

Daily Coping Strategies for Patients and Their Families

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ABSTRACT. The diagnosis of food allergy in a child has an impact on every minute of every day for the child and the child's family. The patient and family must learn how to read labels, adapt recipes, and educate other family members, child care providers, camp counselors, and teachers. They must know how to recognize symptoms of a reaction and what to do during a reaction. Decisions such as which restaurant to go to and where to go on vacation take on new meaning, as family decisions must be centered on avoidance of the child's food allergen. It is possible to manage food allergies successfully while allowing the child to participate in common childhood activities. Education of the family is key. This discussion provides the pediatrician or primary care physician with practical information for educating patients and their families about managing food allergy. *Pediatrics* 2003;111:1654-1661; food allergy, anaphylaxis, psychosocial impact, label reading, schools, restaurants.

ABBREVIATIONS. FAAN, Food Allergy & Anaphylaxis Network.

The diagnosis of food allergy in a young patient will have an impact on the child and the child's family and friends. This article discusses the psychosocial impact as well as day-to-day management strategies.

PSYCHOSOCIAL IMPACT

Food allergy avoidance strategies must be in place at all times, and the family must be aware of the dictum that "accidents are never planned." This constant vigilance can be a source of stress to the family. A quality-of-life study showed that "childhood food allergy had a significant impact on general health perception, emotional impact on the parent, and limitation on family activities."¹ Families may also face other family members or friends who do not believe the food allergy diagnosis and attempt to give the child the restricted food, often causing a reaction when they succeed. Siblings of food-allergic children may become resentful of the extra attention given to the allergic child. The allergic children are sometimes the target of teasing and/or harassment by classmates. In 1 case, a child who is allergic to peanuts was smeared with peanut butter; another child, who was allergic to milk, was sprayed with milk and

experienced an allergic reaction. Children who have experienced a severe reaction sometimes develop disordered eating or become withdrawn and fearful. Their siblings sometimes become fearful that the allergic brother or sister will have another reaction and die.

Mothers of young children, particularly children who have been breastfed, often report feelings of guilt in causing their child's food allergy. These feelings are more intense in families in which the mother reports eating peanuts or tree nuts while pregnant or nursing and the child subsequently develops an allergy to those foods.²

Extra attention should be given to ensure that patients and their families are not paralyzed with fear of a reaction. Statements such as, "This is the most allergic child I've seen in my practice," or, "The next reaction will likely be fatal," have created an atmosphere of fear and dread in the patients and their families. Indeed, some parents take these statements to heart and home school their child, keeping them in virtual seclusion for fear of that fatal reaction. Parents should be encouraged to seek professional counseling if they or their child find that their fear or other emotional concerns are impeding their ability to function day to day.

Thousands of children in schools across the United States have food allergies. These children participate in sports, go to camp, attend sleepovers, and do not allow their food allergies to restrict unnecessarily any of their activities.

Patients should be warned of how serious food allergies can be while being told the importance of achieving a balance for their allergic children. Empowering a child to participate in food allergy management strategies will yield a confident child who is less likely to make mistakes or take unnecessary risks and who can rebound after an allergic reaction. A follow-up visit with a physician a few weeks after diagnosis may provide families with an opportunity to clear up concerns or ask questions that have come to light since the diagnosis.

LABEL READING

Until there is a cure for food allergy, strict avoidance of the allergen is the only way to avoid a reaction. Label reading is the cornerstone of food allergy management.³ Because ingredients can change without a warning on the front of the package, parents must read the ingredient statements for all products each time they shop, a task that, for some, can take as much as 2 hours. Often families read the label at the store, again while they are unpacking the groceries,

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TABLE 1. Partial “How to Read A Label” List

| | |
|----------------------------------|---------------------------------|
| Other names for eggs on a label | Other names for milk on a label |
| Albumin | Casein hydrolysate |
| Globulin | Casein |
| Ovalbumin | Ghee |
| Other names for wheat on a label | Lactalbumin phosphate |
| Cereal extract | |
| Couscous | |
| Durum | |
| Spelt | |
| Semolina | |

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and a third time before they serve the food to their allergic child. Some report that they have noticed the allergen only on the third reading, thus justifying the need for this extra cautious approach to label reading.

Today, ingredient statements are written for food scientists, not consumers; as such, families must be taught how to read a label and decipher the various synonyms for common foods (Table 1). The Food Allergy & Anaphylaxis Network (FAAN; 10400 Eaton Pl, Ste 107, Fairfax, VA 22030-2208; 800-929-4040; www.foodallergy.org) provides wallet-size laminated or magnetic “How to Read a Label” cards to train patients how to identify common food allergens. The cards are updated regularly as new terms are identified.

Collective terms such as flavors and spices should not be ignored. There have been reports of children experiencing a reaction to milk, for example, in “natural flavors.”⁴ Families should be instructed to call manufacturers if they have any questions about terms on an ingredient statement. To get the information for which they are looking, they should be as specific as possible, for example, ask, “Does this product contain milk?” rather than, “What is in the natural flavors?” Most large manufacturers willingly provide this information. Families should be counseled to avoid companies that do not provide answers to their ingredient queries. They should also avoid imported foods, as labeling standards in other countries are not as strict as those in the United States, and often ingredient declarations for these products are incomplete.⁵

A survey of FAAN members indicated that close to 90% believed that ingredient labels were difficult to understand.⁶ Joshi et al³ recently reported on 91 sets of parents who participated in a label-reading study that indicated that <10% of those avoiding milk were able to spot the “milk words” on a label, only 54% of those avoiding peanuts correctly identified peanuts on a label, and only 22% correctly answered

soy (of those with perfect scores, 90% were FAAN members), supporting the need for proper education of patients once a diagnosis is made.

Labels must be read for bath products and cosmetics, as some contain natural extracts of foods such as almonds,⁵ and for pet foods, which commonly contain milk, egg, and even peanut. It is common for toddlers to eat a piece of pet food that they find on the floor,⁵ and reactions have also been reported in children who were licked by a dog whose food contained the food to which the child is allergic. Patients should assume nothing, as common ingredients can appear in unexpected places (Table 2).

Another labeling loophole of which to be aware is that products advertised as “nondairy” often contain casein, a milk protein.⁷ Each year, children with milk allergy experience reactions because a parent, grandparent, or other caregiver who read “nondairy” on the front of the package mistakenly believed that to mean that the product contains “no dairy” and they did not read the ingredient declaration on the back of the product.

The safest, most accurate—and, in the long run, most efficient—policy for avoiding a reaction is to read the specific label for all foods all of the time. Lists of commercially prepared “safe” foods should be avoided because manufacturers change ingredients without warning. Thus, a list can quickly become outdated and the incorrect information on the list can lead to a reaction. Over time, most patients and their families come to rely on certain products or companies whose labels they can trust, and they purchase only those products.

Occasionally, a manufacturer makes an error and inadvertently includes an undeclared allergen in a product, puts a product in the wrong packaging, or uses an out-of-date label with incomplete ingredient information. These situations pose a special hazard to those with food allergies. The products whose labels are incorrect are required by the Food and Drug Administration to be recalled from the market.

TABLE 2. Common Ingredients in Unexpected Places

| Milk | Peanuts | Tree Nuts | Fish |
|--------------------------------|-----------------|-------------------|----------------------|
| Coffee whiteners | Brown gravy | Salad dressings | Imitation shellfish |
| Nondairy products (has casein) | Barbecue sauce | Desserts | Worcestershire sauce |
| Hot dogs | Baked goods | Sauces | |
| Some deli meats | Meat sauce | Ice cream topping | |
| | Egg rolls | Barbecue sauce | |
| | Enchilada sauce | Pie crusts | |
| | Hot chocolate | | |

TABLE 3. Sample Substitutions for Milk, Eggs, and Peanuts

| Replace Milk With | Replace Each Egg With | Replace Peanuts or Tree Nuts With |
|-------------------|--|-----------------------------------|
| Water | 1½ tablespoons water and oil; 1 teaspoon baking powder | Raisins |
| Fruit juice | 1 packet plain gelatin, 2 tablespoons warm water (do not combine until ready to use) | Dates |
| Rice or soy milk | 1 teaspoon yeast and ¼ cup warm water | Crispy rice cereal |

FAAN has developed a Special Allergy Alert system designed to get information quickly to patients about the situation, product name, code, and other criteria. Patients may sign up for these alert notices to keep abreast of food safety issues that may be of concern to them.

Advisory Statements

Voluntary allergen advisory or “may contain” statements are appearing on an increasing number of products.⁸ This has caused frustration and confusion to patients and their families.⁶ These statements are voluntary; companies elect when to use the statements and what language to use. The statements are used by some companies to indicate that there may be a risk of cross-contact with an allergen in another product. Others use it to indicate that the allergen is present somewhere in the manufacturing plant. From a patient’s perspective, because ingredients have not changed between products with and without these advisory statements, the families question whether there truly is a risk of cross-contact or the company has placed these statements to cover their legal liability in case a reaction occurs from inadvertent cross-contact with an allergen.⁶

As the food choices are minimized in light of the increase in these advisory statements—there are currently well more than a dozen versions of these advisory statements on the market—a growing number of families have decided to ignore these advisory statements; others avoid all products that indicate “may contain (allergen)” or “processed on shared equipment with (allergen).”⁶ In lieu of advisory statements, some companies list the allergen as the last ingredient in the product if the product is processed on shared equipment with an allergen and there is a chance of cross-contact.

Ignoring the advisory statements or the allergen when it is listed as the last ingredient is akin to playing Russian roulette, as there is a chance that the allergen will appear in the product. In 1 tragic example, a teenage patient regularly ignored the allergen when it appeared as the last ingredient, believing that it is never actually present because she had not had a reaction. Unfortunately, on 1 occasion, the allergen was present in a product that she had eaten and experienced a fatal reaction. Patients should always avoid consuming a food that lists the food to which they are allergic. Until these advisory statements are regulated and one can be certain what they mean, patients should be advised to avoid consuming products that have allergen advisory statements pertaining to their specific allergen.

COOKING

Avoidance of the allergen will require families to learn to adapt recipes and make appropriate substitutions (Table 3). In some families, everyone follows the restricted diet, thus minimizing the amount of cooking needed and making home a safe place because the allergen is not present. The degree of difficulty in doing this changes with the type and number of foods to be avoided. For example, avoidance of pecans may not be too difficult, whereas avoidance of milk and eggs and peanuts or avoidance of wheat may be more burdensome.

Conversely, some families bring the allergen into the home and use it as an opportunity to teach the child how to avoid certain foods. They have designated areas of the pantry and refrigerator for allergen-free foods,⁹ and many place stickers on “safe” or “unsafe” foods to help the child and other family members correctly identify these foods. Others have specially colored dishes, spoons, and glasses for use by the allergic child. This helps keep food allergy at the top of the mind for the entire family when they are serving food.

When cooking, the allergen-free meal should be prepared first, covered, and removed from the cooking area to be sure that it is not accidentally contaminated with the allergen.¹⁰ Keeping an extra supply of “safe” foods in the freezer comes in handy for days when the family schedule is stretched thin or when a babysitter or other family member is taking over the cooking responsibility.

Some individuals may react to the inhalation of cooking fumes during frying or steaming the food to which they are allergic. There are several reported cases of fatal reactions caused by inhalation of shrimp protein¹¹ and 1 rare case of an 8-year-old girl who was allergic to garbanzo beans (chick peas)¹² and died shortly after inhaling the fumes released by a pressure cooker filled with these beans. Families should be advised of these potential risks, particularly for foods such as fish and shellfish.

In any case, each family must determine which strategies work best for them. Their decisions will change as the child ages and wants to take more control of the food allergy or as the family situation changes. Children with multiple food allergies should be referred to a registered dietitian to ensure that the child’s elimination diet is nutritionally sound.

SCHOOLS

Roughly 2 million school-aged children have food allergies, and this number is believed to be on the

rise. Food allergies in schools have become a hot issue, as families, fearful that their child will have a reaction, may demand that the allergen (most commonly peanuts) be completely banned from the school. School officials often find themselves caught between meeting the needs of children with allergies and those who do not have food allergies.

Several studies have reported reactions in schools. In 1 study, Sicherer et al¹³ reported that the majority of reactions from peanuts or tree nuts in the school setting were caused by food used in class projects, and up to 25% of these reactions were first-time reactions. Nowak-Wegryzn et al¹⁴ reported that of 132 children studied, close to two thirds had accidental ingestions in the preceding 2 years. Milk was the most common cause of reactions in preschools (32%); peanuts were the most common cause of reactions in elementary schools (29%).

Under federal law, schools cannot exclude children with food allergies from participating in school functions because of their food allergies. In addition, they are required to provide allergen-free substitutions for a child who is participating in the free breakfast or lunch program at no cost to the family, provided that the child has written documentation from the physician about the child's food allergies.¹⁵

Schools are also required to administer the child's medications, including EpiPen, during a reaction, even if they do not have a full-time nurse.¹⁶ All children with food allergy should have a written emergency action plan from their physician for their school staff (Fig 1).

The key to managing successfully food allergies in schools is to train the staff to minimize risks, recognize symptoms, and act quickly once a reaction occurs. The FAAN's School Food Allergy Program is a multimedia comprehensive program designed to aid the school staff in developing a school-wide food allergy awareness program. The Be A PAL: Protect A Life From Food Allergies program educates the classmates about how they can help prevent a reaction. Both of these programs have been well-received and are in place in thousands of school across the United States.

For school celebrations or snack time, many parents elect to provide their child's food so that they can ensure that it is safe. Others send enough snacks or party fare to school so that their child can share, therefore eating the same food as classmates. Some school policies require that only commercially prepared food that contains a preprinted ingredient statement may be sent to school. The teacher or the child's parent then reads the ingredient statement to determine whether the food is safe.

Another school policy that is growing in popularity requires nonedible treats for class parties or celebrations, for example, stickers, colorful pencil erasers, sports cards, and other child-friendly collectibles. Children's birthdays are celebrated by reading a book to the class and donating that book, in the child's name, to the school library. Holiday celebrations include costumes or pictures depicting what a particular holiday means to each student.

Most children bring their own "safe" food for lunch. Reactions that occur in the cafeteria often occur as the result of children's trading their food with their friends and unknowingly getting an allergy-containing food.¹⁷ This risk can be eliminated by implementing "no food trading" policies for all students. Some schools create a "safe eating zone" for these children, such as a peanut- or milk-free table. Children should not be required to sit at these designated sections, and they should not be isolated from their friends. Most schools report that the child's friends avoid bringing in peanut or milk, for example, so that they can sit at the special table with their friend. In addition, the seating arrangements in the cafeteria should be revised as the child ages.

Risks increase when the regular school-day activities are interrupted, for example, during field trips. Special care should be taken by the parents, school staff, and others to be sure that chaperones know who the children with food allergies are, know how to avoid a reaction, and can recognize symptoms and implement the child's emergency plan. Someone should review upcoming field trips to be sure that they do not pose a risk to the student with food allergies. In 1 case, a student with an allergy to walnut was forced to sit outside a museum waiting for her classmates, when it was discovered that the hands-on exhibits contained crushed walnut shells.

DINING IN RESTAURANTS

Convincing wait staff that food allergies are real and getting accurate information about ingredients while eating away from home are just 2 examples of the difficulties that individuals with food allergies may encounter. From the restaurant's perspective, high-turnover wait staff who are distracted with hungry guests at a number of tables and who are uninformed about the potential seriousness of food allergy can be a recipe for disaster. In almost all cases of an allergic reaction, the individuals mistakenly believed that the food they were eating was allergy-safe.¹⁷ There is much that we can learn from the reactions in restaurants.

Sicherer et al¹⁸ reported that these reactions were caused by the individual's not telling the wait staff about the food allergy; cross-contact, primarily from shared ice cream equipment and from cooking/serving supplies; and establishment error. In 50% of the reactions, the foods were "hidden" in dressings, egg rolls, or sauces. Reactions were caused by desserts (43%), entrées (35%), appetizers (13%), and other (9%).

Selecting the Restaurant: Minimizing Risks

Those who are allergic to peanut or tree nuts should avoid Asian cookery. These ingredients are common in Asian dishes, and the chances of cross-contact between foods during meal preparation and cooking is great. Indeed, a number of reactions and fatalities have been reported to individuals with peanut allergy from eating these types of foods. Some Mexican restaurants are now using peanut butter, for example, in enchilada sauce. Caution should be the rule when eating Mexican food as well.

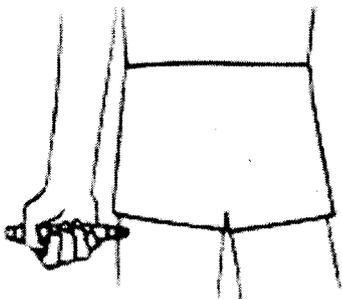
| EMERGENCY CONTACTS | TRAINED STAFF MEMBERS |
|------------------------------|-----------------------|
| 1. | 1. _____ Room _____ |
| Relation: _____ Phone: _____ | |
| 2. | 2. _____ Room _____ |
| Relation: _____ Phone: _____ | |
| 3. | 3. _____ Room _____ |
| Relation: _____ Phone: _____ | |

EPIPEN® AND EPIPEN® JR. DIRECTIONS

1. Pull off gray activation cap.



2. Hold black tip near outer thigh (always apply to thigh).



3. Swing and jab firmly into outer thigh until Auto-Injector mechanism functions. Hold in place and count to 10. The EpiPen® unit should then be removed and taken with you to the Emergency Room. Massage the injection area for 10 seconds.

For children with multiple food allergies, use one form for each food.



Fig 1. Continued.

risk for cross-contact. The food is often so close to each other that small amounts of 1 food can easily fall into the serving dish for another food. Diners commonly dip 1 spoon into several dishes, and ingredients are rarely identified. Similar risks arise in

ice cream shops, where toppings are close together and the ice cream scooper is kept in a general tub of water. Bakery products, which are often prepared on shared equipment and stored close to each other in a display case with only 1 service utensil for all vari-

eties, are another potential source of cross-contact and should be avoided.

Once a restaurant has been selected, patients should ask to speak to the manager and explain their food allergies. Wait staff may not answer questions about ingredients and menu items as carefully and thoughtfully as necessary.

Menu Selection Strategies

Patients should order simply prepared foods with a single ingredient, for example, a baked potato, steamed vegetable, and a broiled meat dish. They should avoid sauces, desserts, foods prepared in a pastry covering, and combination foods, such as stews and fried foods.⁵ It is a common food industry practice to cook several types of foods in the same fryer. As a result, the fried food may contain protein from other foods cooked in the same oil. In 1 example, an individual with a fish allergy experienced a reaction after unknowingly eating French fries that had been cooked in oil previously used to cook fish.

Individuals with food allergies should ask detailed questions about ingredients used and ask for advice on selecting menu items. Some teens and young adults use a “chef card” to convey key information. The cards are personalized by the patient; the intent is to alert restaurant staff about the allergy, the potential seriousness, and the ingredients that need to be avoided. Some teens print this information on a laminated card that is handed to the manager for the chef’s review; others print the information on business cards. Regardless of the mechanism used, if there is any doubt that their questions and concerns are being taken seriously, the food-allergic individual should not hesitate to leave the restaurant and eat elsewhere.

SPECIAL OCCASIONS

As with the day-to-day management of food allergies, preparation, planning ahead, and minimizing risks are the key ingredients for success. When attending a birthday party or visiting a relative’s house, families may call ahead and alert the hostess of the food allergy. Bringing their own “safe” food ensures that there will be something that the child can eat. When going on vacation, many rent places with kitchenettes and bring or ship food to the vacation site.¹⁰ Some who send their child to sleep-away camp provide the child’s food or review the menu to determine which foods their child can eat.

When traveling by plane, it is best to avoid eating any food served by the airline, as ingredient lists are not usually available. Some families of children with peanut allergy request that no peanuts be served on their flight. No airline can guarantee a peanut-free flight because they may have peanut ingredients in their meals or other passengers may carry peanuts on the plane with them. However, some airlines do not serve peanut snacks, others are willing to serve nonpeanut snacks on request, and some will make no accommodations. It is best to check with the individual airline when booking the flight and confirm the arrangements before the trip.¹⁹ Families should always carry their medications with them in case a

reaction occurs. The medications should be stored in carry-on bags and kept with the patient at all times.

ACCIDENTS ARE NEVER PLANNED

Despite best efforts at avoidance, the chances are that an accidental ingestion will occur. In a study that followed 83 children with peanut allergy, Vander Leek et al²⁰ reported that 60% had a total of 115 documented adverse reactions caused by accidental exposure to peanuts during follow-up. Several studies that reviewed fatal food-induced cases reported that the patient unknowingly ate the food to which they were allergic.^{17,21}

Patients with a history of allergic reactions to foods should be given a written plan for handling their allergic emergency. They should receive information about emergency medical identification systems such as MedicAlert (Turlock, CA; www.medicalert.org). If EpiPen is prescribed, then patients should be given instructions for when and how to use the life-saving medication. Huang²² reported in a study of 98 patients that 60% did not know to hold the EpiPen until they heard a clicking sound and to hold it in place for at least 10 seconds, close to 50% were not aware that the EpiPen can be used without removing clothing, and 25% did not know to place the auto injector in the lateral thigh. Patients must be instructed to seek professional medical care after using their EpiPen; they should remain under observation for 4 to 6 hours.

Schools, child care providers, camp staff, and anyone who is caring for the child should know what to do if a reaction occurs. Often school staff call the patient’s parent before administering medication, or they rely on asthma inhalers for treating an anaphylactic reaction. Both should be avoided. School staff should follow the written protocol from the child’s doctor, call the rescue squad, and then attempt to call the student’s parents. Parents should be given instructions for follow-up with their primary care physician or specialist after a reaction occurs, and they should be reminded to refill medications after a reaction.²³

Teens: A Special Concern

Studies of fatal food-induced anaphylactic reactions have shown that high-risk patients for a severe or fatal reaction include adolescents and young adults with food allergy (particularly peanut or tree nut allergy) and asthma. One study of 32 fatalities reported that 54% were in the 10- to 19-year-old age range.²¹ This age group poses unique situations because they are increasingly spending more time away from home in the company of their friends.

In an effort to “blend” in with friends, adolescents may go to places or eat foods that pose a high risk for a reaction, for example, Chinese food for a peanut-allergic patient. Once a reaction occurs, they may not want to call attention to themselves and often go off alone. In several tragic cases, teens were discovered by friends, collapsed on the restroom floor clutching an asthma inhaler. Most do not carry their EpiPen because they do not expect to have a reaction. Some, particularly boys, complain that the autoinjector is

difficult to conceal and does not fit easily into their pockets. There are several EpiPen carriers now on the market; patients can visit FAAN's web site (www.foodallergy.org) to see a picture.

In another case, the friends of a teenager stood helplessly and watched their friend lose consciousness; it had not occurred to any of them to call the rescue squad. Extra efforts should be made to educate adolescents and their friends about avoiding risks and taking control when they begin to have a reaction. FAAN's *Stories From the Heart: A Collection of Essays From Teens With Food Allergies* and *Friends Helping Friends* video are good resources for showing teens that the situations in which they find themselves, their need to fit in with their friends, and other social issues that they are experiencing are universal. Proper attention to food allergy management can prevent reactions that will run counter to what they most want—to be just like their friends.

Emergency Medical Services

A FAAN state-by-state review of epinephrine laws and emergency medical technicians revealed that epinephrine use varies by state and within districts in some states. The majority of states do not allow emergency medical technician basics (who compose 70% of all EMTs and are often the first to arrive on the scene) to carry and administer epinephrine.²⁴ In some cases, if they tell the 911 dispatcher that the patient is having an allergic reaction and needs epinephrine, then an advanced life support vehicle will be dispatched to their home. Patients should be instructed to find out what their local emergency medical staff's policy is regarding epinephrine before they have a medical emergency.

CONCLUSIONS

The diagnosis of food allergy in children affects the entire family. Schools, camp counselors, child care providers, and others who care for the child should be educated about food allergy management strategies. Patients should always be prepared to handle an allergic emergency; they must be taught that proper management of food allergies requires constant education. In short, managing food allergies is a process, not an event.

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