



TORONTO ANAPHYLAXIS EDUCATION GROUP

MEETING MINUTES - Wednesday, January 28, 2015

TOPIC: Transitions To Independence

Meeting Overview:

With every transition come new experiences and new adjustments in managing allergies. During this panel session, we looked at building independence whether it's preparing your child for their first playdate or entering the workforce with allergies and any of the experiences in between! We had a variety of voices sharing their experiences as allergy teens, allergy parents and recent grads working with allergies.

Participants:

NAME	Personal Info
Lindsay	22 years old and a first year medical student. She is allergic to peanuts, tree nuts, soy protein and is also lactose intolerant
Nicole	24 year old Kindergarten teacher. She is allergic to tree nuts, peanuts, shellfish, fish, crustaceans, sesame, peas and beans
Marcus	19 years old and in second year university, currently pursuing a double degree of Composition under the Faculty of Music and Life Sciences under the Faculty of Arts and Science. He is allergic to Peanuts & Nut Derivatives (almonds, walnuts, cashews, etc.).
Lavender	Marcus' mother. She is an IT professional and works as an independent consultant for companies' IT departments. She has two kids who are 19 and 15.
Christopher	Consultant who provides communications and advocacy services for non-profit organizations. His favourite client is Anaphylaxis Canada. Chris is allergic to peanuts, tree nuts and seafood. He is married and has an infant son.
Phil (didn't attend in person, sent notes)	23 year old solution engineer for a technology company. He's allergic to peanuts and legumes

QUESTION: CAN YOU DESCRIBE HOW YOU MANAGED YOUR ALLERGIES IN A PARTICULAR SITUATION?

NICOLE – TRAVEL:

My sister is a flight attendant, so I recently went away with her for a weekend. Flying with her is great, b/c she knows my allergens & keeps me safe. I flew back on my own at the end of that weekend. I was flying with a different airline and I was quite impressed with them. I flew stand-by, so I wasn't able to give them any advance notice of my allergies. Normally, I let them know when I book my ticket and again at the gate. This time, I told them at the gate and the "cabin safety manager" (flight attendant in charge of safety) came to see me before we took off, and asked about my allergies, where my auto-injectors were, whether I had packed my own food, etc. They made an on-board announcement in English & French asking people to refrain from eating nuts. I always pack my own food when I travel, so that I am certain it is safe for me. I take extra in case there are delays.

LINDSAY – GOING AWAY TO UNIVERSITY:

I went away to university for my undergrad. I lived in residence my first year. I had to be able to trust the cafeteria and my roommate. Obviously, allergies were not my biggest concern in picking a university, but it was something I needed to consider in making my decision. My mother & I went to a big "university fair" in downtown Toronto in my last year of high school and at each school's booth, we would speak to their "hospitality" rep about allergy accommodation. At University of Guelph (where I went), the cafeterias post all of the ingredients of food that they make, so it was easy to determine if something was safe for me. I would go into the kitchen and speak to the chef to make sure.

Apparently, I could have asked for a single room b/c of my allergies, but I didn't know that at the time. I ended up having a roommate. I got her contact information in the summer and I contacted her before school started. We discussed my allergies, and she agreed not to eat nuts in our room. As it turned out, there were 2 other people with nut allergies on my floor, so everyone was very aware and conscientious of keeping us safe.

CHRIS – MANAGING ALLERGIES IN THE WORKPLACE:

It seems that there are more & more people with allergies around now, so it is no longer strange to have an employee with food allergies. My previous employer was very open to putting policies in place to manage allergies. I had a co-worker with allergies who was very young & very shy about asking for accommodation, so I decided to go to the HR Dept and talk to them about my concerns. They asked if I could make suggestions about how they could accommodate us, so I helped them develop a policy. I suggested things like: no eating at desks, only eat in the lounge and wash hands afterwards; when serving food at meetings, ask attendees about allergies & try to accommodate them, etc. A Human Resources magazine wrote a story about that company's allergy policy.

MARCUS – HIGH SCHOOL & DATING:

It was a big transition from elementary school to high school. My elementary school had a strict "no nuts" policy, and all food containing nuts was confiscated. In high school, you're "on your own", so I had to be responsible to not share foods or eat unsafe things.

My mom made my lunch for me most days. When I would occasionally eat in the school cafeteria, I had to speak to the staff about the ingredients and preparation. I really only bought a few things and stuck to those same things. If I was tempted to eat something, I would ask myself: "Is it worth taking the risk?" and

I would remember the feeling of having a reaction and how awful I felt. I carried an Epipen and Benadryl in my backpack and I always had my backpack with me.

I dated a good friend for a while. She knew about my allergies before we started dating, but that is different than living with them. I would have to ask her what she had eaten before kissing her. She obviously didn't want to hurt me, but I still had to be on my guard b/c she wouldn't think about the fact that she had had Thai food for lunch, for example.

LAVENDER – HAVING A CHILD WITH ALLERGIES:

When we first discovered Marcus' allergies, I was very anxious. I was worried daily and everything seemed very scary. We talked about these concerns at home and talked to him regularly about the need to be cautious. The worries lessened over time.

I have no complaints about the schools he has gone to. Elementary school was excellent. In high school, the kids can bring any food they wanted, but by then, Marcus could look after himself. In university, the food services will accommodate allergies if you talk to them. We discovered he could get a single room if we requested it.

I feel very lucky that we live in Canada. People here are familiar with allergies and take them seriously. This is not the case when we have travelled to visit family in Hong Kong. They don't take it seriously there.

PHIL – FIRST TIME AWAY FROM HOME:

I always have my Epipen with me. I always told other parents/ teachers/ coaches about my allergies. Most people "got it". Those that didn't, probably never will, so I didn't waste a lot of time trying to convince them.

When I went on sleep-overs, my family always spoke to the host family beforehand and I always brought my Epipens and Benadryl. As I got older, I became less shy about telling people about my allergies. In college, some of my friends didn't get it at all. One of them had a mild allergy, and he told them all that I was overreacting. That made me pretty mad.

QUESTION: HAVE YOU EVER HAD A SERIOUS REACTION? HOW DID YOU HANDLE IT?

MARCUS:

I had one reaction in high school. I was about to perform a piece of music I had composed in a concert, and asked a friend to buy me some food at a restaurant beforehand. She asked the restaurant if the food contained any nuts, and they said no, but when I ate it, I knew that it had nuts.

In retrospect, I made a very bad decision about how I handled that reaction. I took Benadryl instead of Epinephrine and I still performed. Then I went to the hospital afterwards. Looking back now, what I should have done was given myself my Epipen and gone to the hospital right away. I was very lucky that the reaction didn't get more serious. But no performance is worth that. I won't do that if I have a reaction in the future. I will take the Epi and go to the hospital right away.

NICOLE:

I think there has been a change in philosophy from when I was younger. Before, Epinephrine wasn't the first line of treatment; we were told to take Benadryl and wait.

I had a reaction on Christmas morning when I was in grade 2 or 3. A family member always brought us Worthen's candies, which were safe, but this time, they brought candies that had nuts in them and I ate them without realizing. I knew immediately I was having a reaction: I had a metal taste in my mouth and my tongue felt funny. I started vomiting and my throat felt funny. My parents took me to the hospital, but didn't use my Epipen. It was a very scary experience.

Because as a child, I was always told to take Benadryl and wait, I have been hesitant to take Epinephrine when I have had other reactions. Like taking it would be an admission of how serious the reaction is, or something. Recently, I had a reaction and went to the hospital. When I told the nurse I had never taken Epinephrine, she gave it to me to prove it wasn't so scary. She was right. It wasn't so bad. It was a good lesson: I will definitely take it the next time I have a reaction.

LINDSAY:

I had a serious reaction as a young child. I ate what I thought was a cheese sandwich, but it actually contained peanut butter. My mom realized right away and made me spit it out. I didn't swallow any of it. My mother didn't give me the Epipen. I think she was worried about traumatizing a young child with a needle.

I developed my soy protein allergy 5 years ago. I didn't realize all the foods it was hiding in, so I had a few reactions.

CHRIS:

I was 3 yrs old when I had my first reaction. I was really sick to my stomach, but I didn't have any breathing problems. It wasn't until I was 17 that I had a reaction that compromised my breathing. I think it is actually much scarier for family members to watch the person having the reaction.

When I had reactions as a child, it was b/c I didn't know how to take care of myself. Now that I am older, I can take care of myself and decrease risks. The reactions I had as a young adult were mostly due to stupidity and bad choices. But the general awareness about allergies is so much higher now, I am much more confident in being able to manage my allergies.

QUESTION: HOW DO YOU TEACH AN ALLERGIC CHILD TO TAKE CARE OF HIM/HERSELF WHEN THEY ARE OUT DRINKING?

NICOLE:

I think you ingrain good habits early: label reading, carrying an Epipen, etc. I get anxious if I leave the house without my Epipen & Ventolin. I will have a panic attack and have to go home to get them. I even carry them when I go clubbing, in my tiny purse. I have left parties where I didn't feel safe (one party in particular with big bags of peanuts where people were throwing peanuts into each other's mouths).

CHRIS:

Drinking increases the likelihood of engaging in risky behaviours. Drinking & driving, taking drugs, etc. Eating unsafe food is a risky behaviour for an allergic person. You can't just go out after the bars close and head to the nearest Chinese restaurant. You have to know how to make good decisions.

LINDSAY:

Another important thing is to know what you are drinking. Some kinds of alcohol can have nuts in them. Amaretto is obvious, but someone gave me a drink with Southern Comfort in it. I was about to drink it, but something held me back. I Googled it on my phone, and discovered it contained tree nuts, so I gave it to a friend. Some kinds of gin contain nuts, as do some liqueurs. You have to know what you are drinking and whether it can make you sick.

QUESTION: DO ANY OF YOU HAVE PROBLEMS WITH ANXIETY?

LINDSAY:

Yes, when I was younger I used to worry about touching things that had been in contact with my allergens and contaminating my own food. I still get anxious if I am sitting near someone eating nuts or if I can smell nuts. I think I have gotten better as I have gotten older, and have tried to be more rational.

CHRIS:

As I said earlier, I didn't have a major reaction until I was 17 yrs old. I got more anxious after that, and was worse when I was on my own. I get anxious if I am at a sporting event and can smell peanuts.

I also sometimes get anxious about having to explain about my allergies. I don't like being the centre of attention, so I try not to make a big deal about things, but when people ask me why I have an EpiPen, or why I am avoiding eating certain things, I try to think of it as "educating" rather than "explaining why I'm different". Explaining is very tiring.

NICOLE:

After having a reaction, I was more cautious. I went to Cuba with some friends a few years ago, and I had a reaction while I was on the trip. The "what if"s drove me crazy, and I became very paranoid about the food there. I basically only ate the granola bars that I had brought with me as 'emergency snacks', because I was afraid to eat anything else. It can be really difficult, b/c many of the symptoms of anaphylaxis are similar to panic attacks – shortness of breath, feeling faint, etc. – so it's hard to determine whether those feelings are due to anxiety or allergy sometimes.

I am also very observant of people in social situations. I pay attention to what they've eaten, what they've touched.

QUESTION: MY SON IS 6 YRS OLD. I'VE HEARD THAT THE EARLIER KIDS ARE TRAINED TO MANAGE THEIR ALLERGIES. THE BETTER THEY ARE AS ADULTS. WHAT DID YOUR PARENTS DO TO EDUCATE YOU ABOUT YOUR ALLERGIES?

NICOLE:

I always wore a medic-alert bracelet. I always had a fanny pack with my emergency medicines. I read ingredient labels as soon as I could read..

LAVENDER:

I think it's important to let the child know about allergies when they are young. Tell them there is no fault or shame in having allergies. Encourage them to speak up for themselves.

QUESTION: (for Lavender) AT WHAT AGE DID YOU FEEL COMFORTABLE LEAVING MARCUS HOME ON HIS OWN? (E.G. WALKING HOME FROM SCHOOL, BEING HOME ALONE FOR A FEW HOURS)

LAVENDER:

Marcus used to take the bus home from school. There would be kids on the bus eating nuts; so he knew to keep away. I felt like he was ok if he was surrounded by friends & schoolmates, they knew about his allergies. If he's going to the movies with his friends, he would take his own snacks.

QUESTION: I HAVE A 13 MO. OLD DAUGHTER WITH A SESAME ALLERGY. WHAT DID PEOPLE DO ABOUT PLAYDATES? CAN YOU ASK PEOPLE TO CLEAN THEIR HOUSE/ TOYS BEFORE WE COME OVER?

(Other TAEG Member):

I ask people to not have the allergen out when we came over. I always scan the environment when we get there, to make sure they haven't missed something.

You do have to be vigilant when kids are really young b/c they put things in their mouths. So, even if the house looks safe, you don't know if the toy your kid is sucking on was previously in the mouth of another child who just ate your kid's allergen.

I know some allergy families worry about going to other people's houses, and always invite people to their house. I guess that's one way to feel safe. I just didn't want to NOT go to other people's houses.

CHRIS:

Some people "get" allergies, and some people don't. You learn pretty quickly who you can trust and who you can't.

I find that sometimes people want to accommodate you, but aren't sure how. I think they appreciate it if you make suggestions about what they can serve, or better options that would keep you safe (i.e. serving "plated" food as opposed to a buffet where things can get cross-contaminated).

(Other TAEG Member):

You have to remember to ask people and restaurants EVERY time about how the food was prepared. We recently went to a restaurant that we had been to many times before and were assured the first time was safe, only to discover that they had changed things in the kitchen, and now the food was no longer safe. We only found that out by accident, b/c an employee heard us talking about allergies, and we don't know

how many times we had eaten there thinking the food was safe, when in fact it wasn't. I felt terrible that I had potentially exposed my kid to danger, when I assumed we were safe.

QUESTION: HOW HAVE YOUR FRIENDS BEEN IN DEALING WITH YOUR ALLERGIES?

LINDSAY:

I've had a good group of friends, so I've been lucky. Certainly, some people don't "get it" as well as others, so I haven't been as close friends with them.

I also try to have a balance. I know that I can't impede other people's plans all the time b/c of my allergies. So I don't always ask them change the restaurant they are going to. Sometimes I just sit it out if they are going for Thai food, for example.

CHRIS:

People are good or bad influences in your life. Allergies are no different. You have to know who you can trust. The people you can't trust about your allergies probably aren't going to make good friends in other ways either.

I will say, it is much better now than when I was growing up. There is much more awareness of allergies and people know how serious they can be. The older generation doesn't "get it".

MARCUS:

I have a good group of friends, and they are supportive. But I do have to remind them about my allergies sometimes. Like, ask them: did you wash your hands after eating those nuts? Are there any nuts in these cookies? Or remind them that I can't go to a certain restaurant.

I know that they don't mean to hurt me, but they don't have the same limits that I do. They don't have to think the way I do. And I can't expect them to.

LAVENDER:

I agree with Chris about the older generation. My mother lives with us and she still has no understanding about allergies. She keeps trying to get Marcus to eat nuts. We can't convince her that they will make him very sick.