Inquiry into allergies and anaphylaxis - submission to Parliamentary Committee Inquiry

6 October 2019 By Maria Stipic

Summary of Recommendations

1. Food challenges should be used more frequently to confirm diagnosis of food allergy especially in patients who have never consumed the suspected allergen. Avoidance of an allergen based on Skin Prick Test alone should not occur, there should be a medically supervised food challenge to confirm the allergy.
2. Clinics and hospitals should be funded and equipped to provide a greater number of food challenges to patients who need them, eliminating long waiting lists for food challenges and providing greater certainty in the diagnosis of food allergies.
3. Support should be provided for the supervision of first food introduction in infants determined to be at high risk of food allergy, by maternal child health nurses or allergists.
4. More social and psychological support for suffers of food allergy and their carers, so that there is a real recognition of the anxiety and social implications of living with food allergy.
5. Oral Immunotherapy (OIT) should be made available as a treatment option for food allergy sufferers in Australia.
6. More education and awareness around the five hypotheses relating to the increases in the prevalence of food allergy, especially targeted to parents embarking upon conception.
7. A&AA to be funded to provide training for parents of allergic children or other interested persons to become 'allergy friends' to provide phone advice and support to allergy sufferers and carers much like the breastfeeding counsellors that are available for support to new mums.

Term of reference 4: *Access to and cost of services including diagnosis, testing, management, treatment and support.*

<u>The diagnosis of food allergy using food challenges</u>

In Australia the diagnosis of food allergy is most reliably made by way of Skin Prick Testing, after the ingestion of a food that results in an allergic reaction. When ingestion has occurred and resulted in an allergic reaction, especially in infants trying first foods, it is quite obvious to clinicians and parents that an allergy exists to the food in question, if that food was the only food introduced at the time. For example, an infant tries egg for the first time, resulting in redness, hives, swelling and vomiting. An allergy to the egg protein is probable. The child receives medical care from an Emergency Department. The child is then referred off for Skin Prick Testing. If the child attends a private allergist, the wait may be short, a few months at most. If the child attends an allergist at a public hospital, the wait can be much, much longer. Priority may be given depending on various factors which may include the number of allergies suspected, whether the foods are considered staple foods, the reaction which occurred and the age of the child.

When the child is referred for Skin Prick Testing, testing often occurs for other allergens that the child has not yet eaten. This may be on the direction of the allergist, or the parent. The results can produce a 'false positive' showing a probability of allergic reaction (when there is no true allergy).

But how do clinicians and parents know if there is a true allergy? The gold standard and only sure way to know is to ingest the food, through a food challenge. Food challenges are heralded as the gold standard in food allergy diagnosis. However they are only performed at selected private clinics, where the cost of each individual challenge can exceed many hundreds of dollars. In public hospitals the waitlist for a food challenge can be up to two years.

Recommendation:

1. **The diagnosis of food allergy in patients who have never eaten the food should only occur by supervised food challenge.**
2. **Speciality clinics and hospitals should be equipped with a greater capacity to perform a greater number of food challenges.**

The following quote is taken from Allergy and Anaphylaxis Australia's website; *allergy.org.au, Food allergy challenges FAQ's*:

"A positive food allergy test using skin tests or blood tests for allergen specific immunoglobulin E (IgE) antibodies, means that a person's immune system has produced an antibody response to that food. This is known as sensitisation. It is possible to have sensitisation without allergy, which means that the person can eat the food without any symptoms."

Given the above why are diagnoses being made without food challenges? The main reason is the accessibility of food challenges, the cost involved and the fear of a reaction.

There has never been a death from food challenges in Australia or New Zealand. Approximately 8,000 food challenges are conducted per year. In 2017 there was one reported death from a food challenge in the USA. Whilst extremely unfortunate, death from food challenge clearly remains extremely rare, more rare than death from anaphylaxis due to accidental ingestion. Hence the risk of food challenges is not sufficient to warrant an unnecessarily cautious approach to providing them.

<u>Impact of proposed recommendation 1 and 2</u>

- Patients are no longer unnecessarily avoiding foods. There is a 'win' for the patient in reducing their number of allergens and opening up their diet to less restriction and monitoring. The individual may gain confidence and reduce their anxiety by reducing the number of allergens to be avoided.
- If it is the only allergen, a successful food challenge can eliminate the need for the individual to carry mediation such as an Epi Pen. This creates savings on both an individual level and for the PBS. This also eases the pressure on supply of Epi Pens which are in frequent short supply.
- There is too a nutritional benefit, especially in individuals who are following very restrictive diets due to food allergy.

Even if the food triggered a reaction during the food challenge the benefit is knowing, with certainty, that the individual is truly allergic and the food needs to be avoided.

Challenges are considered risky as there is a risk of anaphylaxis, given that the patient is being asked to consume their allergen. However hospitals are well equipped to deal with these situations. Given the cautious approach of slowly increasing doses, a mild reaction is unlikely to go unrecognised.

Even if a patient has a reaction there are benefits for the patient; the patient sees how the reaction is treated and the patient gets a real example of symptoms which may help in the future identification of symptoms resulting from accidental exposure.

Challenges should be conducted by all allergists, allowing patients to remain with their allergist through the process; this is the best option for consistent and personalised patient care.

Recommendation:

3. **Maternal Child Health Nurses or Allergy nurses should be available to challenge/introduce first foods with parents and infants, meaning that infants identified as at risk of food allergy are supervised in clinic (or even at home) with their parents.**

Factors that may contribute to this referral could be having an older sibling with food allergy, having a parent with food allergy, having had a reaction to breast milk or formula milk, and having eczema as an infant.

There is no known support provided to parents of food allergic children. These parents, mostly by way of self-referral , end up in Face Book forums comparing notes with other food allergic children's parents about how to manage their situations. The allergy community is a supportive and compassionate one. There is much knowledge and experience in these groups. However for new parents navigating this unexpected journey, more support is required. Maternal and Child Health nurses should be trained to identify at risk infants and refer to a program which provides in home support for parents without a diagnosis, to introduce new foods with the support and medical know how of a Maternal Child Health nurse. Parents with a diagnosis should have in clinic, or in hospital challenges, unless otherwise recommended or arranged by their treating professionals.

A&AA's 'nip it in the bud' campaign goes some way to educate parents, but it is the in person support that is required. Extra funding, to provide training and in home support is a real and tangible way to support parents who have infants suspected of having allergies and children who are already diagnosed.

<u>Impact of proposed recommendation 3</u>

- These patients are then diverted away from clogging up waiting lists for in hospital challenges, if they are seen and challenged by nurses
- The anxiety associated with first food introduction will be reduced for parents
- High allergen foods are more likely to be introduced young, as presently recommended, if parents are supported as recommended above. This may reduce the incidence of allergies in these infants

Food introduction protocols routinely given to patients who are asked to introduce a food by an allergist, (perhaps following a subsequent negative skin prick test) should be made publicly

available. These protocols, if followed, would reduce the incident of severe allergic reaction by educating parents on how to introduce first foods to infants.

Recommendation:

4. **More social and psychological support for suffers of food allergy and their carers, so that there is a real recognition of the anxiety and social implications of living with food allergy.**

The anxiety associated with food allergy, in both parents and children, should be more widely recognised. Specialist services can provide assistance to parents by directing them to support services like A&AA or to their GP for referral to psychological counselling and support. Counsellors or psychologist with a keen interest or expertise in food allergy (or the treatment of anxiety related to the management of medical conditions) should be clearly identified by registering their details with A&AA.

Impact of proposed recommendation 4

- improved quality of life for carers and food allergic individuals

Term of Reference 5:

Development in research into allergy and anaphylaxis including prevention, causes, treatment and emerging treatment (such as OIT)

Oral Immunotherapy treatment currently offered overseas should be made available in Australia by way of trials (not studies) supervised by willing clinicians. Numerous overseas clinicians are willing to collaborate with Australian practitioners. One such doctor is Dr Douglas Jones of the Rocky Mountain Tanner Clinic, Utah, USA, who has treated many Australian children. He has personally hosted information sessions in Australia, attracting interest from many families wanting to find out more about travelling overseas for treatment.

Recommendation:

5. **Oral Immunotherapy (OIT) should be made available as a treatment option for food allergy sufferers in Australia**

Research in Australia currently focuses on finding cures for food allergy. It is well accepted amongst food allergy parents that OIT is not a cure, but rather a treatment, that needs to be continued in order to effectively maintain desensitisation to the allergen. Patients and families must be given the choice to accept the limitations of the treatment as it currently stands, whilst advances are made in the background through research. Whilst the concept of a cure is enticing, for many food allergic individuals, reducing the risk of a severe reaction is making an astounding difference to their everyday lives. Many will take up the option of OIT as a treatment, in an effort to reduce the risk of a life and death situation. It is this ongoing risk and the required vigilance that can lower the quality of life experienced by food allergy sufferers.

Impact of proposed recommendation 5:

- Many sufferers of food allergy will live with a far reduced risk of experiencing anaphylaxis, or allergic reaction of any kind
- Allergic individuals can eat freely, as long as they maintain their dosing
- Allergic individuals can live with less anxiety and vigilance in social situations involving food
- Hospital admissions for anaphylaxis may reduce due to desensitisation of individuals
- Increased treatment options and choice for the allergy sufferer
- Possibility of achieving sustained tolerance

Term of reference 1: ***The potential and known causes, prevalence, impacts, and cost of Anaphylaxis in Australia***

Recommendation:

6. **More education and awareness the five hypotheses relating to the increases in the prevalence of food allergy, especially targeted to parents embarking upon conception.**

Current research by the Murdoch Children's Research Institute which has generated five hypotheses known as the '5 D's' should be more widely published and disseminated, as should an emphasis on the emerging research into the gut heath of the mother and infant in understanding the increased rates of food allergy in Australia. Consideration should be given to the following:

- Vitamin D should be monitored and prescribed if necessary (as per folate), to women hoping to conceive and those who are pregnant.
- Mother and infant diet should be given greater attention, including the National Infant Feeding Guidelines
- Eczema care should be part of prenatal classes run at all hospitals
- Clinically proven probiotics to reduce the incidence of eczema should be taken by expectant mother
- Eczema care for infants presenting with eczema should be taken more seriously
- Recommendations for new parents as to the type of home cleaning products and personal care products, supporting the hygiene hypothesis as well as eczema care, should be developed and disseminated.

Impact of proposed recommendation 6:

- More public awareness of the possible causes of the increased risk of food allergy may work to increase the likelihood of less infants being affected

Recommendation:

7. **A&AA to be funded to provide training for parents of allergic children or other interested persons to become 'allergy friends' to provide phone advice and support to allergy**

sufferers and carers much like the breastfeeding counsellors that are available for support to new mums.

More support needs to be provided to counter the social impact of food allergy and the psychological impact of anaphylaxis. Symptoms like post-traumatic stress can occur after a patient experiences anaphylaxis, for the patient and/or the carer.

AAA to provide training for parent 'allergy friends' much like the breastfeeding counsellors that are available, on a volunteer basis, by telephone, to new mums. There is a lot to be said for the benefits of receiving phone counselling from a parent who has also been through what you may be experiencing.

Impact of proposed recommendation 7

- Parents of allergic children would feel more supported, less isolated and appreciate the one on one phone counselling in relation to their allergic children.