

Submission to Parliamentary Inquiry into Allergies and Anaphylaxis

To whom it may concern,

I am Dr Emily Amos, a General Practitioner, International Board Certified Lactation Consultant and mother to a child with multiple food allergies. I would like to present to you two different perspectives on how allergy and anaphylaxis affects Australians. One, as a mother of a child with food allergies, as obviously this is closest to my heart and the one that affects my family and I every day. And two, as a doctor and advocate for my patients.

First I would like to share with you how it feels to parent a child with food allergies.

Every day is scary.

The fact that something we all do every day, eat, can be potentially fatal for my child is one of the scariest concepts I've ever had to get my head around. Some days are less anxiety provoking, like the ones where we are staying at home and I know I have carefully checked and prepared all food and I have total control over what goes in their mouth. Yet even then, I am acutely aware that I am relying on the accuracy of food packaging and manufacturers to be diligent in their duty of care to my child and my family.

On the rare occasions that we eat out, I pour over the menu carefully weighing up all the options and the likely risk of cross contamination or other exposure to our known allergens. Cognisant of the fact that my countless questions to wait staff hold them up from serving the others around us. Always worried that I will annoy them 'too much' with my questions and they may off handedly say "no" when I ask about allergens, just to hurry me along. We often opt for hot chips when it all gets too much and I have hungry children waiting to be fed.

I live every day with the knowledge that my apparently healthy child can be taken from me because of one small mistake, one over sight, one hurried read of the ingredient panel when I was not focussed enough. Did you know that some brands of parmesan have egg in them? I am literally the gate keeper of my child's health. Not yet old enough to take that responsibility yet themselves, I (and those few around me whom I have entrusted to help me shoulder this burden) look in my child's eyes and explain "yes, this is safe" or "no, I'm sorry but you can't eat that".

Like every person with or parent of a child with food allergies, I take this responsibility seriously. Constantly made aware that I need to teach my child to one day shoulder this burden themselves. While simultaneously trying not to instill in them a fear of food. Worrying if I have prepared them well enough to ever consume food outside of my presence.

Now you understand my context I would like to address the specifics areas of inquiry.

1. ***The potential and known causes, prevalence, impacts and costs of anaphylaxis in Australia-*** As both a parent and doctor, I believe the general public needs to be made aware of more of the evolving research into food allergy in Australia. When pregnant with my section child I poured over Pubmed searches to try and do anything I could to 'prevent' food allergy after having it strike our family with no past history of atopy. I have a university degree that includes training in epidemiology, this was something I could do. Most can't.
2. ***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)-*** "May contain traces of". The four words that seem to absolve all manufacturers of any blame. We get it, you can't guarantee perfectly safe manufacturing processes. But by saying this on all most all foods, those of us who's lives depend on this, are forced to make an educated guess

as to the actual risk of cross contamination or eat very little. And as someone with a medical degree, my 'educated guess' might be different to others. My suggestion would be to enforce wording that assisted us in making this decision. Some companies include phrases "made in a facility or on a production line that also processes peanuts" (etc etc for other allergens). This alone allows me to actually decide if the risk of cross contamination is high or if this manufacturer is simply covering themselves legally.

3. ***The adequacy and consistency of professional education, training, management/treatment standards and patient record systems for allergy and anaphylaxis-*** In my discussions with my child's kindergarten/school, I believe that the training my child's teachers received in allergy and anaphylaxis was better than that which I received as a doctor working in the public hospital system. This may have changed in the 5 years since I worked within the hospital system however so I won't comment further.
4. ***Access to and cost of services, including diagnosis, testing, management, treatment and support-*** I am fortunate to have colleagues who have been instrumental to us accessing timely and affordable care. My own experiences notwithstanding, I know from my experience referring patients to paediatric and adult Allergists that most Australians don't have this experience. The wait times can be months and months and the costs for single visits running into the hundreds and hundreds of dollars (depending on how many allergens may be tested for). All the while, patients and parents are left feeling like a ticking time bomb waiting for another reaction until they are able to access that "holy grail" of the allergists appointment. As a GP, I have looked into doing the training that would allow me to do skin prick testing and rudimentary management of newly diagnosed allergies and I feel that expansion of access to this training (including perhaps financial support for training) would vastly assist patients who are waiting for access to Specialist Allergists.
5. ***Developments in research into allergy and anaphylaxis including prevention, causes, treatment and emerging treatments (such as oral immunotherapy)-*** Thankfully as a family, we are now accessing Specialist Allergists at a tertiary centre

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which is beginning to open our eyes to options in treatment including oral immunotherapy. Prior to this, living over an hour from this hospital, we were not being made aware of these options. It boggles my mind that even as a doctor, a lot of what I know about the treatment and management of food allergies has been made through my own research since our families diagnosis. I feel that there should be more invested into say nurse practitioners who can provide up to date evidence based management of food allergies in the community (including locations far from tertiary settings), in the same way that we have Diabetic Educators. There are a lot of resources available out there but the fact that I as both a mother of a child with allergies and as a GP do not know about them tells me that a better way to access them would be helpful. Families with food allergies should all have access to easily accessible and trustworthy sources of knowledge so they are not forced to “do their own research”. As I mentioned before, my “research” involves medical training and an understanding of statistics, this is not the level of understanding of everyday Australians.

6. ***Unscientific diagnosis and treatments being recommended and used by some consumers-*** I get it. I have been desperate and willing to cling to anything to help my child. Put yourself in our shoes, our children can go from healthy to potentially very unhealthy in an instant. There is no ‘grey area’. Desperation will breed misinformation. How do we address this? Information. Purely and simply, we need better access to reliable, caring and reputable sources. The ASCIA website and fact sheets are amazing. The “Epiclub” reminder system where you can register the details of your epipen to get reminders of when it needs replacing is fantastic. The facebook group “Allergy and Anaphylaxis Australia” are a terrific form of support and mode to disseminate up to date information on food recalls etc. But imagine if we had a nation wide register of individuals who had been diagnosed with food allergy (similar to how we register newly diagnosed Diabetics)? Where SMS could be sent out to all potentially affected individuals the same way our disaster alert systems work? If these people and their families were able to access subsidised visits every 6-12 months to a registered Allergy Educator who could update them on any new

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advances pertinent to them and feed back to Allergist and GP? I know that all our fabulous over worked Allergists are trying to do this, but they are also trying to diagnose, treat and research into how to find cures for us. As a doctor I know only too acutely that you can't do everything in the short amount of time we have with patients. Our current allergist in a tertiary centre does have this 'Allergy Team' management approach, but how about extending this outside of tertiary centres for those of us with difficulty accessing these services?

7. ***The impact of unnecessary drug avoidance due to unconfirmed drug allergies and its management, such drug allergy 'de-labelling'*** - I feel unqualified to respond to this point.

Thank you for reading my submission and please feel free to contact me to discuss any part of it.

Kind regards,

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