



Allergy: The reality of the unmet need

**A report from the All Party Parliamentary Group for Allergy
in conjunction with the National Allergy Strategy Group**

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The National Allergy Strategy Group is a coalition of the patient charities the Anaphylaxis Campaign and Allergy UK and the British Society for Allergy and Clinical Immunology which provides the secretariat for the All Party Parliamentary Group for Allergy.

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Foreword

Professor Ilora the Baroness Finlay of Llandaff

Ten years ago in 2004 the House of Commons Health Select Committee held an inquiry into the state of NHS allergy services and confirmed there was an unmet need for the growing number of people living with allergic disease. The committee outlined a number of recommendations which you will see in this report yet, a decade on we are still seeing a significant unmet need which is impacting hugely on the quality of life for those affected by this condition.

The National Allergy Strategy Group (NASG) has been campaigning for over a decade to improve the quality of NHS provision and their most recent survey of families and individuals living with allergic disease shows the reality of day to day life and how a lack of an accurate and timely diagnosis and advice on long term management can severely affect how allergy is managed in both families and the wider community.

Having chaired the 2007 House of Lords' Science and Technology Committee report on allergy and as vice-chair of the All Party Parliamentary Group for Allergy I understand the issues covered in this report and fully support the NASG in their continued campaign.

Introduction

For over a decade the National Allergy Strategy Group (NASG) has been campaigning, with others to improve NHS care for the growing numbers of people affected by allergic disease. Despite numerous reports and inquiries during this time there is still a considerable unmet need and the key messages remain the same:

- Allergy services are poor. There is a wide and unacceptable gap between patient need and service provision. At all levels in the NHS there is insufficient expertise in allergy
- There are only a small number of allergy specialists and few doctors are being trained in allergy
- There is a lack of funding and priority for commissioning for allergy. Services are commissioned inadequately, often due to a lack of awareness of the need
- There is a lack of knowledge amongst GPs to ensure that patients are diagnosed or managed in primary care or referred appropriately
- Providing an effective allergy service is cost effective by reducing ongoing illness and the demands this places on the NHS
- Allergic disease is preventable or controllable if patients have access to specific allergy diagnosis, management and support. Identifying and avoiding the trigger e.g. in food or drug allergy can stop disease.

Background

Ten years ago in 2004 the Commons Health Select Committee inquiry into NHS allergy services recommended that it was necessary to:

- Train 40 new specialist doctors – 20 for adult and 20 for paediatrics. Once trained it was hoped that these doctors would join the allergists already at work in the NHS to become the core of a modern NHS allergy service which could be available to patients across the country when they need it.
- Create a minimum of 40 allergy consultant posts for these qualified doctors to move into once they are trained. It was hoped good doctors would be attracted into the profession as a result.
- Have a major specialist centre, in adult and paediatric allergy, for each area of the country. This was recommended as a “key step” as it would provide the whole NHS with the expertise and infrastructure to support other developments in allergy care.
- Publish and put into practice an “action plan” to bring allergy into the mainstream of the NHS.

In the longer term the committee said that the scale of need for allergy care would require the national allergy service to ensure that:

- All health care professionals working in primary care have appropriate exposure to the diagnosis and management of allergy as part of their clinical training.

- All primary care providers have a named person with responsibility for allergy.
- All PCTs to have a team of health care professionals with a Special Interest in allergy who can be available to help and advice on allergy case diagnosis and management.
- All teaching hospitals have a specialist allergy clinic run by consultants in allergy which would be a resource both for patients and for training and research.
- Regional specialist centres act as centres of excellence, manage the more complex cases of allergy and support the regional network of allergy care.

The reality

In the decade since this inquiry and the subsequent recommendations the National Allergy Strategy Group (NASG) has been campaigning to improve NHS service for the growing number of people affected by allergic disease. Despite this and numerous other reports, inquiries and national reviews, including the House of Lords Science and Technology inquiry of 2007, there is still no serious attempt to increase the number of allergy specialists in the NHS workforce and as a result we still see only a small number of consultants in allergy – an estimated 40 currently offering a specialist service. In addition to this lack of specialists, knowledge in primary care is often still inadequate. More needs to be done to improve teaching for GPs and to include allergy in the undergraduate curriculum.

Patients surveyed by the NASG often felt that they struggled to get the support they needed when presenting to their GP with symptoms of allergy. One parent told us of her battle to get her son diagnosed following problems with feeding from day one. She says:

*“Aged 14 months we finally get a full set of skin prick tests after two previous episodes which resulted in wheeze, floppiness and an ambulance to hospital. The first time we were told he must have choked but after the second time I knew it was more serious. A month later the blood test results are in. The list sits at highly allergic to all legumes, cow’s milk protein and root vegetables, cinnamon, white and sweet potato, cabbage to name some. Now aged two years he has a very restricted diet, has impaired speech due to reflux damage to his oesophagus and **I’m a wreck.**”*

*Much of this could have been avoided had the alleged professionals considered his allergies from day one. **He has been shockingly let down by the system and a string of lazy doctors, nurses and midwives.** Neurotic parents are neurotic for a reason and the sooner they listen the less money they will cost the NHS. I dread to think what we have clocked up in expenses so far and we haven’t finished yet.”*

In a similar story a parent tells how a lengthy wait for diagnosis impacted on the whole family:

*It took me eight months of my new born baby’s life to get a diagnosis during which time I became **exhausted, defeated, lost and helpless in the situation.** My baby wasn’t able to keep milk down, had eczema, and was screaming in pain all night with constant diarrhoea. My relationship with my partner and my other child suffered. **Now my son has a diagnosis, do I feel any more supported? No!!!***

Another parent told us about her struggle as recently as January this year:

*"My eldest daughter was diagnosed with a severe peanut allergy in January this year following an anaphylactic reaction after eating a kit kat. Our GP arranged allergy testing for her and when the results came back, the practice nurse called me and read out the results to me over the phone and booked us in to see the GP again "to talk Epipens" (nurses words) so we attended the 2nd appointment with the GP who just read the results of the report to me. **The GP was then going to let us leave the surgery without a prescription for an Epipen or a referral to an allergy specialist.** When I asked "what about an Epipen" the GPs response was disappointing as she seemed to **imply it was not good value for money to prescribe one.** I then asked "what price are you putting on my child's life?" Both I and my husband are UK tax payers and have always worked and paid our National Insurance yet we were almost denied the one thing that could save our child's life!! The GP then reluctantly prescribed us an Epipen.*

Before we left the GPs surgery, I said "what about a referral to a Paediatric allergy specialist?" To which she replied "she doesn't need one; just make sure you avoid nuts"

We left the surgery but as a parent of a newly diagnosed severely allergic child, I didn't feel we were receiving satisfactory care/information.

I work at a hospital, so the following day I made some enquiries and felt even more strongly that we needed a referral to an allergy specialist so I rang the GP practice and spoke to the nurse and she said she "fully understood my concerns" and "she would book us an appointment with another GP at the practice. At the appointment with the other GP, I explained that despite us completely avoiding ALL nuts, she was still reacting to something else as her lips were itching and swelling on an almost daily basis. This GP said he would "do us a referral to Dermatology" he then changed his mind and said "Immunology" and then changed his mind again and said "Dermatology" and gave us a slip of paper to take out to the receptionist who "would make the referral for us". I did this and the receptionist looked at the slip of paper and said she would try and find out whether we needed to be referred to Dermatology or Immunology and ring me the following day. That was over a week ago and I still haven't heard from her and we are now 6 weeks post diagnosis and no further on with a referral to a specialist.

For adults presenting with allergy the story is the same. One adult who developed latex allergy told us:

I had a struggle to get referred to an allergy clinic 18 months ago after suffering swelling in my throat and ending up in A&E three times in three weeks.

I was initially told that there are only allergy clinics for children; I am in my 30's. I was strong enough to refuse to leave my doctors office until I was happy with an answer. The GP treating me eventually agreed to discuss with the practice manager and call me by the end of the day. They did and I have been receiving ongoing

*treatment by specialists. **I do worry about those who would not be strong enough to fight for the treatment they deserve in the same situation I was in.***

Another common problem is that GPs continue to refer to organ based specialists. One adult told us she has **“confirmed multiple IgE allergies from childhood but as an adult my GP insists on sending me to different consultants to treat the symptoms each time. I really want a referral to specialist who can treat the allergy as a single issue”**

This lack of knowledge and a reluctance or inability to refer leads to huge anxiety for patients and their families. An Anaphylaxis Campaign survey showed that a worrying **58% of families felt they had not received adequate care from the NHS with 50% saying they had received contradictory advice.** One mother told the NASG:

My daughter (almost 6 now) had an anaphylactic reaction when she was two years old. We are STILL awaiting confirmation and adrenalin injectors. We have been told that unless she has another reaction we won't be entitled to adrenalin injectors.

Our doctors just say 'what would you like us to do? You know what she's allergic to just don't feed her it!' If only it was that simple!

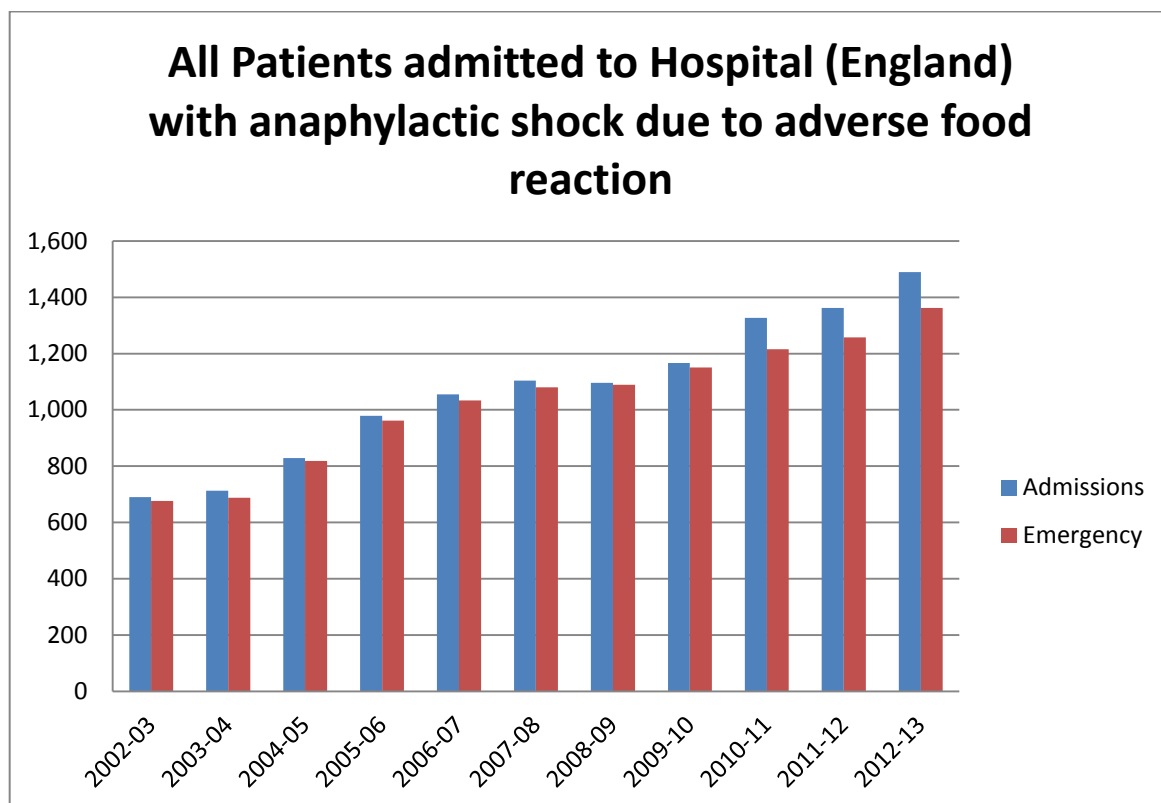
And those patients who are lucky enough to get referred often have to travel some distance to their appointment and whilst they are more than happy to do this to be seen by a specialist, one Mum tells us:

I live in Nottingham and have to visit Leicester for a specialist consultant as Nottingham does not currently have paediatric allergy provision. Although geographically they are not a million miles away, an average trip with travel time, parking and time for tests etc is an entire day.

*To be honest, it is more of an inconvenience than anything and I would travel to the end of the earth because the service is truly amazing. However, I recently met a lady whose son had allergies and she was frustrated with the lack of provision. When I mentioned Leicester she was tearful because as **a single parent with two children, travelling was just not an option for her.***

This highlights the need for a regional centre of excellence to be an option for all those requiring specialist treatment. **6 – 8% of children have a proven food allergy with 50% living with some type of allergic condition** so we can see that allergy is still on the increase and the UK is currently in the top three countries in the world for incidents of allergy

Although fatalities remain steady we are seeing a continued increase in hospital admissions year on year.



This graph has been produced by Hazel Gowland with annual data collected from <http://www.hscic.gov.uk/hes> for T78.0.

Patient support groups the Anaphylaxis Campaign and Allergy UK report that families and individuals living with allergic disease who have received timely and accurate diagnosis and a subsequent management plan are less anxious and, as a result, feel more able to live with the condition. This is backed up by a study carried out at Addenbrookes, Cambridge which found that risks decrease if the patient has expert assessment and participates in a management plan. Fewer patients have further reactions. When they occur, they are mostly mild. (Reference: Ewan P.W., Clark A.T. Long-term prospective observational study of patients with peanut and nut allergy after participation in a management plan. *Lancet* 2001; 357: 111-15).

Without effective diagnosis and management many who live with allergic disease find themselves struggling with anxiety and have a lower quality of life as a result. This can impact on many aspects of day to day living as one Mum told us:

“Just doing the weekly shopping is a struggle. Reading labels and knowing whether to risk those which say “may contain traces” is a nightmare.”

Another Mum who has a nine year old daughter told us:

“We deal with this on a day to day basis – people don’t care – they’re not interested. They can’t see it, they don’t have to deal with it and they don’t have

to live with it. We can't just book a meal, a holiday, a day out. We have to make it a military operation, taking into account a gazillion risk factors. She can't enjoy Easter, she can't enjoy birthdays, she can't enjoy going out for a meal – **her “kit” is her lifeline – without that she could die – simple! If we forget her kit – she could die! That burden is on us all the time.** But nobody recognises this except us and her.

Allergy can also affect people by increasing anxiety levels to unmanageable levels as one 24 year old told us when recalling how things spiraled after leaving home:

*“I was on my own. I started reading the ingredients label on everything, washing my hands, washing plates and utensils, even though they had never been used. At the age of 16 I was told I had OCD as well as anxiety, this all stemmed from the avoidance of nuts. **I was so scared my life was going to end I struggled to eat, go out and have fun like most normal teenagers.** I went to therapy which was no help, they believed it was a deep childhood trauma I had suffered and they only way to cure it was through talking, as you can imagine I did not buy into this. I thought it was best I would try it on my own. So gradually I started to gain more confidence in what I was eating, stated to trust people once again, started to drink out of glasses at the pub, share chips and this was only possible because of myself belief and the help with my friends and family.*

*I now have learnt how to control my OCD and anxiety, I take medication to help but this can't last forever. I wish there was some sort of support or something to help me gain the knowledge and understanding of my allergy, there might well be but it was never given or even offered by my doctor or by medical professionals. People need to understand that growing up with any allergy this dangerous is more than just a physical effect it also creates mental uncertainty. I compare it to a game known as Russian roulette **with most things I eat I'm safe with but with every pull of the trigger I could be getting closer the loaded barrel.**”*

And even for those people who have their allergy managed and under control a lack of awareness elsewhere, including at school and in the community, will inevitably lead to further struggles and an effect on quality of life. This is illustrated by the experience of this young person who has her allergy well managed yet still finds life a struggle, her Mother tells us:

My daughter was very nearly refused a place on the A level biology field trip because her biology teacher didn't want the responsibility/worry of her allergies. This was despite the fact that the trip was a vital to gather data for her coursework, and not going would have impacted on her grades, and therefore potentially her access to higher education (not to mention missing out on the fun!). I managed to persuade him to let her go - but it was a close run thing; a good hour on the phone - lots of patience, humour, broken record technique needed etc. This allergy business really does seem to expose the more nervous and/or selfish individuals in the teaching profession. As it turned out, she spent five blissful days at Slapton Sands up to her knees in muddy water counting duck fleas (to check the quality of the water) - and it confirmed her suspicion that this is the kind of thing she

wants to do with her life. The suggestion was she could stay behind and do something similar in the school grounds, unsupervised, but it wouldn't have been the same would it?

Conclusion

Despite numerous reports, inquiries, reviews and recommendations over the last decade, the NASG continues to see an unmet need. Allergy is increasing and more needs to be done to address the growing demand for services both in primary care and for more specialist needs. The solution remains the same:

- Better implementation of the NICE guidelines for diagnosing allergy in children in primary care which give clear guidance on what to do when a young person presents with a suspected food allergy plus NICE guidelines on the assessment and treatment following an emergency admission for anaphylaxis which show what to do after a severe reaction.
- GPs need to have better awareness of allergy and need to be given clear guidance of where to access additional training as well as the importance of doing so
- More doctors are required with a knowledge of allergy
- The specialty of allergy needs to grow – we need to train more doctors as specialists in allergy, and create more posts for consultant allergists
- Improved commissioning of local allergy services. NHS England need to recognise allergy as one of the key long term conditions affecting children today and realise that improved long term management will lead to fewer childhood healthcare problems across the country.

For more information on the work of the NASG visit www.nasguk.org or contact Mandy East mandy@nasguk.org