

My name is Louise and I have suffered from Idiopathic Anaphylaxis for the past 18 months. I have had close to forty admissions to the emergency department and wards during this time. True idiopathic anaphylaxis is quite rare and as such treatment is expensive.

I was initially diagnosed with a nut allergy but after having severe anaphylactic reactions every 2-3 days it was revised to a preservative allergy. I started a diet consisting entirely of fresh fruit, vegetables and unprocessed meat. This diet seemed to lessen the number of reactions, however they were becoming more severe. As Mareeba is a rural town and doesn't have a tertiary hospital, I was air evacuated to The Cairns Hospital on three occasions and road transported on several others. My reactions are incredibly severe requiring a large amount of adrenaline intramuscularly, via a nebuliser and intravenously. I can not work for at least one week post reaction. The Mareeba ED knows me well and the hospital has written a specific treatment plan that is laminated and located in the front of my chart. I always carry at least two epipens with me and I have a further three located around the house. Unfortunately, the epipens do not provide much relief and my survival relies purely on getting to hospital as quickly as possible, on most occasions via QAS.

After seeing a very overworked public immunologist in Cairns I ended up travelling to Sydney to see Professor Connie Katelaris, a private immunologist. This drained me of all of my savings. She diagnosed me with Idiopathic Anaphylaxis and started me on a treatment regime of montelukast, ranitidine and cetirizine to try and dampen my reactions. This was unsuccessful and I am soon to start a monthly injection of Xolair – a monoclonal antibody, to try and block the immune process. This drug was only available to those suffering severe allergic asthma so my doctor had to get TGA approval. She approached the drug manufacturer and they are trialling me for three months on compassionate grounds (normally \$900 per injection). It is a very costly situation requiring me to pay for tele-health conferences from my GP's practice due to rurality (there are no GP's who bulk bill in Mareeba and it is hard to get an appointment), pay for travel and accommodation to Sydney when required and pay for medications that are not on the PBS for my condition.

Being idiopathic, I can react to anything, anytime. My social life has become limited to where I can and can't eat out. This stresses me as my friends and family always seem to have to cater for my needs. I often prepare and eat my own food before I go out. I am a member of QLD SES and have to provide my own food during activation (when food is generally provided to all). This becomes difficult when I am deployed for 4 days or more, especially in an area that has limited refrigeration. I had plans to travel through Asia but I can't now for fear of reacting to unknown foods in a country that doesn't have the treatment capacity available here in Australia. I have experienced a number of emotions – fear, depression and anger being some of them. My family have been fantastic support, to the point where they have changed their own diets to accommodate mine.

When eating out I always ask what the food contains and how it was prepared. I have often faced vendors who have not taken me seriously, to the point where they have actually mocked me, thinking that my reactions were simply a lifestyle choice. As a result, I have reacted to an ingredient not disclosed upon enquiry on one occasion. When admitted to hospital I have faced many difficulties with the food provided. Fresh food has been in VERY short supply. While an inpatient I have had several reactions to ice cream, gravy and chocolate. The Queensland Health menu does not cater well for fresh food, with sandwiches and processed foods being the 'go to' meals. I believe this is an area that is in dire need of investigation and revision. While an inpatient for three days at The Townsville Hospital all I was able to eat the whole time was three bananas and even they were hard to come by.

I have reacted to the influenza vaccination and this has placed in me a difficult position. I work in the healthcare industry and this vaccination is often a requirement.