and other manufacturers enable users to register their devices online or by text, so receiving a reminder when it is about to expire.

Important too is a clear message that devices need to be carried with sufferers at all times. The scale of the issue is significant. A recent survey by the Anaphylaxis Campaign found that, of 520 anaphylaxis sufferers between the ages of 15 and 25, more than a third acknowledged they did not always carry their injectors, putting them at risk of a fatal reaction.



Don't forget: sufferers must carry their auto-injector devices everywhere they go

'More than a third of sufferers said they did not always carry their injectors, putting them at risk of a fatal reaction'

Consider the potential for wider education

"When you look at the prevalence of severe allergies now, it's highly likely that individuals will come into contact with a child or adult who is affected," points out Ms Regent. That means that the need for education on anaphylaxis and its treatment will become increasingly pressing and need to involve larger numbers than ever before.

"If you were in a crisis situation and the patient had an adrenaline auto-injector, you would like somebody to be able to administer it to save their life, and that might be almost any member of the public," argues Sarah Crotty. "I don't pretend that we have completely cracked this in Buckinghamshire and got the health education message out to everybody that we would like, but that would obviously be a longer term aim."

Seek advice

National guidance may not be comprehensive, but it does exist.

"There are care pathways and NICE guidance that are available on dealing with these issues and the British Society for Allergy and Clinical Immunology (BSACI) is now working on further guidelines," says Lynne Regent.

"And the Anaphylaxis Campaign is always ready to work with healthcare organisations when they're formulating their policies and trying to deal with the issues relating to severe allergies."

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