



# Anaphylaxis

## *A patient perspective*

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In order to help us better understand our patients' experiences, *Australian Family Physician* is pleased to introduce the first in a series of articles written by people who are willing to share their stories.

Ella was requested to write this article by *AFP's* Editor in Chief. Ella is now a year 11 student at Williamstown High School, Victoria.

I have been allergic to nuts all my life. I had my first anaphylactic reaction when I was 18 months old. I am now 16 years old and have been told that I will be allergic all my life.

My allergy is manageable within my family unit, but whenever I go to a school camp, a restaurant, or a friend's house, it becomes that much more complicated. We have to make people aware that there cannot be any nuts – no nuts at all – in anything. It can be really frustrating (and sometimes embarrassing). People can be so stupid; they think that it will be okay to cook with peanut oil (because somehow that's not a nut), or cook satay on the BBQ as long as my food isn't near it or I don't touch it... as if. Sometimes it's easier not to eat anything at all in these situations. I remember when I was in primary school and the principal didn't want to ban nuts from the school camp because he 'didn't think that making other children go without peanut butter for a few days was fair'... my mum and our GP gave him such a hard time.

Now that I am getting older, my parents worry more. They are reluctant to let me go to parties with alcohol or without parental supervision, not because they don't trust me, but because of the dangers of 'hidden' nuts, or even of me kissing a boy who has eaten a nut (my mum does research all the time!). It kind of ruins my night because I have to be

so conscious of everything. And what will happen to me if I eat a nut and people around me 'freak out' and make it worse, and I don't get to the hospital in time? I don't want to die over something so lame.

Having such a severe food allergy doesn't only restrict everyday life. For instance, I love to cook but could never be a chef; I love to travel, but couldn't realistically go to countries like Thailand with ease. You'd think that with so many people around the world dying from severe allergies like mine (and sometimes worse allergies), more money would go into research. Millions are spent on research into cancer, diabetes and other diseases. Why not do research into immunisations against allergies (like measles and tetanus immunisation), or a cure?

I have been to doctors and specialists both in Australia and the United Kingdom. I don't actually remember the last time I had a reaction (I was only 5 years old), but each time I visit a doctor they ask me about it. It would be nice if they could offer more than just asking if I've had an 'episode' recently and whether I carry my Epipen around with me (just because I carry an Epipen doesn't make life easier). It would be more beneficial to me if they asked me questions about how the allergy affects me, and gave me advice on how to act if I think I have ingested a nut but I'm not sure. Sometimes I think I'm just

an interesting file being updated. Not one medical person has ever asked me how I actually feel, if I am coping mentally, or acknowledged how difficult it must be.

Recently our GP gave me a referral for the Royal Children's Hospital in Melbourne to be re-tested. The waiting list was 8 months. Our GP was really helpful and came back with some private specialists (their waiting lists were only 3 months). I am not looking forward to being tested again.

My mum is not that keen on specialists; she doesn't like the way they speak down to us. She thinks that while they may need to be very 'basic' with some people, they should assess the family's ability to understand and retain information, and adjust their communication accordingly... she has a point.

For my parents – but especially for my mum – the hardest part will be when she can no longer check for me. By the time I leave home she will have spent the best part of 20 years reading labels, asking questions, demanding people take the situation seriously... I will have to do that for myself. Maybe by the time I am an adult, there will be a cure and I can eat my way around the world!

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