TEN THINGS

Children with food allergies want you to know

Gina Clowes

Copy Edits by Luanne Stevenson
Writers1Stop.com

Design & Layout by Ginger Marks
DocUmeantDesigns.com

Photos by Lisa Kyle
Photo of Sara and Sabrina Shannon courtesy of Sara Shannon

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Each child's condition is different, and the information presented in this book may or may not be appropriate for your child.

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To Sara and Sabrina Shannon,

the advocate and the angel.

TABLE OF CONTENTS

Foreword

On September 30, 2003, my 13 year-old daughter, Sabrina, died from an allergic reaction to a trace of dairy on French fries that she had eaten in her school cafeteria.

Knowledgeable about her allergies, Sabrina checked the ingredients of the French fries and determined that they were safe. Sadly, she neither saw nor tasted the invisible traces of dairy that cross-contaminated her fries through a serving spoon. Without early treatment with epinephrine, her allergic reaction escalated quickly, causing her throat to close and shut off oxygen to her brain. She was unconscious within minutes. After a day on life-support, my only child died. My worst nightmare had come true.

Just before she died, I had made a promise to my daughter and I'm hoping that through this writing, my promise will be fulfilled. I promised her that I would do everything possible to prevent a similar tragedy from happening to another family or child.

Some of you reading this may believe that food allergies are exaggerated or that parents and schools have over-reacted in their efforts to protect children with allergies. It's easy to be an armchair critic about the way others manage a health condition, when you don't live with the health condition every day.

As Sabrina grew up, all of us had to be on board to keep Sabrina continually safe with food. Food was a friend and an enemy to Sabrina; a vibrant girl who was engaged in many aspects of life. She had lead a busy life and quickly learned to be her own advocate and was constantly vigilant. At times, she was faced with deadly suggestions like; "Just eat around the cheese" on the pizza. Sabrina learned to say no to well intentioned, but ill informed, adults.

Throughout my daughter's short life, there was never a time when I was not in the process of educating others about the dangers of food allergies. Most of the time, people responded with a sincere attempt and a desire to learn. Other times, I encountered disbelief, snickering, and even outright hostility. Once I was accused of making up the allergies to draw attention to myself!

Sabrina's condition was a serious, life threatening medical condition but to the outside world who admired her beautiful red hair flying in the wind as she ran on the playground, her condition was invisible, hard to see, not easily understood or perceived as threatening. This invisible condition masked the reality that was; my beautiful daughter was truly vulnerable.

But like a forest fire, an allergic reaction may start slowly, appear without warning and at first, not be perceived as a threat. All it takes is one match, one bad decision, one wrong call, one little mistake and that could lead to a tragic outcome for the child living with food allergies.

In life, we learn many lessons. When we're young, we're told "Don't play with matches" because that can start a forest fire. As parents we learn "Be educated, be prepared, and be proactive." That rule may help us one day save the life of someone we love. Let's not allow anyone to be blinded by life's looking glass, too focused on what can only be seen and untrained to detect what may be hidden. Some medical conditions may be invisible but please never ignore them. It's a lesson no one wants to learn the hard way.

If this book has found its way to you, consider it a blessing. Read it and consider making your home, party or classroom safer for allergic children. Take food allergies seriously.

As my friend Gina Clowes likes to say; "We don't get a sign from God or the Universe on the day that something bad is going to happen. We have to be vigilant every day."

Thank you Gina, for helping me to keep my promise to Sabrina. And thanks to all of you who will read this book with an open heart and mind.

Sara Shannon

Ten Things Children with Food Allergies Want You to Know

1. **I long to be included.** I would like to look, act and eat like everyone else. I'd like to buy my lunch and sit wherever I want. I know I can't, but I'm happy when someone cares enough to provide a safe potato chip, cookie or Popsicle for me. It's nice when I can have something similar to what the other kids are eating and I love it when I can eat the same thing as everyone else. Whenever it's possible, please think to include me!

2. **I'm scared I could die from my food allergies.** I've heard my parents and teachers mention "life-threatening" food allergies and I remember having some reactions where I felt very sick and really scared. I saw how frightened my parents were too. Sometimes, I could use a little reassurance that I will be okay.

3. **I feel like I'm the only one sometimes.** If you have a support group or know another way for me to meet other children who have food allergies, I would really like that. It would be nice to know that I'm not the only kid who has food allergies. Having another friend with food allergies in my classroom or to eat with me at lunch would help me too.

4. **I get confused when grown-ups offer me food.** I know I'm supposed to be polite and listen to grown-ups, but my parents have told me I should only take food from them. When you offer food to me (especially candy), I'd like to take it but I'm unsure and don't know what I should do.

5. **If grown-ups kiss me, right after they've eaten something I'm allergic to, I'll get itchy spots.** If your dog licks me, I'll get itchy spots too. I don't feel quite brave enough or know how to tell you this, but I'm hoping you will remember; if you've just eaten something that I'm allergic to, I may get hives so please don't kiss me right after you've eaten that particular food.

6. **I'm embarrassed when people fuss over what I'm eating.** I know I have to eat my own safe food, but it's easier for me when I'm not singled out. Sometimes, I feel very embarrassed when grown-ups ask me a lot of questions. More than anything, I just want to fit in.

7. **I hear all adult conversations about my food allergies.** My ears perk up when I hear grown-ups mention my name or my food allergies. Please don't pity me or act terrified because that will cause me to feel frightened. Food allergies are just one part of me. Instead, let me overhear you list all the wonderful things about me!

8. **Sometimes I'm sad about having food allergies.** It's hard to be the only kid in the class not having a birthday cupcake and having to eat something different from my box of "safe treats". What makes it worse, is knowing this will happen a lot throughout the year because there are 20 or more other birthdays in my class. I know it's not the end of the world, but from my perspective, it's pretty tough at times.

9. **I'm watching you!** You may think that I'm too little to notice, but I know when you forget my EpiPen® and return home to get it. I watch you every time, when you're reading the list of ingredients on my bag of Skittles. You are my role model and I'm learning how to manage my food allergies from you!

10. **I will do about as well as you do.** My parents and other grown-ups "can-do" attitude will help me cope with the challenges of living with allergies and ensure that food allergies don't stop me from being everything I was meant to be!

Introduction

Would it surprise you to know that once every 15 minutes, a child is rushed to the emergency room with a potentially life-threatening allergic reaction?

On October 30, 2006, Daniel, my six-year-old son, became part of this statistic.

After eating five tiny Halloween candies, he experienced anaphylaxis, a severe allergic reaction. Within minutes of eating the candy, he was vomiting, then clawing at his throat and having trouble breathing. I injected him in the thigh with his EpiPen®, held him tight and watched helplessly. The longest seconds of my life ticked away as I waited and prayed for the medicine to take effect.

The ambulance arrived within minutes and as I carried him out of our house, I noticed all my neighbors watching. They were wearing expressions of concern, fear and sadness. As we rode away in the ambulance, I knew Daniel was also afraid. No child should have to endure this kind of heightened anxiety and fear. As we rode to the hospital, I held his tiny hand, and looked into his frightened, beautiful blue eyes. I kept thinking; this was not the life I had imagined for him. He asked me if I thought he was going to die. I didn't know how to answer his question.

My son's allergies are so severe that he reacts to even the slightest contact with some of his allergens. Throughout each and every day, during each and every routine activity, his father and I try to balance his need for safety with his need to live a normal life. He has never had a piece of the birthday cake at a friend's party or an ice-cream cone from the local ice-cream parlor. His dream is have a slice of pizza out of a box.

Because there is no treatment, my family must maintain constant vigilance to ensure that Daniel avoids contact with the foods that are allergenic to him. And even with this extreme vigilance, mistakes happen. I can't bear to think about what the outcome of Daniel's anaphylactic reaction might have been if we had not been prepared with the knowledge and proper training or not had life-saving medications on-hand. As frightening as it was, I'm thankful that we had a positive outcome. Compared to the many other tragic endings or events, that so many families have had to endure, in the same or a similar situation, I consider us very lucky. Children die from their food allergies; at school, on field trips, and at parties. It's terrifying to know that even a well-intentioned caregiver could make a mistake that could easily endanger my child.

Managing food allergies on a day-to-day basis is a huge undertaking. The learning curve is steep and there is no room for error. The emotional toll that this invisible condition takes on the child and the family can be even more difficult than managing the practical aspects. On a daily basis, as a family and occasionally to celebrate with friends and extended families, we break bread to socialize. When food allergies change the dynamics of a weekly dinner or Thanksgiving feast, the associated stress can impact relationships. When you have a food-allergic child, you quickly find out where your true support comes from and hopefully some of that support will come from you.

When your child is given a diagnosis of a life-threatening food allergy, it changes how you do everything. For most of us, the world is divided between those who “get it” and those who “don’t get it”. Our child’s physical and emotional well-being depends on us putting you in the right category; the “get it” crowd.

That leads me to explain the purpose of this book. Over the past ten years, I’ve gained a lot of experience as an allergy parent. Many of the day-to-day events that my son Daniel and I have shared have not ended in the way that they were initially envisioned. Daniel lets me know how challenging these times can be. I listen closely, explore options with him and try to place myself in his shoes as best I can, if only for a moment.

As an allergy support group leader and advocate, I have had the opportunity to hear similar stories from allergy moms from around the world. I guess that I shouldn’t have been surprised to learn that the allergy-related events that happened within their family are not any different from the allergy-related events that happened within my home.

One difference that I’ve discovered, between families, is that some parents have difficulty expressing what they need. Many are intimidated by school administrators, teachers, or relatives and they’re afraid to ask for accommodations to be made for their child. Other parents are so anxious, angry or scared that it’s hard for other people to see past their emotions and even begin to consider requests made by these parents. *But, a child’s physical and emotional well-being should not be dependent upon how assertive, articulate or persuasive his parent may be.* My hope is that I can do some of the explaining for them and shed light on why this issue is so important.

If you're reading this book, I'd say you are well on your way to becoming someone who "gets it", and for that I am truly grateful. None of us can make food allergies go away. We want our kids to remain safe and be included as much as possible. So, thank you for reading this and being willing to consider the needs of children, like mine. Who knows, maybe someday, some way, we'll be on the other side of the fence waiting to return the favor.

> *"We live in a world in which we need to share responsibility. It's easy to say 'It's not my child, not my community, not my world, not my problem.' Then there are those who see the need and respond. I consider those people my heroes."*
> *— Fred Rogers*

Chapter 1

INCLUDE ME

I long to be included.

I would like to look, act and eat like everyone else. I'd like to buy my lunch and sit wherever I want. I know I can't, but I'm happy when someone cares enough to provide a safe potato chip, cookie or Popsicle for me. It's nice when I can have something similar to what others are eating, but I love it when I can eat the same thing as everyone else. Whenever it's possible, please think to include me!

What you should know

When my son was in his first year of preschool, the parents were asked to inform me when they were bringing in a birthday treat so I could bring in a "safe" treat for my son.

One day, I came a little early for pick up. I peeked inside the classroom and saw 20 kids eating beautifully decorated cupcakes with icing piled high and decorated with sprinkles. My son sat at a separate table, looking forlorn. He was eating his wheat-free pretzels and drinking spring water.

The parent forgot to inform me and the treat was far from safe for my son who is allergic to milk, wheat, eggs, nuts and more.

I don't know what the teachers were thinking but I've often wondered why they thought it was okay for the parent to serve 20 kids special cupcakes and leave one student out.

In my home, if there are only four popsicles left and I have five kids playing, I explain to my son that we won't be serving the popsicles because one of his friends would be left out. I wouldn't dream of serving a treat that not all the children could share. I think most mothers feel this way.

Some of us have developed the false notion that food allergic kids don't mind being excluded. Once, I actually had a teacher tell me this but my work with hundreds of families over the years has told me a very different story.

The classroom seems to be the place where this exclusion is most difficult. If a child is at a birthday party, he will likely have to bring his own treat but he can participate in the games and fun.

In classroom celebrations, the cupcakes are the celebration. It can be awfully hard to watch 20 other kids sharing the same treat 10 or 15 times during every school year.

Most schools have a policy that students can *only* give out birthday invitations in the classroom, if they are going to invite *all* of their classmates. Understandably, the teachers don't want any student to feel excluded. But clearly, when in-class birthday celebrations occur and everyone is sharing a cupcake except you, you'll feel left out. I've never understood why teachers and staff allow this and think that it's okay.

Some parents and teachers opt for the "safe snack box". By all means, if that option is working well, you should continue the practice, especially if it's the parent or child's idea and it helps the child feel more secure.

I've never been a fan of the "safe snack box", especially when the teacher asks for one, because I see it as the "We're-planning-on-excluding-your-child-box." I think it pretty much guarantees that unsafe food will be brought into the classroom and that the allergic student will be left out of classroom festivities.

It's one thing for a child to bring his own birthday cupcake to an outside birthday party. But if a school or teacher makes the decision to allow birthday cupcakes or other edible treats to be shared in the classroom, it seems only fair that the treat be one that all the children can enjoy.

Some of you may be thinking, "These kids are going to have to get used to it. They have these allergies and things aren't always going to be safe for them."

Trust me; if you have a food allergic child, there are multiple occasions, every, single day where the child cannot take part in sharing food because of his allergies. You don't need to worry about that. They're going to have to get used to going to work every day and having a mortgage and a car payment too, but not in second grade! Let's be fair to our kids.

How you can help

- Start with the parents. Talk to them about safe options for shared treats. You may be surprised to know that even with multiple food allergies there are a variety of options.
- If you know that some of the food will not be safe for the child, ask the parent if there is something he'd like to bring in for his child or for the whole group to share. Many parents are very interested in bringing something in for the whole gang, even if it will cost a little more. They know how much it will mean for their child to have something to share.
- For birthday parties, treat bags or class rewards, think of providing non-edible treats. They work for all kids and enable schools to comply with the USDA Wellness Initiative.
- When hosting food allergic guests, save wrappers and let the parent or teen read the ingredient labels. That label might make the difference between the child being able to consume the food or not.
- During celebrations, dinners or buffets, serve the allergic children first. If a holiday or buffet table contains safe and unsafe foods, the utensils and safe foods can easily become cross-contaminated. A guest could use a spoon contaminated with dairy to serve a non-dairy dish. Also, people can easily drop a nut or a shred of cheese into an otherwise safe dish. If the food allergic child can be served first, these potentially dangerous situations can be avoided.

Chapter 2

REASSURE ME

I'm scared knowing that I could die from my food allergies.

I've heard my parents and teachers mention "life-threatening" food allergies and I remember having some reactions where I felt very sick and really afraid. I saw how frightened my parents were too. Sometimes, I need a little reassurance that I will be okay.

What you should know

One of the symptoms of anaphylaxis is a "sense of impending doom" and when you couple that with the reality of feeling your throat closing or not being able to breathe, you can imagine how frightening this reaction can be.

I clearly recall the time I looked into my sons beautiful, blue eyes as we rode in the back of an ambulance, racing to the emergency room. As the adult, I had to react calmly for my son but I was completely terrified. I can only imagine how Daniel felt.

Research has shown that people who have experienced anaphylaxis (a severe allergic reaction) can develop PTSD (Post Traumatic Stress Disorder). Those of us who have witnessed an anaphylactic reaction are not at all surprised by this. If you've never had to inject a child who is struggling to breathe with life-saving medication, consider yourself very lucky.

Neither my son nor I need to be reminded of how frightening and dangerous anaphylaxis can be, yet sometimes well meaning friends and relatives do just that. Once, when I dropped my then six-year-old son off at a friend's house, the parent yelled "Sam, put that yogurt away. Daniel has food allergies. I told you that it could kill him." Yikes!

I understand that this parent was trying to keep my son safe. I just wish she could have been more sensitive and aware of his emotional state as well. That warning certainly put a damper on my son's enthusiasm for the play date and I often wonder how many other similar warnings he's heard over the years.

How you can help

- Unless you are the parent, don't talk about "life-threatening" food allergies or the fact that a child could die from food allergies. These discussions are best kept between parent and child.
- If you're the parent of an allergic child's playmate or classmate, be careful about how you discuss food allergies with your own child. You might consider explaining that the wrong food could make allergic children "very sick" rather than sharing the worst case scenarios.
- Educate yourself on food allergies and model an appropriate level of vigilance. Learn how to avoid, recognize and treat allergic reactions. Read labels or only feed the child what the parents have approved. Always carry epinephrine. When you're doing everything you can to minimize risk, your confidence will help the allergic child feel more secure and safe in your care.
- Control your own fears. While you should have a healthy respect for food allergies, you need to put the risk of a reaction into perspective. You want the child to be careful but you also want him to engage with the world.

Research has shown that people who have experienced anaphylaxis can develop Post Traumatic Stress Disorder.

Chapter 3

INTRODUCE ME

Sometimes, I feel like I'm the only one.

If you have a support group or another way to arrange for me to meet other children who have food allergies, I'd love to meet those kids. I would really like to know that I'm not alone. Having another friend with food allergies in my classroom or to eat with me at lunch time would help me too.

What you should know

When my son was younger, he was the patient of Dr. Robert Wood, a respected pediatric allergist. Dr. Wood also happens to be severely allergic to peanuts and I made a point to mention this fact to my son, Daniel, the first time we were to meet the doctor.

On the drive home from our first visit, Daniel asked several times "Is Dr. Wood really allergic to peanuts?" And in subsequent visits, he repeatedly asked me the same question. It finally dawned on me; I hadn't exposed him to another food allergic child or adult yet.

I have never forgotten my son's fascination with Dr. Wood's peanut allergy and it ultimately lead me to write my first book, One of the Gang: Nurturing the Souls of Children with Food Allergies, as a way to show children that there are plenty of adults with food allergies surviving and thriving in the world.

I also made a point of initiating play dates between the children of mothers in my local support group. It's heartwarming to hear my son and his buddy, Grant (whose list of allergies is almost as long as my sons), give each other advice about foods to avoid. I've also heard them talk about the scary reactions that they've had and even their medically-supervised food challenges. Just as parents of food allergic children seek out other parents of food allergic children for support and empathy, our food allergic children can be comforted by the fact that they're not alone.

How you can help

- Read my book, One of the Gang: Nurturing the Souls of Children with Food Allergies, to your child. First, it validates the children's feelings and shows them how to cope. The photographs are of children from my local support group who actually have food allergies. It also features pictures of real adults (for example Super Bowl Champ Jerome Bettis) living out their dreams, even if they have food allergies. It clearly gives kids the message that they are not the only ones.

- Talk about other "hidden disabilities" (I know, I don't like that word either). However, sometimes, even within your own family, there are adults or children who are managing an invisible condition (e.g. diabetes, celiac disease). It helps knowing that there are many other people out there managing invisible conditions too.

- Encourage play dates with other food allergic children. You will be amazed by their special bond. My son loves comparing notes with Grant, his food allergic friend. He likes to remind me; "You don't know what it's like to have food allergies Mom!" So, I'm glad that Daniel has a buddy who does!

Chapter 4

DON'T FEED ME (UNTIL YOU KNOW HOW)

I get confused when I'm offered food by other grown-ups.

I know I'm supposed to be polite and listen to grown-ups, but my parents have told me I should only take food from them. When you offer me food (especially candy), I'd like to take it but at these times, I don't know what to say or do.

What you should know

There have been a number of cases where adults (unknowingly, of course) have given an allergic child a food that caused a fatal allergic reaction. There is a steep learning curve when dealing with food allergies and it's often difficult for those outside of the "food allergy world" to understand all of the intricacies of avoiding trace exposures.

Pediatric allergist, Robert Wood, is severely allergic to peanuts. His rule is; never eat baked goods prepared by others. In his book, Food Allergies for Dummies, he explains why this rule is so important. During a holiday party, Dr. Wood was presented with a gift of homemade cookies. The colleague assured him the cookies were carefully prepared and completely peanut- free.

However, the colleague's wife had baked peanut butter cookies earlier that same day and used the same spatula to remove the "peanut free" cookies, intended for Dr. Wood. That invisible amount of "cross-contamination" was enough to cause the most severe allergic reaction that he had ever experienced. He needed five shots of epinephrine (EpiPen) over the next few hours. Since that time, Dr Wood has stuck to his "no cookie rule" and refuses all baked goods prepared outside of his own home. Keep this in mind, the next time you offer food to an allergic child.

Personally, I never offer a child food without checking first with his parents. Food allergies aside, I believe that what and how we feed our children is a very personal decision.

Knowing what I know now, I'm even more careful.

How you can help

- If the parents have not specifically approved the food, do not serve it to the child. Grandparents, in particular, need to be very careful. Experts tell us that grandparents are often responsible for feeding allergic grandchildren foods that cause a reaction. Years ago, food allergies weren't nearly as common as they are today, so the notion of a life-threatening allergy to an innocent food can be hard for this generation to grasp. Make sure that the grandparents abide by the parents rules. There are a lot of ambiguities and you won't get a chance for a "do-over" if the child has a reaction.

- Parents with babies and toddlers might consider purchasing some of the allergy slogan t-shirts that say "Don't feed me" or something similar that will warn people of the child's allergy. Consider this as an additional layer of protection; not the only means of informing others about your child's allergy.

- If you'd like to help at a party or other event, hold the baby so mom can get a bite to eat. Follow the toddler around for a while, to give his mom a break, but don't feed the child. There are many ways to show love that do not involve food!

- Teachers, administrators, and parents should be especially careful with food in the classroom and at holiday celebrations. Sometimes children learn to trust authority figures like teachers, so when the enthusiastic music teachers decides to give out candy treats during the holidays (which they didn't realize contained egg) a young child will willingly take it. Even if he is somewhat unsure, sometimes the lure of a delicious piece of candy will override his better judgment.

- Don't depend on very young children to know, with certainty, which foods are safe. Let the parents work with their children to determine when they're ready to fend for themselves. In the meantime, ask the parent, not the child, if a particular food is safe. (My son once asked his two year old cousin if a particular treat contained peanut. She said "no" so he ate it! Thankfully, it was safe but the point is that kids are not always mature enough to make these calls.)

- If you're a teacher or parent volunteer, never urge a young child to take food home and ask if it is safe. One of the worst places for a child to sneak food and have a reaction is on the school bus. The time to determine the safety of the items served at a classroom party or in the treat bag is *before* the party.

- Be wary of so-called “Safe Snack Lists”. Ingredients change, different sizes and brands of the same product contain different ingredients and there are FDA and other recalls of products. If you use these lists, these snacks should be double checked by the parent.

- Never use “common sense” to determine whether or not a food is safe. Jelly beans and chili can contain peanut flour; lollipops can contain egg; canned tuna can contain milk and there are many potent allergens, like sesame, that can hide behind the words “natural flavors” on ingredient lists. When in doubt, do without.

Chapter 5

PROTECT ME

When a grown-up kisses me, right after they've eaten something I'm allergic to, I'll get itchy spots.

I get itchy spots after your dog licks me too I don't feel quite brave enough or know how to tell you this, but I'm hoping you will remember; if you've just eaten something that I'm allergic to, I may get hives so please don't kiss me right after you've eaten that particular food.

What you should know

I have to admit that I really did not buy into the idea of contact reactions when my son was first diagnosed. I was still eating protein bars with peanuts in our home, until my son's face blew up and was covered with hives, after I kissed his cheek. The only thing worse than worrying about a reaction and if it will progress to anaphylaxis is knowing that *you* caused that reaction.

A few years later, we were on vacation and staying at a new hotel. Within a few minutes of plunking down our suitcases, my boys grabbed the remote and started watching television. I noticed my son's face getting blotchy, but he hadn't eaten anything. I quickly gave him Benadryl and put him in the bathtub. The reaction did not progress but he was very uncomfortable, had red eyes and hives. We couldn't figure it out.

After he was in his pajamas, his father opened up the pull out coach and there they were: dozens of pistachio shells! Apparently, someone had been eating plenty of nuts in the room and that had likely contaminated the door handles or television remote controller.

This is all it takes. So, I'm always amazed when some physicians say that it's not necessary to restrict allergens from the *classroom* because contact doesn't typically cause life-threatening reactions.

I can't see putting a child at risk for even a mild or moderate reaction. Young children are very tactile and oral so when surfaces are contaminated with allergens, they are very likely to put those fingers into their mouths or eyes.

I believe that the classroom learning environment should be kept free of all the child's allergens. Children deserve to be educated in an environment without risking a reaction from food or food residue. Teachers have a lot on their plates and don't need added worry; "Are those pink spots on my student's face the beginning of an anaphylactic reaction? Did my student sneak a bite from his classmate's peanut butter cracker?" Remember that invisible amounts, as small as 1/1000 of a peanut, can cause a reaction. Once a reaction starts; there is no way to predict how the reaction will progress.

How you can help

- If you're a school administrator, instead of thinking in terms of what's "always been done", think about what makes sense in today's world. With six percent of children having at least one food allergy, and other children affected by obesity, diabetes, celiac disease and other dietary restrictions, how much food do we really need in the classroom?
- After all, children are entitled to a free and appropriate education, but there is no *right to cupcakes* in the classroom. (Well, except maybe in Texas.) Even if there are several allergies among the students, there are plenty of foods that can be used safely for classroom celebrations. At a minimum, consider an allergen-free classroom.
- Washing hands as you enter the home or classroom is a good idea for many reasons. Wipes will do a decent job too but hand sanitizers don't work for food allergies. We're trying to eliminate food protein, not bacteria.
- If you're hosting an event where there are food allergic children, it's helpful and safer if you confine the food to one or two areas. For example, if you keep the living

room or basement food-free, the allergic children won't be tempted by unsafe food and your house will be cleaner too!

- Relatives and grandparents love to kiss and cuddle adorable infants and toddlers, but if this causes them to develop welts and hives, it will make them feel awful. Please believe the child's parents when they inform you that the child is contact reactive. Hugs, cuddles and kisses on the head will warm their hearts without causing reactions. If you want to be more affectionate, avoid eating the child's allergens on the days when you'll be spending time with them.

- If you have a pet, be aware that not only can a child be allergic to the dander, but he can react if your pet licks her after eating an allergenic treat. For example, peanut is a potent allergen that is often used in dog treats and snacks. Other pet foods can contain seeds or other allergens, so be careful.

- If you're socializing with a food allergic child or your own baby or toddler, keep an eye on your child's food, Sippy-cup and bottle. These foods and the milk or soy formula that they drink can cause allergic reactions. The allergic child might also ingest them or have a reaction by touching contaminated surfaces or toys.

- If you visit the home of a family with food allergies, you really cannot exercise too much caution. Many of these families make the decision to make their home a "safe haven"—the one place where they don't have to worry about cross-contamination. Their stress level is often high and they may need this protection emotionally as much as physically. Respect their rules and boundaries, even if you don't completely understand them.

Chapter 6

DON'T EMBARRASS ME

I'm *embarrassed* when people fuss over what I'm eating.

I know I have to eat my own safe food, but it's easier for me when I'm not singled out. Sometimes, I feel embarrassed when grown-ups ask me a lot of questions. More than anything, I just want to fit in.

What you should know

Often, a child with food allergies, especially one with multiple food allergies, won't be able to eat at certain restaurants or share food at extended family dinners and other celebrations.

Many times, parents of food allergic children will bring a dish to share with everyone and sometimes they'll bring special "safe" food for the allergic child.

When my son was in kindergarten, I attended one of his classmate's birthday parties with him.

About halfway through the party, 10 boxes of pizza arrived, creating oohs and aahs. The party mom and dad started taking requests and serving the children. "Who wants pepperoni? Who wants extra cheese?" My son had his own, wheat-egg-dairy-free pizza in front of him. I gave it my best effort, but my version couldn't hold a candle to the real pizza. The kids happily munched on the pizza and slurped the stringy cheese. My son whispered in my ear, "Can I just try a bite of their pizza?"

The other parents were trying to be nice and began commenting on my son's pizza. "Oooh, that looks yummy." "Oh, what kind of pizza do *you* have?" They were well meaning but their comments came across as insincere. Worst of all, they drew more attention to the fact that my son was eating different food, something he'd rather avoid. On the way home, my son asked me "Why do they always have to ask me about my food?"

This happens more than you might think because well-intentioned adults are trying to show that they care. But as the parent of a child with food allergies, I can assure you that these children probably always prefer talking about anything other than their special food.

How you can help

- If the peanut-free (or other allergen-free) table works well for the allergic children, that's terrific. If not, there are options that separate the food rather than the child. For example, in some schools they have the "Peanut Table" and children who are eating peanut or nut products sit together and eat their lunches safely without cross contaminating the whole cafeteria. Another option is to have the students eating nuts and peanuts sit at one end of the table with a buffer zone to separate their food from the students with food allergies.

- At parties and other celebrations, where the child is not able to share what others are eating, be nonchalant about the child's special food. When it's time for the cake, make sure that he has his special cupcake or cake. If the child says he doesn't want to eat, don't fuss over him by offering him a laundry list of other options.

- If you suspect the child is afraid to eat what you're serving and you've already worked it out with the parents, you can reassure her about it. For example, you can be discreet and say: "I've checked with your mom and she says you can have this. This is safe for you."

- If you're a teacher and serving birthday treats or other foods where the allergic child cannot partake, allow him the option of an alternate treat or to decline the treat altogether. Even if it worked earlier in the school year, usually at some point, treats from the "safe treat box" become undesirable. Some allergic children will decide to forgo the treat altogether.

- Here's some free advice for all loving adults; Avoid discussions that revolve around the food the allergic child is eating. We all can assume that he'd probably give anything for one slice of "real" birthday cake or a scoop of "real" ice cream. Just let him enjoy his food on his own and initiate a conversation on another topic that might be of interest to him, like the after school sport he plays or a new popular movie that all the kids are talking about. Even if you sense the child is feeling a little disappointed by having to eat his own food, not the groups, understand that it's perfectly normal for him to struggle with his feelings. All kids with food allergies will do this from time to time. Don't call attention to his mood or make a big deal about it. He's likely to snap out of any temporary "blue rut" more quickly, as long as you don't create a fuss that will cause him to feel embarrassed later on.

We don't get a sign from God or the Universe on the day something bad is going to happen. We have to be vigilant every day.

Chapter 7

SEE ALL OF ME

I hear every adult conversation about my food allergies.

My ears perk up whenever I hear grown-ups mention my name or my food allergies. Please don't pity me or act terrified because that causes me to feel frightened. Food allergies are just one part of me. Instead, let me hear you list all the other wonderful things about me!

What you should know

A few years ago, and for the first few weeks of school, I had volunteered my time and helped out with lunch duty, at my son's school. The school had a cafeteria policy of seating the food allergic children at one table. As the children entered the cafeteria to be seated, the cafeteria aide started reading from her roster and called out; "I need three peanut kids and a red dye allergy here." My six year old dutifully took a seat as one of the "peanut kids," but I was appalled that she would identify all of them like that. I gently approached the aide and suggested that she not label them by their medical condition or with terms like "peanut kid". Her response? She said, "They get used to it."

Many of the parents that I meet through my local support group or online share that when they introduce their son or daughter at a school function, the other parent will say "Oh, *he's* the one with all the allergies." Imagine how you'd feel after being greeted with; "Oh *you're* the one with the high blood pressure or fibromyalgia." Just like adults, kids don't want to be identified by their medical issues. School staff and parents of other children need to be sensitive and aware of this fact.

How you can help

- Be discreet. If you have a "horror story" about something you've heard about food allergies or even something about a potential cure (because there is no cure at this point) don't discuss this in front of the food allergic child. Even parents of food allergic children are disturbed by these stories. Imagine how hard it is for a child. Food allergies are often a much bigger part of a child's life than you would imagine and sometimes these kids would just like to forget about them, even for a few hours.

- If you're really scared about food allergies and the potential for a reaction, it's best not to process this within earshot of the child. Studies show that when caregivers are trained in avoiding, recognizing and treating allergic reactions, the frequency and severity of reactions decreases. Have someone train you to use the EpiPen on an orange and make sure that you understand the child's Emergency Action Plan (also known as a Food Allergy Action Plan). Fear will dissipate once you feel competent and confident in caring for the child.

- Sometimes adults are curious about food allergies, especially if the child has multiple allergies. Well meaning adults will say, "Well, what *can* he have?" or "What in the world do you feed him?" While we appreciate that you may be trying to commiserate, no one wants to be thought of as a freak of nature. And while our kids' diets may be extremely limited, they are not eating moon rocks and sea urchins. (smile)

- Ask him about himself and the things that make him special. Does he love baseball? Does he play soccer? Does he collect Pokémon cards? Especially if you're just getting to know the child, make a point to get to know him as a person, not a patient. Discuss things privately with the adults. You don't need to be secretive but children with food allergies don't want to be known primarily for having food allergies. Food allergies are just one part of the child and it's important he learns to view it this way.

Chapter 8

LISTEN TO ME

Sometimes I'm sad about having food allergies.

It's hard to be the only kid in class not having a birthday cupcake and having to eat something different from my box of "safe treats". What makes it worse, is knowing this will happen a lot throughout the year because there are 20 or more other birthdays in my class. I know it's not the end of the world, but from my perspective, it's pretty tough at times.

What you should know

There comes a point in every allergic child's life when they begin to comprehend the magnitude of what having food allergies means. The need for constant vigilance and the fear of a severe or even fatal reaction can be scary and overwhelming.

Then, there is the emotional toll. The unique nature of food allergies limits and affects the way these kids are able to socialize. For example, we break bread to celebrate. Food is at the center of every holiday: candy at Valentine's Day and Halloween; turkey and pie at Thanksgiving; beautifully decorated cakes at birthday parties and on anniversaries, graduation parties and weddings. It's hard to be on the outside looking in.

With a life-changing diagnosis, grieving is involved. Often, when a child is diagnosed at a very young age, they don't fully realize how many foods are restricted or just how difficult it will be to avoid their allergens.

I know I tried to dance around these issues early on and I actually tried to talk him out of his bad feelings. I would repeatedly tell him how things could be worse. Then I remembered how much I loved going out with my "allergy mom" friends because we'd cry, vent and laugh and at the end of the evening, we all felt relief! So why wouldn't I allow my son to feel what he was feeling? Why not validate his feelings the same way my friends validated mine?

Now, I do and when he tells me it stinks to have food allergies, I agree with him, sincerely.

My belief is that when parents and other loved ones experience their own emotions around the diagnosis, they can be even more supportive as the child processes his own feelings. It's like the elegant line in a poem by Hafiz: "Troubled? Then stay with me for I am not." What a relief for a child to know that he can confide in or vent to a parent, grandparent or other trusted adult.

How you can help

- If a child expresses how he feels, using words or facial expressions, validate his sad or angry feelings about having food allergies. Be a compassionate witness and don't tell him how much worse things could be. You can even explain that feelings are like waves in the ocean, they come and go. Another analogy to use might be: feelings are like clouds in the sky. If you watch them, they will naturally glide by.

- Physical contact, hugs, and cuddles can help. Some kids express their feelings best by writing in a diary or through art. My son has been drawing pictures of ice cream cones and apple pies since he was two years old. Sometimes kids feel better when they do something active but once in awhile, it's okay to feel down and get a little tender loving care. Grandparents can be particularly adept in this role.

- If you are the parent, grandparent or loved one, allow yourself time to handle your own grief. I recall my mother telling me that a friend of hers was a tremendous support to her after my son was diagnosed. I remember thinking "Why would *you* need support?" Finally, the light bulb went off and I realized that my mother, my son's grandmother, had also gone through the myriad of emotions that follows this life-changing diagnosis. The more we all work through these emotions, the better we'll be able to support our children and grandchildren.

- Justas as allergy parents share a common bond that other parents may never truly understand, food allergic children find a comfort and camaraderie in their friendships with each other as well. As my son likes to remind me sometimes; "You don't know what it's like, Mom!" and it's true. So I'm glad that his friend Grant truly does!

Chapter 9

SHOW ME

I'm watching you!

You may think that I'm too little to notice, but I know when you go back home to get my EpiPen, after you realize that you've forgotten it. I watch you read the ingredients on the bag of Skittles every time. Adults are my role models and I am learning how to manage my food allergies from you!

What you should know

We all know that actions speak louder than words but sometimes we adults think we can pull one over on kids and just tell them how to do something. It doesn't work and when the stakes are high, as in managing food allergies, our words and our deeds need to be in sync.

Whether teachers, parents, grandparents or other caregivers are very strict or permissive, there are always a few non-negotiable rules that can never be broken. Children learn to abide by these. If you are caring for a child with food allergies, make the rules early on and then welcome the opportunity to reinforce these rules by your actions.

For our family, the number one rule is that we don't go anywhere without the EpiPens. I don't believe my son is mature enough to self-administer at this point. (He just ate gum off of a shopping cart last year, and he wants to work at 7-11 so he can be paid in Slurpees.) But we make sure that he is always in the care of an adult who is trained to avoid, recognize and treat allergic reactions and that they always have two EpiPens along with his Food Allergy Action Plan.

Just last week, we were almost at our dinner destination, a safe restaurant, when we turned the car around and drove back home after I realized I that I didn't have an EpiPen with me. I told my son what we were doing but I believe our actions, turning the car around to go back home, left a bigger impression on him.

How you can help

- Mistakes are a part of life and it's important to use them as teachable moments. When you make a mistake, like forgetting to pack the EpiPen before leaving the house, use the experience as an opportunity to reinforce what you've taught your child. Turn around and go back to get it, even if you don't plan on eating. It's that important.

- Remember; reactions may occur from a few seconds to a few hours after eating the offending food, so it's never safe to be without epinephrine, if it's been prescribed for your child. Teachers can help reinforce this message by making sure they always carry the child's EpiPen with them (if he is too young to self-carry). Recess, field trips, fire drills and just passing in the hall, the teacher should be prepared and ready to assist the child, if an allergic reaction were to occur.

- Demonstrate to the child, so he understands, he *must* read ingredient labels every time. Never rely on common sense to determine if a food is safe. Tuna fish can contain milk. Chili and jelly beans can contain peanut flour. Lollipops can contain egg. Reinforce the rule "If you can't read it, you can't eat it."

- Treat symptoms according to your child's food allergy action plan. If the plan instructs you to give liquid antihistamine (e.g. Benadryl) for hives, then give it immediately. If the plan says to inject your child with the EpiPen for breathing symptoms, then follow the plan. If you expect the child to become independent and follow the plan on his own one day, then it's crucial for you to model the plan to the letter.

Chapter 10

BELIEVE IN ME

I will do about as well as you do.

My parents and other grown-ups "can-do" attitude will help me cope with the challenges of living with allergies and will ensure that my food allergies won't stop me from being everything I was meant to be!

What you should know

My friend Nicole Smith, author and founder of AllergicChild.com, has done an amazing job parenting her allergic son, Morgan. From a very young age, her son has developed self confidence in his own ability to advocate for himself. She's a remarkable mom, having instilled this in her son.

When he was in first grade, he was left out in the hall during an activity because of his food allergies. He was very upset when he came home and naturally Nicole was not happy to hear that her son was excluded. It would have been easy for her to vent her frustration at the teacher, but it would have surely harmed their working relationship. The temporary relief of venting her anger was not the example she wanted to set for her son.

Instead, she asked Morgan to write down how he felt about being excluded from the activity. The following day, with Nicole by his side for support, Morgan told the teacher how he felt. He said *"I don't like to be left out in the hallway. I want to be part of the class. Please don't leave me out again."* He cried, and the teacher cried. At that moment, Nicole knew that the teacher "got it" and Morgan was never left out of an activity again.

Even better, he learned how to stand up for himself, even with an adult.

How you can help

- Keep in mind that every problem contains the seed of an opportunity for growth. When there are trials and tribulations in dealing with food allergies, vent to another adult and not the child. Instead, use the issue as a teachable moment and model problem solving.

- Manage your own stress level. One of the top three characteristics defining effective parenting is having the ability to manage your own stress levels. Frankly, when my son was first diagnosed, I was a mess. I do a much better job now with my own self care, and its no coincidence that when I started doing better, my son did too. Sometimes getting roughed up a little in life brings out the best in us and in our kids too.

- As Wayne Dyer says; "You'll see it, when you believe it." Believe that the child is capable and that he will gradually take over the reigns of managing his own medical condition. But, it won't happen overnight. Always work with the child's parents, but also collaborate with the child. Children, teens and tweens are much more likely to "buy into" a solution for an issue, when they've helped create it.

- While parents of children with food allergies have an additional medical condition to manage, the ultimate goal remains the same for all parents: To lay a strong foundation, enabling them to become competent adults. Grandparents and other family members should be prepared for the fact that parents will change how they parent and how much "rope" they give their child as he grows. Most parents could use your support here because while it's hard to let go of any child, having food allergies makes this stage even more challenging.

- Find ways to get the support that you need as a parent, grandparent, teacher or other caregiver. Remember the words of Louise Hay; "Every word we speak is an affirmation for our future." Speak and think positively about coping and smoothing over the rough spots that come along.

- You don't want the child to look back on his whole life and think it was only about his food allergies. You want his life *and* yours to be about family, friends, fun, adventure, vacations, picnics, celebrations, learning, and love. Show him how it's done!

Resources

Helpful websites

A

Allergy Moms, www.allergymoms.com

Allergic Child, www.allergicchild.com

Allergic Living www.allergicliving.com

Allergy and Asthma Network/Mothers of Asthmatics http://www.aanma.org

American Academy of Allergy, Asthma and Immunology www.aaaai.org

American College of Allergy Asthma and Immunology www.acaai.org

American Partnership for Eosinophilic Disorderswww.apfed.org

Anaphylaxis Canada www.anaphylaxis.org

Asthma and Allergy Foundation of America www.aafa.org

F

FAAN Teen Site http://www.faanteen.org/

Food Allergy & Anaphylaxis Network www.foodallergy.org

Food Allergy Initiative www.faiusa.org

L-Z

Living Without www.livingwithout.com

NIH Food Allergy Clinical Practice Guidelines
http://www.niaid.nih.gov/topics/foodAllergy/clinical/

Please Don't Pass the Nuts http://allergicgirl.blogspot.com/

Why Risk It -Anaphylaxis Canada Teen Site www.whyriskit.ca

Special Medical Needs Websites

EpiPen and EpiPen, Jr. www.epipen.com

Medic Alert Foundation www.MedicAlert.org

Neocate www.Neocate.com

Allergy Friendly Food Companies

A-D

Barney Butter www.barneybutter.com

Cherrybrook Kitchen www.cherrybrookkitchen.com

Cookies for me www.cookiesforme.com

Divvies www.divvies.com

E

Earth's Balance www.earthbalancenatural.com

Ener-G Foods www.ener-g.com

Enjoy Life Foods www.enjoylifefoods.com

G -I

Gimbal's Fine Candy www.gimbalscandy.com

Home Free http://www.homefreetreats.com/

Ian's Natural Foods www.iansnaturalfoods.com

L-P

Lucy's Cookies www.drlucys.com

Nonuttin' Foods www.nonuttin.com

Philly Swirl www.phillyswirl.com

S

Soy Nut Butter www.soynutbutter.com

Sun butter www.sunbutter.com

Surf Sweets www.surfsweets.com

T

Tease Cheese www.chicagosoydairy.com

Tinkyada pasta www.tinkyada.com

V-Z

Van's Waffles www.vansfoods.com

Vermont Nut Free Chocolates www.vermontnutfree.com

Wellshire Kids www.wellshirefarms.com

Yummy Earth www.YummyEarth.com

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Meet the Author

Gina Clowes is the founder and director of AllergyMoms.com, serving thousands of families and professional members worldwide. She is the author of the best-selling children's allergy book, One of the Gang: Nurturing the Souls of Children with Food Allergies.

Clowes is a certified life coach, who specializes in supporting parents in the practical and emotional aspects of managing food allergies. Her advice and parenting tips have appeared in numerous television, radio and print features including CNN, ABC World News Tonight, and People Magazine.

She offers individual coaching, group coaching, live and virtual workshops. For more information, visit www.AllergyMoms.com.