



# Complex Child E-Magazine

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## How to Thwart a Cook

by Jennifer Peterson

How do you cut a cook off at her knees in one easy step? Declare that a family member will react to any contact with food! Nothing gets someone's attention like a loved one breaking out in hives from touching simple toast crumbs or from a minuscule trace of egg on someone's washed hand. Excitement adds when you can't figure out what caused the reaction. It's amazing how often we have to resort to using the Scientific Method to test our theories of causation.

The timing couldn't have been more perfect. I was at the top of my game, stirring up exotic cuisine as well as time-honored favorites. Never had we owned a bread machine, preferring to patiently wait through each rising. After all, it was the twenty minutes of Zen that we craved: the perfect smell of baking bread permeating our home.

It seemed rather ironic that the first time Thomas showed an obvious rash was on the day of his Baptism. (I'm not sure why it felt this way, but the occurrence seemed significant in the fuzzy sense of larger implications.) We had family visiting from out of state and hosted a lavish Asian-style buffet. Looking back, I cannot pinpoint the cause of the hives, other than contact with bread crumbs on someone.

It was a loss that had to be mourned in its own time. Upon later diagnosis of not just allergies, but a serious gastrointestinal condition that rendered his body unable to absorb nutrients, Thomas was put on a special formula and told not to eat the foods that you and I take for granted. Understandably, my husband and I lost a few pounds. Some people in our circle of support call it the "My Kid Doesn't Eat Food Diet." I began to appreciate the "eat to live" versus the "live to eat" mentality.

We had to cope with the way our society centers nearly every event around food but were more than a little motivated to get creative with our approach. My husband's guilty pleasure is Little Debbie Nutty Bars, which he now scarfs down at work. My vice is fried eggs, which must be consumed after the kids are in bed. Recipes once held sacred became subject to safe substitutions or complete banishment. After all, candy, cakes, cookies and any other treat could invariably contain eggs or nuts. One saving grace is that we do not have to deal with allergic reactions to airborne food particles.

Believe it or not, it is completely possible to have a child come away thrilled with an Easter basket filled with trinkets and toys instead of candy. Birthdays, holidays, school events and simple gatherings are affected by the logistics of managing allergies. Multiply

the fun by figuring in the foods other relatives cannot have! Which reminds me, I have to ask my Mother-in-law to keep Great-Grandma's dressing dish egg-free.

The school environment is an allergy behemoth within itself. We are certainly in a more understanding era that allows for better accommodations for students with special needs. Coordinating safeguards with the school is no small task. However, I am more than happy to bring in an allergen-free recipe for the class to use and eat. There is a delicate balance between safeguarding a child and maintaining the rights of their classmates.

A boring existence this is not. Do we wish it were easier? Of course! Obviously, it would be nice not to worry constantly about our child's contact with the outside world. Would we trade our experience for something more mundane? Never. We have gotten used to going down the road less traveled.



*Jennifer Peterson is an at-home parent and uses her experience as a Paralegal to ensure the medical and educational needs for her children. Her son Thomas is a delightfully complex child with the diagnoses of multiple food allergies, Eosinophilic Gastroenteritis with a GJ tube for enteral feedings, High Functioning Autism, and most recently Mitochondrial Disease (Complex II and IV). Despite everything he has been through, Thomas remains a chipper, smart and cute little kiddo with an infectious smile. Although her family has been dealt the tougher hand, they make it by leaning on their offbeat sense of humor, which is the basis for sharing this story.*