

Individual Submission,  
House of Representatives Standing Committee on Health, Aged Care & Sport  
Inquiry into Allergies and Anaphylaxis in Australia

22 October 2019

I write this submission as the parent of two children diagnosed with multiple food allergies, allergic rhinitis, asthma and the allergic disease Eosinophilic Oesophagitis.

### ADEQUACY OF EDUCATION

**Ignorance about allergy and anaphylaxis is the norm in Australia today.** Although we are in the midst of an allergy ‘epidemic’, public and professional awareness is poor. My local public health clinic, library and GP practice have an abundance of pamphlets and posters about common medical conditions but **literature on anaphylaxis is notably absent.**

Australia has public awareness campaigns that tell us how to recognise a stroke or heart attack and warn us to avoid smoking. There is nothing for anaphylaxis – an increasingly prevalent life-threatening medical emergency.

Consequently, when my infant son had an anaphylactic reaction to a cashew nut, I had no idea what I was witnessing. I possess three university degrees, yet my ignorance could have killed my son.

### ACCESS TO SERVICES

**It is common to face long delays to obtain a diagnosis or specialist assistance.** Despite having severe allergic symptoms from birth, my son took 2 years to be diagnosed with food allergies and 4 years to be diagnosed with Eosinophilic Oesophagitis.

His waiting time to see immunologists and gastroenterologists has typically been 6 to 12 months. Dietitians who specialise in allergies have been a greater help to our family, as we have been able to more readily access their services and receive immediate practical support.

### FOOD SERVICE PROVIDERS

**Ignorance about allergens is commonplace in establishments that serve food.** It is relatively common for people to be unable to determine which category of food an allergen belongs to – for example, cafe staff thinking that eggs are ‘dairy products’ or that coconut is a ‘tree nut’.

My children have been hospitalised seven times in different states of Australia and on every occasion **the hospital has been unable to safely cater for my child** and our family has had

to supply safe food from home. On several occasions, I have physically intervened to stop nurses giving my children food they are allergic to.

I believe **mandatory training in food allergens should be established** for all who work in the food industry, especially hospital staff.

## **COSTS OF ALLERGY**

**Eligibility criteria for Carer Allowance, Carer Payment and the NDIS place minimal focus on the cost of food and difficulty of food preparation.** Yet managing children's dietary restrictions is time-consuming and expensive. It involves the purchase of specialised ingredients from multiple stores, the need to cook from scratch and the reduction of the primary caregiver's ability to participate in the paid workforce.

As an example, one of my children only tolerates a specialised wheat-free, soy-free bread that costs \$9 per loaf and comes from a shop that is 10 kilometres from our home. Outsourcing meal preparation is often not an option, as services generally do not exist to provide meals for individuals with multiple allergies.

In addition, **many allergy medications are purchased over the counter and are not subject to a Health Care Card.** Some families have several members who require daily antihistamines, nasal sprays and eye drops and must eat allergen-free foods, yet little or no financial assistance may be available to them.

A 2016 study found that health care costs for individuals with food allergies were nearly double those of people without allergies.<sup>1</sup> In my family, the cost of allergen-free foods and medicines is approximately **\$3,500 per year per child.**

## **IMPACT OF ALLERGY**

While allergy and anaphylaxis are considered to be a disability for the purposes of the *Disability Discrimination Act 1992*, **discrimination is rife.** Where some establishments would go to great lengths to accommodate an individual with a disability, there is rarely any recognition that a similar moral duty exists to include a person with an allergy, whose 'special needs' are not immediately obvious. Those with food allergies often face resistance, ridicule and even dangerous attempts to 'disprove' their allergies.

**Keeping allergic children safe relies on parental expertise,** as other providers of care have difficulty interpreting food labels and understanding the risks of cross-contamination. Since my children were babies, I have had lengthy negotiations with childcare centres, family day care, schools, after-school activities, camps, holiday programs, indoor play centres, sporting clubs, hotels, restaurants, cafes and parents of my children's peers to ensure my children could safely attend these places. In many cases, even a doctor's letter and an EpiPen have not been sufficient to garner cooperation. Rather, reception is often hostile and disbelieving. I believe **widespread social change needs to occur so people recognise that food allergy is a disability** which they have a duty to attempt to accommodate.

<sup>1</sup> Antolín-Amérigo, D., Manso, L., Caminati, M. et al. Quality of Life in Patients with Food Allergy. Clin Mol Allergy (2016) 14: 4. <https://doi.org/10.1186/s12948-016-0041-4>.

People with allergies also face **social, cultural and religious exclusion**, in that they do not eat what their family or cultural group has historically eaten. In fact, **allergy neatly fits the social model of disability**, in that negative social attitudes and social exclusion are the principal factors that prevent people with food allergy from participating fully in society.

Although as a society we go to great lengths to keep children safe, few people think of an allergic child's psychological welfare or wonder what it is like to be surrounded by peers eating a food (such as dairy in Easter eggs) that has previously triggered anaphylaxis. Reduced quality of life and social exclusion can have **profound social and psychological impacts**.<sup>2</sup> There is little recognition that a child who has nearly died as a result of anaphylaxis may experience anxiety or Post-Traumatic Stress Disorder and require ongoing social and psychological support.

## RECOMMENDATIONS

I recommend that:

- the government fund a public awareness campaign about anaphylaxis
- the government develop programs and incentives to increase the number of allergy specialists practising in Australia and reduce patient waiting times
- psychologists and counsellors be routinely included in patient support teams and in funding for allergy and anaphylaxis services
- 'Responsible Service of Allergens' training be established for all food service providers, including hospitals
- eligibility criteria for Carer Allowance, Carer Payment and the NDIS be revised to reflect the evidence-based cost and burden of managing specialised diets
- literature about food allergy specify that it is a recognised disability and that the *Disability Discrimination Act 1992* confers protection on individuals with an allergy.

---

<sup>2</sup> DunnGalvin A, Cullinane C, Daly DA, Flokstra-de Blok BM, Dubois AE, Hourihane JO. Longitudinal validity and responsiveness of the Food allergy quality of life questionnaire—Parent Form in children 0–12 years following positive and negative food challenges. *Clin Exp Allergy*. 2010;40:476–85.