

Dear Committee,

I have had food allergies my whole life. I was diagnosed with an egg allergy when I was less than one year old, after being fed a small amount of egg custard by my mother, which caused a reaction. I do not have an anaphylactic reaction to egg, however it has been an annoyance and frustration for me for as long as I can remember.

I would particularly like to address two terms of reference in regards to my egg allergy, which, although it is not life-threatening, still has a major impact on how I eat and conduct my life.

- 1. The adequacy of food and drug safety process and food and drug allergy management, auditing and compliance (including food allergen labelling by manufacturers and food service providers):** I have found that, particularly when it comes to goods that may potentially have egg baked into them, that labelling is inadequate. It is often either non-existent, such as in bakeries with goods on display, or so broad it is impossible to tell if the item has egg (or any other allergen) in it or not. Blanket labels for foods served or produced in organisations such as bakeries that read 'Products cooked in this store many contain the following...' then a list of just about every known allergen, are deeply inadequate. Bakeries, including chain bakeries (e.g. Muffin Break) that operate in Australia should be required to have ingredients for all products on display in a place where all customers can access them. Blanket statements should be banned: if a company does not know what is in their food, they should not be allowed to serve it.

Further to this, when producing food, manufacturers should no longer be able to make blanket statements regarding possible traces of allergens in their products, or merely that it may have been produced on equipment or in an environment that also produces foods containing common allergens. Given the prevalence of allergies in Australia and the growing awareness of how allergy sufferers's lives are affected by their condition, it does not seem unreasonable that companies and manufacturers should be required to ensure that they take steps and implement procedures to prevent cross-contamination and that different equipment is used to produce foods containing common allergens and those without. I find it extremely irksome when attempting to

shop and almost every single packet I pick up will state that 'This product was made on equipment which also produces...' followed by a list of common allergens, including egg. I have to take a calculated risk every time I shop, wondering if this product which 'may contain traces' or 'was produced on equipment that also produces' will cause me a reaction. I am fortunate that I rarely react to traces, however *rarely* is the key word. I have reacted to traces of egg in goods before. I also have a deep empathy for allergy sufferers who regularly react to traces and so have to source their food from a variety of locations, such as supermarkets, fresh produce markets, online, and other ways, which can be expensive, to ensure that they do not inadvertently consume something which will cause a reaction.

These type of blanket possibility labels should be scrapped and manufacturers should be required to have systems in place that ensure zero cross-contamination and that, if goods do contain traces, it is clearly labeled as containing traces of the relevant allergen, rather than being included in a broad list.

- 2. The adequacy and consistency of professional education, training, management/treatment standards and patient record systems for allergy and anaphylaxis:** In all areas of my life I have found professional education regarding allergies, particularly among food servers, to be extraordinarily lax. This is a huge concern, as when allergy sufferers go out to eat, we (sometimes literally) place our lives in the hands of the servers and staff to tell us accurately what is in the dish we are being served. I have attended restaurants where, upon informing the staff of my allergy and asking if there is egg in any of the dishes, they have not been able to tell me with accuracy and, even upon asking the chef, have sometimes told me that 'we can't guarantee anything on the menu is without egg'. I consider this to be unacceptable! Food servers should be able to access full and proper ingredient lists for all dishes and customers should be able to view these on request.

I have also experienced incompetence from food servers on the rare occasions when I

have experienced a reaction in a restaurant, which some advising me to have water 'to dilute the allergen' and others dismissing me completely with 'what do you want me to do about it?'. Food servers should be trained on how to deal with customers experiencing any type of allergic reaction, from mild to life-threatening, and should respond in an appropriate and sensitive manner. Having antihistamines available and offering these to customers experiencing mild to moderate allergic reactions would be beneficial, and any meal which caused an allergic reaction should be immediately removed from the customer's bill.

Further to my life-long, but non-life threatening egg allergy, I was diagnosed with anaphylaxis to peanuts earlier this year, after inadvertently consuming peanut butter at a function and having a reaction. I would like to state that my concerns above relating to the terms of reference I have quoted specifically regarding allergies apply to anaphylaxis also. Companies should not be able to label foods 'may contain', they must take all action to ensure zero cross-contamination, and if a food does contain traces of any allergen, it must be clearly labeled as containing those traces. Blanket lists of 'may contain' should be banned: this is one thing I feel particularly passionate about. All allergy sufferers should be able to safely shop at their local supermarket and buy produce without having to take calculated risks based on possible traces, and this is especially true for anaphylaxis sufferers.

Specifically regarding anaphylaxis within **the adequacy and consistency of professional education, training, management/treatment standards and patient record systems for allergy and anaphylaxis**: I have found that most venues and restaurants that serve food are aware and knowledgeable about anaphylaxis and treat it much more seriously than they do mild to moderate food allergies. While I am pleased that this is the case, I would like mild to moderate allergies to be treated with the same seriousness and understanding as anaphylaxis. Someone should have to be at risk at dying before their condition is taken seriously!

Not only am I an allergy sufferer, but I also work in the early childhood industry and, as such, attend regular anaphylaxis training for my job. In regard to the first aid training for anaphylaxis for professionals, I feel that training once a year is inadequate. Mandatory training every six

months for all professionals in education, health and industries where the workers have a duty of care to clients (e.g. personal training, aged care, disability etc.) on how to administer an epi-pen and what to do in an anaphylactic emergency. Having trainer pens in common location (such as break rooms) but away from any first aid kits or other areas where epi-pens are stored, and for managers and supervisors to be required to carry out random testing of staff to demonstrate they know how to use an epi-pen and respond to an anaphylactic emergency.

I would also like to address the following point specifically regarding anaphylaxis:

- 1. Access to and cost of services, including diagnosis, testing, management, treatment and support:** The cost of having anaphylaxis in Australia is horrifying and the barriers to receiving an epi-pen, a life-saving medical device, are shocking. When I experienced my first reaction, I was fortunate enough to be close to a hospital and still well enough when I reached the emergency department to inform the nurses that I was having an anaphylactic reaction, although my condition deteriorated rapidly. When I was discharged the following day, I was given a script for epi-pen, however only discovered when I went to get it filled that the doctor was not able to give me a script for epi-pen on the PBS and it would cost me more than \$200 for a single epi-pen! I was utterly gobsmacked and horrified. On the advice of the pharmacist, I did not have the script filled and went to see my GP, who explained the regulations about getting an epi-pen on the PBS and that I would have to see an allergy specialist. I was fortunate that my doctor was able to refer me to a specialist who bulk-billed and could see me the following day, but it did mean I was without an epi-pen for almost a week from my first episode of anaphylaxis to obtaining one, due to delays in being able to see my GP. This was a frightening time, particularly when I saw no reason why I needed to be diagnosed by an allergy specialist, given I had already been seen by two doctors at Sunshine Hospital and my regular GP, all of whom agreed it was unquestionably anaphylaxis.

I was deeply grateful for the assistance in eventually gaining my epi-pen, but I also do have to acknowledge my privilege in this matter. Had I not been able to access a bulk-billed specialist, I could have paid privately and the wait wouldn't have been much

longer. However, had I not been able to see a specialist privately to receive my prescription, and had had to wait on the public system, it would have been a minimum wait of six weeks before I could have secured an appointment. While this may vary from service to service, this is a shockingly long time to wait to receive a script for medication that is literally life-saving. My other option would have been to try and somehow dig up more than \$200, money that many families, particularly those living at or below the poverty line, do not have. I know friends with anaphylaxis who go without an epi-pen because the wait to see a specialist in the public system is prohibitive, the cost of a private appointment is exorbitant and \$200 for medication without a PBS script is simply money they don't have.

If only one thing was to come out of this inquiry, I would like it to be this: that GPs, and doctors working in hospitals, can prescribe epi-pen on the PBS after a first episode of anaphylaxis without the patient being required to go to a specialist first. Given adrenaline is not addictive, has a specific use, and is literally life-saving, this does not seem like a significant cost to the public purse and would boost confidence in the health system Australians with allergies and anaphylaxis rely on.

I do hope the committee will take into account the matters I have raised here and look forward to hearing the outcomes of this inquiry.