

afraid of

If a serious allergic reaction has left you too frightened to eat even 'safe' foods, you are not alone. Anaphylaxis can exact a huge psychological toll – but there are ways to stop fear from eating you up.

by JENNIFER VAN EVRA



It wasn't until Sandra Schwartz was on a camping trip in Northern Ontario in August 2005 that she felt the full force of the fear. Just a couple of days earlier, the 36-year-old Ottawa resident had been lying in an emergency room, experiencing her second-ever reaction to shellfish after eating a plate of shrimp. Unlike the minor reaction she'd had a year before, when she turned red and her face swelled, this one was full-blown anaphylaxis: Schwartz's entire body turned crimson red and covered in hives, her heart raced as she grew lightheaded and dizzy, and her face swelled beyond recognition. But the food didn't just set off a dramatic physical response, it also triggered a psychological tidal wave.

"They always talk about that feeling of impending doom, and I had it times 10," says Schwartz. "The doctors were saying I was OK, but I said, 'I feel like I'm going to die. Please don't let me die.'"

Though she had yet to realize it, that was the night Schwartz's fear of food began. The next day, thinking she was well enough to travel, Schwartz left on a planned camping trip with her boyfriend. As they drove along the increasingly remote highways, the "what ifs" began to creep like tendrils into her psyche: *What if I react again? What if medical help can't get to me on time?* And, because Schwartz had been diagnosed with a shellfish allergy a year earlier, but didn't understand that she was supposed to avoid it altogether, she had continued to eat shellfish. In fact, only a month before, she had eaten a plate of shrimp without incident. As a result, she didn't fully believe that it could have triggered such a massive reaction. That raised another terrifying question: *If it wasn't the shrimp, what was it?* Maybe it was fruit. Or wheat. Or something else. Suddenly, every food was suspect, and Schwartz became terrified to eat.

Photography: (Woman) KC ARMSTRONG; (Snake) KENNETH WILLARDT/Nonstock/Firstlight

FOOD



Pam Lee with her 9-year-old son, Aaron Schroeder.

A couple of days later, her panic peaked. “We were in the middle of nowhere, I was chewing a piece of gum, and I started not being able to breathe.” Schwartz thought it was another reaction, so her boyfriend drove full tilt to the next town. Once in the hospital parking lot, Schwartz realized it wasn’t a reaction that she had experienced. It was a major panic attack. “I just sat crying in the car. That’s when we realized that there’s a real psychological element to this.”

The couple cut the trip short. Still, Schwartz only felt safe eating cereal and pasta. She saw an allergist and got retested (once again, shellfish was the allergen), and tentatively added a few more foods to her diet, but the fear persisted. By the time she got married three months after that camping trip, Schwartz joked to friends that allergies were the best pre-wedding weight loss plan around. Feeling like every bite was potentially lethal, she had lost over 20 pounds. “Every time I ate, it was like taking a plunge out of an airplane,” she says. “And I wasn’t sure if the parachute was going to open or not.”



TIPS TO COPE WITH ALLERGY FEARS

from DR. SCOTT SICHERER

Don't forget the rest of life.

Parents need to see a child as a child, not as a walking food allergy. Give positive reinforcement for their accomplishments.

Get informed. Talk to your allergist and read as much as you can from reputable sources.

Seek expert help. If your or your child's quality of life is being diminished by fear or anxiety, a therapist can give you strategies to work through this.

Find support. Join a support group in your area or online, and talk to others about your allergies and the fears they trigger.

Take baby steps. If you don't feel comfortable sending your child on a play date, go with him and talk to the other

parents about your child's allergies. The next time, go again, but leave for part of the time. Break everything down into steps you can manage.

Stay healthy. You'll be better able to fight anxieties. If you have limited your diet or your child's, talk to your allergist about steps to take to expand it.

Remember the odds. Yes, be constantly vigilant. But deaths from anaphylaxis are rare.

Build on successes. Give yourself a pat on the back every time you face your fears and overcome obstacles.

Don't be hard on yourself. Fear will win the occasional round. That's normal – and the challenge gets easier with time.

Lauren Alexander came to know that feeling. The 24-year-old was diagnosed with a life-threatening allergy to tree nuts as a baby, and other than the occasional reaction, she had been leading a normal life. Then in the spring of 2006, a reaction to some nut-laced salad dressing at a restaurant plunged her into a world where she felt surrounded by foods that could kill her. Alexander, who lives in Washington State, dropped 20 pounds in two months. She even began taking Benadryl before eating – just in case. “This huge swell of paranoia came over me,” she explains. “It was like nothing I had ever experienced.”

Dr. Scott Sicherer says cases of food fear such as Schwartz's and Alexander's are not at all unusual. Sicherer is an allergist, associate professor of pediatrics at the Mount Sinai School of Medicine and author of *Understanding and Managing Your Child's Food Allergies*. Nearly every day at his New York office, he sees food allergy patients who express varying degrees of anxiety. Some become afraid to eat, in rare cases to the point of anorexia; others become panicky when they feel the slightest allergic symptom; some severely restrict the foods in their diets; and others withdraw themselves or their allergic children from society in an attempt to prevent reactions.

Such responses may appear to be irrational, but Sicherer uses an analogy to make sense of them. “If I stood next to you, pulled out a gun and held it at your head,” he says, “you're going to shake, you're going to sweat, and you're going to fear for your life, because you know that gun could hurt you. So if you've been hurt by food, that type of fear can become a huge part of your existence.”

It became part of daily life for Pam Lee, a Vancouver teaching assistant. Her son, Aaron Schroeder, was a

Pam Lee and her family would go to the beach and see peanut shells everywhere: 'I began to feel like Princess Diana in the minefields.'

toddler when he had his first major food allergic reaction: after eating a peanut butter cookie, his whole body swelled up and his breathing became laboured. He fully recovered, but his mother's psychological response endured for years. "We would go to the beach and there seemed to be peanut shells everywhere. They probably always were there, but I had never noticed them. I began to feel like Princess Diana in the minefields," Lee says. Soon, she was terrified to feed her son any food he hadn't eaten before, and told him that if he even touched a peanut he would die.

But while she was desperately afraid, Aaron was wild and fearless – the kind of kid who would use the top of a plastic storage container to sled down the basement steps or test a hot stove with his finger. Then one day in the first grade, he shared a snack and a serious allergic reaction landed him in the hospital. All of a sudden, Aaron was no longer the daredevil. "He would ask me over and over and over, 'Have you checked the ingredients?'" Lee says. He refused food brands he didn't know, and no longer wanted to go over to friends' houses. Even when Lee took a safe cake to a birthday party, he didn't want to touch it. She would tell her son, "You've got to trust me. I wouldn't endanger you."

What people like Lee, her son, Schwartz and Alexander have experienced are likely symptoms of post-traumatic stress, says Dr. Gordon Cochrane, a Vancouver psychologist who has written extensively on anxiety-related issues. While that condition is usually associated with soldiers who have returned from war zones or car crash survivors, the trauma caused by a life-threatening allergic reaction can be equally scarring. In order for us to function in the world, he explains, we need to uphold the belief that we are safe from harm. For example, when we leave home in the morning, we need to believe that we aren't likely to get shot at or hit by a car; otherwise, we wouldn't be able to go anywhere. In the same way, when we eat, we need to believe that our food won't kill us. So when that belief gets badly shaken – as it can with a severe allergic reaction – a floodgate of perceived dangers opens up.

"People think, 'If this happened, then that might happen, and then that might happen,' and so on. And with an allergic response, the possibility is there every time they eat," Cochrane says. "As a consequence, they could easily narrow their intake down to almost survival food." If a major reaction rattles that sense of security, fears can expand well beyond food. Suddenly a world of dangerous possibilities opens, and a trip in a car or an elevator ride can turn terrifying. Untreated, such anxieties can have a profound impact on people's working lives, relationships and sense of well-being. That in turn creates a vicious

cycle: being in a state of perpetual anxiety is exhausting, and once a person is exhausted, they are much less capable of overcoming their fears.

Cochrane also notes that when it is parents who are immersed in fear, they tend to look only at the consequences of under-protecting allergic children, not of over-protecting them. Severely restricting a diet can be one form of over-protection. Dr. Janice Joneja, a B.C. immunologist, dietitian and author of several books (including *Dealing With Food Allergies*), has seen the consequences in dozens of patients who are so fearful of food that they have reduced their children's diets, or their own, to almost nothing. At that point, malnutrition can become a greater danger than the allergy itself.

In one case, the mother of an allergic son was so afraid of him dying from a reaction that she had fed him only six or eight foods all of his life. When she brought him to Joneja at the age of 14, he was so poorly nourished that he looked several years younger and

wore a hat to hide his thin, brittle hair. “He had been instructed that, ‘If you eat anything else, you’ll die,’” recalls Joneja. “With children, it can lead to permanent damage if they’ve got a deficiency at a stage where they really need the nutrients,” she says. “So if people take a food out, they need to always add a nutritionally equivalent food in.”

But not all fear is bad. The medical experts say that some level of anxiety is not only an understandable side effect of food allergies; it keeps people vigilant about avoiding dangerous foods. The question becomes: how much fear is too much? In short, says Sicherer, if it’s limiting the patient’s quality of life, it’s a concern. For example, if malnutrition becomes a risk or a patient’s job is affected, or if parents don’t allow their kids to socialize or are home-schooling them simply because they are afraid of possible reactions, they may be giving fear too much control.

“I tell my patients with food allergies to do the same things that everyone else does, except eat the food they’re allergic to,” he says. It is important to emphasize that this is a potentially life-threatening condition, he adds, but it shouldn’t be the topic of every conversation. “I tell families to think of their child as a child and *not* as a food allergy, and to give positive reinforcement for the normal things they accomplish.”

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Knowledge and support are two of the best antidotes to fear. Sicherer finds some patients’ concerns are rooted in misunderstandings about how allergies work, what can and can’t trigger reactions and what’s necessary to prevent them. Of course, many patients understand their allergies all too well – and if their anxieties become consuming, Sicherer suggests they see a counselor, psychologist or psychiatrist who specializes in the treatment of anxiety or post-traumatic stress. There, they can learn strategies to cope with their anxiety, from relaxation techniques to ways of stemming the tide of mental worst-case scenarios that make them afraid to eat, to socialize and, sometimes, to leave their homes.

For instance, Cochrane will encourage a patient to

STEPS TO FIGHT ANXIETY

from DR. GORDON COCHRANE

- **Respect your opponent.** Anxieties caused by life-threatening allergies are completely normal, but not easy to overcome.
- **Find tools and strategies that work for you – long before the anxiety arises.** This will give you a better chance against the fear when it surfaces. These can include breathing exercises to help you relax and visualizations (for example, a happy childhood event or a favourite vacation moment) that direct your focus away from the source of anxiety.
- **When the anxiety begins, try to stay clear and focused.** Ask yourself: is there something I can do about this situation? (For example, if you walked into a clambake and you’re allergic to shellfish, you can leave.) If the answer is yes, do it. If the answer is no, and the fear is rooted in “what ifs”, use those coping tools and strategies. The sooner you can bring the surfacing anxiety under control, the less chance it will take over.
- If the tools and strategies don’t work the first few times, don’t give up. They take time and practice.

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practise conjuring up a memory that’s rich with vivid details. Then, when the patient feels the early rumblings of panic, she can absorb herself in that memory rather than the anxiety, and dissipate the emotional tornado *before* it gains momentum. For many, even talking about their fears can be a big help.

In Lee’s case, finding a good allergist who took the time to address her concerns was the first step. A support group was also hugely beneficial, and came with an unexpected bonus: her son became the best friend of the son of another member, and the two boys provided support for each other. And when Aaron was in the throes of anxiety, Lee used a tool she picked up in a teacher training course about autism: the social story.

“I made him his own little book that said, ‘My name is Aaron and I have a peanut allergy. And sometimes it makes me afraid, but when I get afraid, I know there are things I can do,’” recounts Lee, who included coping mechanisms in the book, such as talking to his mom or his best friend and doing relaxation exercises. “It also said, ‘I’ve only had three reactions in my life, so the chances that I will have a reaction are very, very small. And if I do have a reaction, I have an EpiPen. And I will be a superhero who protects myself – Super Aaron,’” she says with a laugh. “He used to read it over and over. I think it really helped.” Today, Aaron is an active, energetic 9-year-old who loves football, practical jokes and scary movies.

With some help from a support group and a therapist, Sandra Schwartz has also come a long way since she was sitting panicked in that Northern Ontario parking lot. While the spectre of another anaphylactic reaction still looms large, she has significantly expanded her diet, eats out in restaurants that she knows are safe, and is doing more socializing. But Schwartz firmly believes that family doctors and allergists need to pay much more attention to the emotional effects of the diagnoses they are giving to their patients. “No one explains the psychological impact and what kind of help might be out there,” she says. “That I had to seek on my own, and I think that’s a huge, huge gap in dealing with food allergies.”

Sicherer emphasizes that when it comes to the emotional side of food allergies, it’s absolutely normal to have ups and downs, and even to feel overwhelmed once in a while. For that reason, he advises people to speak with their allergists about what they should and shouldn’t worry about. If anxiety continues to consume them, there is help available. “This is a life-changing illness, but it doesn’t have to strangle you,” he says. “People live very successfully with this.”

While overcoming fear is far from easy, Cochrane notes that the health benefits – as well as the sense of personal achievement – make it worthwhile. “It’s the feeling that you have faced the lion and handled it.” In the past couple of years, Schwartz has faced that lion hundreds of times. She still has days when she feels frustrated and afraid, but with each one that passes without a major reaction, and with each food that she safely reintroduces, she feels more in control. “I still have anxiety every time I go out to eat. I still have anxiety if I eat something new at home. I still have anxiety when I go over to a friend’s place and I know they’re serving shellfish,” she says. “But I’m not going to let that stop me. I just have to live life.”

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