

Where do I go from here?

General advice on the management of children with severe food allergies

Once a diagnosis has been made, and the Paediatric Specialist has recommended food avoidance, many families feel overwhelmed at the task of readjusting their lives to accommodate the changes.

Whatever you do,

- * Don't blame yourself; it's not your fault;
- * Take time at home to discuss the Doctor's visit, and what you learnt.

Hints for inside the home

- Be realistic when planning what action to take at home, with allergy foods. Can you stop accidental contamination? Is the food (e.g. Peanut butter) essential? Would it be better not to have the food in the house?
- If you decide to have a food-allergy-free house, explain it to other children. They will be more helpful if they understand the importance;
- If you decide the food is vital to the other family members rethink where you keep foods. Cows milk sitting next to soy milk in a refrigerator door is more likely to be accidentally used;
- Keep allergic foods out of the reach of young children. A non-allergic toddler may handle it and pass it to an allergic toddler. Setting aside a special shelf for allergic foods to be used by adults, and at adult height, may offer some solution;
- Traces of egg white in uncooked cake mix can be enough to start a reaction. Make sure the child does not have access to the bowl, beater or spoon. They may not realise that the cake mix contains egg, and licking the bowl may be tempting!
- Accidents happen at times when parents are distracted by, for example, the telephone. If leaving allergic foods unattended make sure they are out of reach. Food can be as life threatening as fire, or boiling water;
- Understand that dishcloths used to wipe multiple knives, or spoons used for more than one saucepan, can transmit traces of food, check the ingredients. Plan food preparation to avoid accidents;
- When friends or family bring food into the home, ask if it contains any of the allergy food;
- If friends bring packet food, check the ingredients. Your research will quickly show you that you have a better understanding of food labels than they do;
- Never be afraid to ask. It may be your child's life at risk, and they can't ask the question.

Hints for shopping

- Only buy foods that are well labelled. "Buying in bulk" or from unmarked containers gives you no indications of the contents. Read the label each time you buy the product. Manufacturers change ingredients without warning and you cannot guarantee that, because the food was allergy free last time, the food is allergy free today;
- Until you remember all the 'hidden' words take the word lists with you, so you can interpret the packaging;
- Be careful in 'deli' sections, where one spoon may be used for various containers;

- Ask staff to open a new packet or meat roll and ensure that they understand the need to use a clean knife. Be prepared to ask them to wipe the knife on e.g. A paper towel (not a dish towel) after washing it to avoid contamination;
- Educate shop staff, and ask to be served by the same attendant, if possible. Building up rapport, and introducing them to your child may help them feel positive and involved in the process, rather than seeing you as a ‘troublesome customer’;
- Don’t shop in a hurry; haste is a well-known contributor to accidents.

At parties outside the home

- Don’t decline the invitation because you are scared of accidents. Children need to feel included.
- Work out your plan well before the party date;
- Talk to the host of the party days before the event, so that they understand your child’s allergies.
Politely, but firmly, advise them of the reactions that can occur if an accident happens;
- Advise them of the allergies when you accept the invitation;
- If necessary, offer to stay at the party to ‘help out’, but allow your child to mix freely with the other children, so that your presence isn’t equated to that of a security guard. You could even supply the ‘party food’ for your child (on their own plate/container) if you think this is best;
- Ensure that you have any emergency treatment (such as the EpiPen) in your handbag;
- Take special food for your child, so they have their own treats when the treats are handed out;
- Explain your reasoning to your child;
- Never leave you child at a party unless you are satisfied that it is safe to do so;
- If you are leaving the child at the party;
 - Make sure that the party host knows where you will be;
 - Remember to leave your mobile phone switched on!
 - Remind your child to tell the party hosts if any symptoms present.
 - If host is willing, educate them on how to use the EpiPen and leave it with the host.

At parties inside your home

- Only agree to people bringing food if you are sure that they understand the nature of the allergy. Once the party starts it’s hard to supervise all the food;
- Only give your child food which you have prepared;
- Barbecues contain additional risks for food allergy children, with everyone ‘bringing a plate of meat’.
- Relatives may not realise that, for example, chicken marinades and sausages often contain peanut.
- Barbecues are also often relatively unsupervised events.

At relatives

Many parents have expressed educating family members as the hardest part of living with food allergies. Older grandparents are often seen as ‘set in their way’ and there are strong cultural traditions which cause additional pressures. Telling ‘Nona’ not to cook pasta or ‘Yia Yia that egg and lemon soup is life threatening is difficult for some parents of food allergic children. Many family members have the attitude that ‘a little bit won’t hurt’ or a ‘little bit will get them use to it’

Also, grandparents are assuming a greater role in childcare. Dealing with professional childcare workers allows parents to feel comfortable about setting the rules. Telling your mother and mother-in-law how to bring up children takes a more delicate approach. Unfortunately many family members won't really believe a parent until they have seen the reaction themselves.

- Take a caregiver to the Dr's appointment, so that the professional can emphasize the importance of situation;
- Reinforce the message until you feel comfortable that they have a good understanding of the issue;
Give them any available literature to read, and lists of additives, if they will be food shopping for the child;
- Give them recipes that you have found work well, and that the child likes;
- Send food with the child, and emphasize that only that food may be given;
- Encourage other sympathetic family members to speak on your behalf, particularly those family members who are respected. "Will you talk to her? She will listen to you!"
- If you don't trust the family member, don't leave your child there. The safety of the child outweighs the family argument. Don't feel guilty. You are doing this because you know it is right for your child;
- In difficult circumstances ensure that the family meets at your house where you prepare the food.

Choosing a school

- When initially enquiring about a school, tell the school about the allergy, and assess the response. Does it sound as if this surprises them? Do they offer the information, and the feeling, that they understand your child's situation? Do they mention any other children with allergies?
- When visiting a prospective school, take a list of questions to which you want the answer. For example, are there other food allergic children? How many? What is the school policy? How are the policies implemented? What are the procedures?
- Question the school about the preparation of school lunches. Is there a canteen at the school, or are school lunches delivered from outside the school? Where do the prep students eat their lunch, and are they supervised? Are they prepared to take the extra supervision of your child?
- The school may already have students who require the presence of an EpiPen. Check the policies and procedures that the school has implemented for these children, and see if they match your expectation;
- If the school has no students with food allergies, initiate questions that allow you to gauge their acceptance of your expectations and needs. They may have no experience, but are open to learning, and adjustment;
- Question the school on pro-active measures to ensure that your child won't be bullied for 'being different'. The teacher's may be confident in the area of food allergies, but how will the other children respond?
- If the school does not meet your expectations or cannot satisfactorily allay your concerns, ask other schools. It is preferable to do the research before your child enrolls, rather than move your child later in the year;
- Be reasonable in your expectations. For example, banning foods at school is not recommended for a few reasons. It may lead to bullying, and products may be labelled with names that other parents do not know, making it difficult for them to accurately avoid specific foods.

Once enrolled at school

- Plan ahead, and put your plans into action before the school year begins. You may find it better to provide the school with all your information at your child's orientation, which usually occurs in Term 4, the year before;
- Discuss and provide an anaphylaxis action plan with a photo of your child for the staff to display appropriately to notify all responsible adults;
- If your child has an EpiPen
 - Provide one for the school (with a copy of the action plan is kept with the EpiPen) and make sure that ALL staff are trained in it's use, where it is kept and aware of the action plan
 - Make sure that staff knows that the EpiPen must be taken on all school excursions, camps or anytime the child is not on school premises (ie sports carnivals, walks to library etc) and that a trained staff member should also be present. If a trained staff member is not available, then a parent should attend. School excursions are very exciting, and it is preferable for a parent to go than the child miss the excursion;
 - Provide an EpiPen that has not expired, is clearly labelled with the child's name and is in the original packaging;
- Ensure that all staff are aware of your child's needs
- If staff need specialised training in the management of allergy emergencies, the NSW Anaphylaxis Training Program Nurse (for the Hunter Region), Jan Belcher, can be contacted on 49213000, page 5284.

Once attending school

- The day before your child commences each year, contact the school to make sure that everything is 'in place'.
- Check that all your plans have been implemented, and that the management of anaphylaxis is understood by all staff;
- Assist the school in initiating care plans. Remember, you will probably know more than they do;
- If your child catches a bus/rides/walks to school, consider necessity for child to carry their EpiPen from home.
- Provide a container of safe treats from home, for times when other children bring, or are given, treats;
- Ensure that no food sharing or swapping is occurring;
- Check all foods and ingredients used in cooking or food experiments, if your child is involved;
- At art, emphasize that food containers or packages that contained the allergic food must be used;
- Check all art/craft products for hidden ingredients;
- Negotiate ongoing concerns with the school. Talking is always better than allowing misunderstandings to occur.

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