

Best Practices Guide

for parents and kids living with multiple
severe food allergies

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WRITTEN FROM AGE 10-13



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Written at age 10

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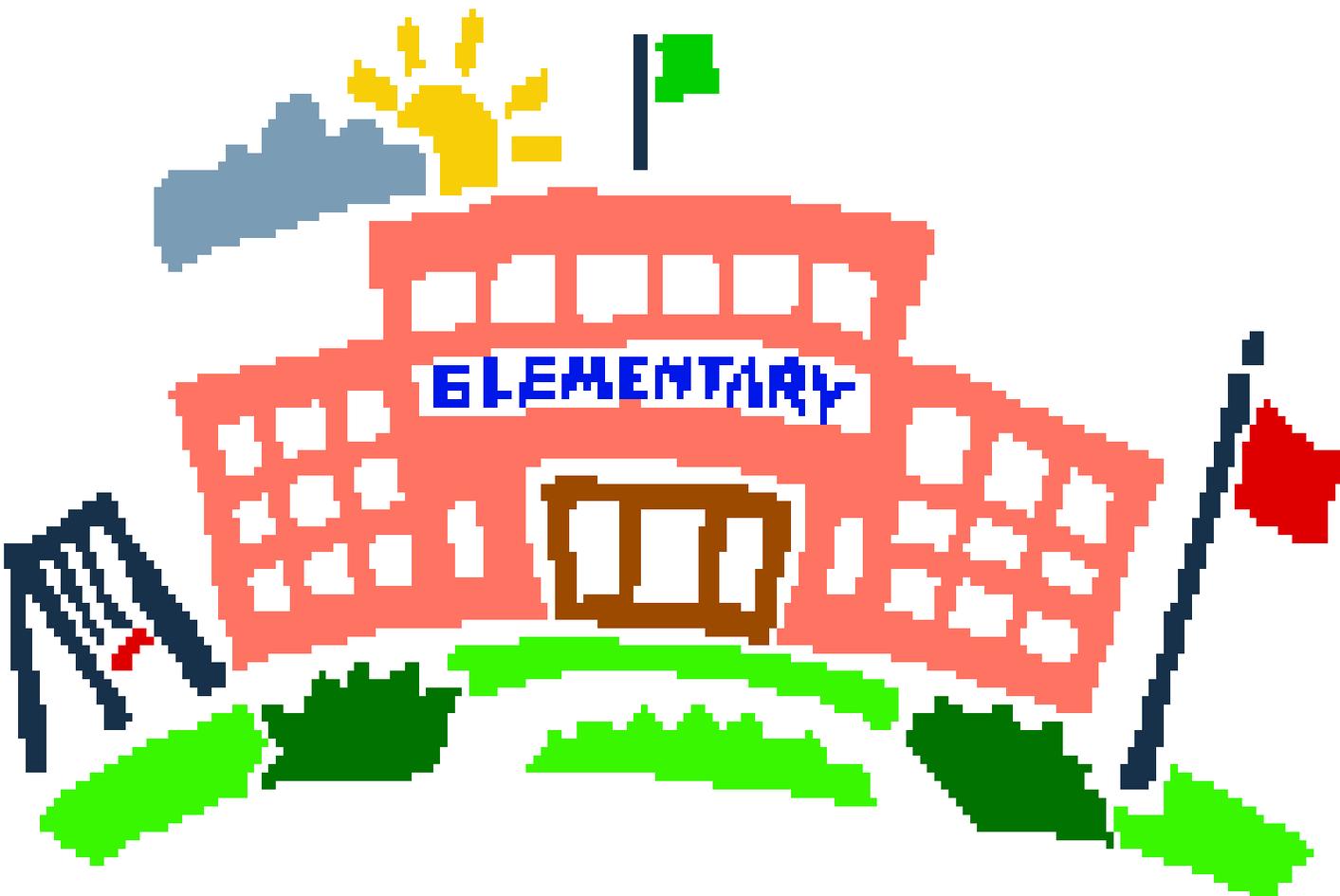
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Foreward

I was born with multiple severe food allergies to dairy, nuts, seeds, some antibiotics, as well as being sensitive to soy, beef, cats, dogs, dust, grass ... but I will stick to foods only for this guide. Severe means that I can have an anaphylactic reaction, in other words I can stop breathing. For the past 13 years I've had to manage this in the classroom, at friends' homes, restaurants, holiday dinners, school field trips and any situation where food is involved.

I started writing down my best practices for others like me when I was 10 and I had compiled several for elementary school, now that I have one more year of middle school I have more to share and I will keep sharing my learning's through high school and college as the opportunities to learn just keep coming – these are “common sense” tips and best practices my parents and I have had to learn along the way and I hope they help you or anyone you may know living with food allergies.

Chapter One: Elementary School



Birthday Parties and Holidays

Whenever I go to a friend's birthday party I always take my own food which is 100% safe. I learned early on that even if there is fruit there that seems safe that it can also have residue on it from fruit sauce or dip like caramel that comes with packaged apples. I remember once thinking I could eat the fresh strawberries at a party because they were just strawberries but they were right next to a bowl of whip cream and in this case the residue from the whip cream would not be seen. If other kids were grabbing the clean looking strawberries and had whip cream residue on their hands this becomes the problem.

Always bring an EpiPen or Twinjet to the party and make sure the parents of the child having the party know how to use it and know what to do if there is a food accident.

We always take cupcakes or even cake – with no dairy, nuts or seeds – and we always take plenty to share. This way others can share in the cupcakes or cake that we bring as well as the main birthday cake.

With holidays and this is common sense but we always cook all of my food to ensure there is no cross contamination from anyone else's kitchen – as safe as everyone tries to be this is always important to ensure that accidents don't happen. Most people, even the closest family members do not understand the severity if they are not living with food allergies or have a direct family member living with them. For Thanksgiving we make pumpkin pie with soy milk, we use Nucoa margarine which is 100% dairy free and we use pre-made Pillsbury rolled pie crust – also dairy free.

Halloween – a funny holiday when you have food allergies – my mom reminds me when I was very young I took my pumpkin up to a door where they offered me something with nuts and I said – I have allergies but thank you anyway. Now I just have them fill my bag and my parents or friends help separate it so I don't get residue and I do eat the sealed sugar only kinds of candy like skittles, starburst, red vine licorice, bubble gum. I always wash my hands right away when I get home from trick or treating or after I help separate the candy.

Going to School

When you first go to school with food allergies you need to remember one important thing that you will need to always do often – wash your hands. If there is food residue on desks or play equipment or lunch tables or anywhere – washing your hands after lunch, after recess is very important.

It is also very important that your parents educate your teacher and other parents in a way that people really understand. Even after my parents educated my first grade teacher she still gave us a math exercise with buttered popcorn and then told us to eat it which I ate one piece and then my teacher remembered and my mom was called to take me to ER where they gave me both Benadryl and Prednisone right away and this held off a potentially much worse reaction.

I always bring lot's of safe cupcakes to school parties and a large stash of safe candy that my teachers always keep in a safe container in the back of the room for un-expected party days, which allows me to always have a safe alternative in the classroom. If there is a room mom my parents always ask to know when every birthday party will take place so I can always bring in extra safe cupcakes – something safe for me and more to share.

I not only have an Epi-pen and Benadryl and prednisone in the nurse's office but I have it in my backpack at all times because it's too far to the nurse's office. I also carry two Epi-pens since they only last about 20 minutes each.



When Eating At a Restaurant

You should never eat restaurant food unless you are 150% certain that it contains none of the food allergens you have. There is so much to consider beyond the food, how the equipment gets cleaned, if the fry oil is used for many foods or only the french fries you may want. There is a lot of cross-contamination – that means other bits of food you are allergic to can get in the food you are not allergic to and you would not be able to see it.

If you are 150% certain you can have a certain food in a restaurant you will still need to double check how it is cooked, what else gets cooked on the same equipment as the food you think you can have. If a sterile knife or other equipment are being used. If other food was prepared in the same area as the food you think may be safe.

I remember at one of the safest Japanese restaurants we eat at – where I get plain fresh raw fish, steamed white rice and edema me – where we had two food accidents. The chef whom we have known for years said there was no dairy what so ever in one of his new fish dishes but when I tasted it I knew immediately something tasted funny and then he told us that there was in fact butter in the dish – which he did not know was dairy, he thought dairy was only nuts. Another time the miso soup which I have safely eaten for years looked different and when we checked we found this particular recipe had milk, I did not try this soup because it looked whiter and murkier than usual. So just when we thought we had a safe choice the recipe changed. This happens a lot even with food in the grocery store – just recently SILK brand soy milk now comes with a warning about Almonds.

To be 150% safe – always bring your own safe food from home to restaurants – make sure to always bring along a yummy safe dessert. Then you can eat with your family and always be sure you will be safe and not have a stressful time eating out.



Food Accidents

If you or your child accidentally eats a food they are allergic to it is extremely important to act quickly. The first thing you should do is find an experienced adult who can help you administer your medication. When you get older you can give yourself your own medication – I don't know how old that is because I am 13 and I do not yet do this.

You should always take Benadryl or whatever allergy syrup has the exact same ingredients as Benadryl since Benadryl has had a recent temporary recall – the main active ingredient your syrup should have is: 12.5 milligrams of Diphenhydramine. Liquid is best. The adult should give you the allergy syrup right away then the Epi-pen which should be given by pressing with a lot of pressure against the thigh and held. The Epi-pen deploys a needle into the thigh that releases medicine into the body.

There are certain signs to look for in order to know if the Epi-pen is needed but you and your parents need to be very clear on what these are as they can change with different reactions but the general signs are hives, swelling of the tongue, swelling of the throat, itching, coughing, and wheezing. The most critical sign is trouble breathing. You really need to work with your allergy doctor on understanding when it's best to use the Epi-pen and what signs to look for.

This situation can happen by not reading all the labels on packaging – watch out for the fine print – manufactured on shared equipment or watch out if the ingredients don't list an allergen but the packaging also does not mention that allergen is not 100% in the product. For example we bought the bare foot contessa's brownie mix and the ingredients did not list dairy or nuts but it also did not say anything about how it was manufactured so we called and they said that they could not be 100% it did not have - trace nuts in it. We also looked at a pudding and the part that says *contains* listed only wheat but the first ingredient was milk. So reading all the ingredients and fine print is critical to staying safe.



Chapter Two: Middle School



When Approaching a New Teacher to Tell Them about Your Allergies

In elementary school, my parents and I would go have a meeting with my new teacher about my food allergies. We would tell them what I was allergic to, how to use an Epi-pen, and more.

Now I'm in middle school, and I have not one teacher but six! So I write a detailed letter every year stating everything they need to know about my allergies. I make six copies of this letter and hand them out to all my new teachers on the first day of school.

Sometimes, my teacher calls me to discuss my allergies on a deeper level, but the letter is always important because if my new teachers don't have time to call me, they'll at least know the basics; such as what I'm allergic to, what a reaction looks like, and what to do when I'm having a reaction.



Amusement Parks

Whenever I go to amusement parks, I bring food along. Even if we check the ingredients on the food in the concession stands, we can never trust that it doesn't have allergy residue on it.

If the park doesn't allow food inside, we take the time to explain that I have life-threatening and they will usually understand. I also try to wash my hands often after touching handle bars on rides or anything that could have allergens on it. For example, a person could have been eating cheesy nachos and then they could have touched a handle that I touched directly after them, that's the time to wash up!



When Meeting Someone Who is too Overprotective about Your Food Allergies

When I meet someone who is too overprotective about my food allergies, or when I meet someone who constantly points me out as the “food allergy kid” or when a teacher has me sit on the other side of the room or outside during class parties because I can’t eat the food that the rest of the class is eating; I usually try to give them constant reminders that I’m not some kind of alien.

I’m still a normal, ordinary kid. I just have to avoid certain foods. I tell the person that I’m just the same as ever not some kind of alien.

I’m still a normal, ordinary kid. I just have to avoid certain foods. I tell the person that I’m just the same as every other kid in the room, the only difference is that I can’t eat something that they can.

Even though having the “food allergy talk” can be sometimes awkward and potentially embarrassing, it has to be done. Eventually, you’ll get used to having this talk and it will get easier and faster as time goes by.



Movie Theaters

When I go to the movies, I usually pop my own popcorn and bring my own snacks. Since there is so much buttered popcorn and nutty candy being spilled on floors and chairs and being transferred from a person’s hand to the armrest of their chair, I try not to touch a lot of things. If I do, I keep my hands away from my face and I wash my hands thoroughly directly after the movie.



Field Trips

Last year my choir won the honor to perform in a national competition called Heritage Festivals in San Francisco. It was a four day trip and every meal was at a restaurant that of course I couldn't eat at.

My mom requested detailed restaurants and meal descriptions for the entire four days that we were in San Francisco. Both my parents took off work to go on the trip with me.

My dad attended as a chaperone so that he would be around should an accident happen, and with forty kids there were only four chaperones.

My mom packed a suitcase that was more or less a mini kitchen and she cooked every one of my breakfasts and dinners that somewhat matched what the other kids were eating. For lunch, I would find a restaurant that I could eat at such as Subway.



Baking

I've also learned how to bake creatively; I can bake almost any recipe without dairy or nuts. I can also use alternative ingredients, such as soy cream cheese instead of sour cream, butter milk, or cream cheese. I can also use nucoa margarine instead of shortening or butter.



What I've Learned

Lactic Acid-can be derived from dairy, so I can only eat food with lactic acid in it if the ingredients say: *LACTIC ACID (not derived from dairy)*

Sodium Lactate-is not derived from dairy, but Potassium Lactate is.

Some foods that I've been able to eat for years change their labeling to say that they may contain dairy or nuts.

911 ALLERGY Text Message

If you have or will get cell phone, then this might be a useful tip. In my cell phone, I have texted myself a 911 contact entry stating what I am allergic to, what an allergic reaction looks like, and what to do if I am having an allergic reaction. I wrote this because if I am having an allergic reaction, the person or people that I'm with will be able to take a look and have a much better understanding of how to react.



Restaurant Meal Card

Whenever I come across a restaurant that has food that I can eat, I personally talk to the chef then give him a card I have created specifically for this event. This card states my first and last name, what I am allergic to, and more. The card is supposed to stay with my order at all times to alert the culinary staff and should be given back to me when my food is presented. I give them this card after taking the time to explain my food allergies in detail to the chef, and it helps me feel safer about what I'm eating.