



Living Confidently With Food Allergy

A guide for parents and families

Michael Pistiner, MD, MMSc Jennifer LeBovidge, PhD Laura Bantock Lauren James Laurie Harada

PLEASE READ THIS NOTE BEFORE READING THE HANDBOOK

The information in this handbook is general in nature and for information and educational purposes only. It is meant to help people learn how to manage a child's allergies. It is not meant to give specific medical advice, recommendations, diagnosis, or treatment.

Readers should not rely on any information contained in this handbook as a replacement or substitute for professional medical advice or diagnosis or treatment. Nor should they delay getting professional medical advice or treatment because of information contained in this handbook. Medical knowledge is constantly developing.

Please speak with your child's doctor or other healthcare professional before making any medical decision that affects your child or if you have any questions or concerns about their food allergies.

The authors of this handbook – Michael Pistiner, Jennifer LeBovidge and Anaphylaxis Canada – as well as individual contributors and reviewers will not be held responsible for any action taken or not taken based on, or as a result of, the reader's interpretation or understanding of the information contained or referred to herein.

Managing Anxiety & Feeling in Control

As a parent it is very common to feel worried about your child having an allergic reaction.²⁵ This concern can help to motivate you and your family to learn how to manage food allergies.²⁶ With the right information, you begin to understand the possible risks for your child and how to reduce them. This helps to keep your anxiety under control so that you can help your child feel confident about managing allergies. Here are some things to keep in mind.

Get the facts. If you are not sure about the level of risk in a certain situation, talk to your child's doctor, patient organization or a local support group. If you don't have the facts, it is easy to worry and difficult to find solutions.



Remember that ups and downs are normal. It is normal to experience some anxiety after major life changes, including when your child is first diagnosed with a food allergy or when they start a new activity, such as entering childcare, starting school or going to a friend's home. You will learn to find routines that keep your child safe and work for your family.

Find a support group in your area. Allergy support groups can provide valuable information and understanding and show you that other families are successfully living with allergies.

Remember that your child learns from you. When your words and behaviour show that you are confident, your child will feel the same. Try not to use words that can scare your child such as describing them as "deathly allergic" or saying "this food can kill my child". Instead, talk about the fact that food allergies can be managed.

The lessons you teach your child when they are young will help them to self-manage as they get older.

Empower your child. Increase your child's sense of control by involving them in managing their allergy. Help them build their skills, such as reading food labels and learning how to use their auto-injectors.

Prepare your child for new situations. Visit new places ahead of time and introduce your child to the adults who will take care of them. Tell your child about plans to keep them safe, including emergency steps.

Problem solve with your child. If your child is worried about a situation, talk to them about their concerns and ask them what they and others could do to help. For older children, writing the plan down may make it feel more "official".

Be available for difficult conversations. If your child thinks that a topic is off limits or makes you feel uneasy, they may not talk to you. Sometimes they fill in the details with their imagination, which can be more frightening than reality.



If you or your child is feeling increased anxiety, talk to your doctor. They may refer you to a specialist who can help you develop coping strategies that work for you.

When Children Feel Different or Frustrated

Sometimes children may feel different because of their allergy.²⁷ It is normal for them to want to be just like other kids. You can help your child when they go through a difficult time.

Listen to your child. When your child is upset or worried, listen without interrupting them. You may want to say, "It will be fine" or to try to fix the problem but remember that it can be helpful for them to talk about their concerns and let them know you "get it".

Help them come up with solutions to problems. Children can feel more in control if they participate in making decisions. Even young children can be involved in decisions such as choosing safe snacks.

Teach your child how to handle bullying and teasing. These are serious matters that should never be ignored. Tell your child to get help from an adult if they ever feel threatened. Let them know that it is their right to be safe and treated with respect by others and they are not tattling on others. Speak with the teacher or principal about your child's situation when necessary.

Thank your child for coming to you with their concerns. Tell them that you always want to know if they are having a difficult time.

Remember that there is more to your child than just their food allergy. Do your conversations focus only on their allergies? Make sure that you talk about their achievements.

Let your child know that you are proud of the choices they make. The opinions of their friends and classmates matter, but yours does too! For example: "I know it was hard when you couldn't eat the treat at school today, but I was so proud that you said no thank you. Let's pick out a great snack now."

Teaching Children

- Role play with your child to practice what to say in common social situations.
- Show them how to teach their friends about their food allergies. When friends get involved they are usually helpful and want to choose activities that include your child. This helps your child feel supported and confident.
- Use children's books, videos and other resources to help your child and their friends learn the facts about food allergy.
- Encourage your child to participate in a wide variety of activities. This is important for all children to reduce stress and feel good about themselves.

You are a Role Model

Teaching your child about food allergies is necessary for their safety and confidence. Your goal is to empower your child with the knowledge and skills that will help them safely participate in all daily activities.

Be reliable. When you always read labels and carry emergency medication, your child will learn that this is important to do in order to stay safe. Even young children are watching and learning!

Teach your child why it's important to follow allergy rules. Try to teach in a way that they can understand. This will differ by age and development. Routines give your child a sense of comfort and security. Use children's allergy books as teaching tools to encourage habits such as hand washing. Even toddlers can learn this practice.

Plan ahead for food-related events. Children may enjoy preparing for events like birthday parties. Help them to find ways to deal with common problems that may arise.

Teach your child how to say "no thank you" politely. If they are not sure if a food is safe, they should feel confident about saying "no thank you". This skill should be taught as early as possible. Use role playing to practice the words that they can use so that they feel confident in real situations.

Encourage honest and open communication. Your child should feel able to share their feelings and information, without fear of being punished. This includes situations where allergy rules were broken. If a child is afraid, they may hide this information from you and you will lose the chance to problem-solve together.

Try not to use terrifying words to describe allergy. Your child is listening to conversations that you have with others, so try to avoid using words like "deathly allergic". For young children, phrases like "eggs can make you sick" or "peanuts are not safe for your body" may work. As children get older, they may be able to understand the role of the immune system. For example, "the immune system, the part of the body that usually fights germs, mistakes the food for something harmful. When the immune system fights back, that causes the allergic reaction".

Teaching Others about Food Allergy

In order to keep your child safe, you must become confident with educating others about food allergies. When other people look after your child, it is important that you teach them about your child's allergy, including details on how to prevent and how to treat a reaction.

Be patient as others try to learn about your child's allergies. Food allergy may be new to them. Take the time to explain why certain steps are necessary to prevent an allergic reaction and what to do in an emergency. Use language that is easy to understand and keep in mind possible cultural and age differences in people's understanding of allergy.

Speak in a calm manner. You should explain that although food allergies are serious, they can be managed. Be open to answering questions and talking about concerns that others may have.

Avoid using scare tactics or high emotion to convince others to take allergies seriously. Such tactics will probably have a negative effect. People may think that you are over-reacting or they may feel uncomfortable taking care of your child.

If you are having difficulty getting someone to understand or take your child's allergies seriously, try a different approach. There may be times when you feel others "just don't get it", no matter what you say or do. This could be due to a number of reasons. It can be helpful to give information from trusted sources, such as your child's doctor or an educational handout or website. Sometimes, asking someone else to speak with the person can help, too.



References

- 1. "Sulphites One of the nine most common food products causing severe adverse reactions." Health Canada. 2009. Web. 8 August 2012. http://www.hc-sc.gc.ca/.
- ² National Institute of Allergy and Infectious Disease (NIAID)-Sponsored Expert Panel. "Guidelines for the Diagnosis and Management of Food Allergy in the United States: Report of the NIAID-Sponsored Expert Panel." The Journal of Allergy and Clinical Immunology 126.6 (2010): S1-S58.
- ^{3.} Sampson, H.A. et. al. "Second symposium on the definition and management of anaphylaxis: Summary report—Second National Institute of Allergy and Infectious Disease/Food Allergy and Anaphylaxis Network symposium." The Journal of Allergy and Clinical Immunology 117.2 (2006): 391-397.
- 4 Canadian Society of Allergy and Clinical Immunology. Anaphylaxis in School & Other Settings. 2nd Ed. Revised. 2011.
- ^{5.} Maloney, J.M., Chapman, M.D., and Sicherer, S.H. "Peanut allergen exposure through saliva: Assessment and interventions to reduce exposure." The Journal of Allergy and Clinical Immunology 118.3 (2006): 719-724.
- ^{6.} Simonte, S.J. et al. "Relevance of casual contact with peanut butter in children with peanut allergy." The Journal of Allergy and Clinical Immunology 112.1 (2003): 180-182.
- ⁷ Wainstein, B.K. et al. "Combining skin prick, immediate skin application and specific-IgE testing in the diagnosis of peanut allergy in children." Pediatric Allergy and Immunology 18 (2007): 231–239.
- ^{8.} Kim, J.S. and Sicherer, S.H. "Living with Food Allergy: Allergen Avoidance." Pediatric Clinics of North America 58.2 (2011): 459-470.
- ^{9.} Tulve, N. et al. "Frequency of mouthing behavior in young children." Journal of Exposure Analysis and Environmental Epidemiology 12 (2002): 259–264.
- ¹⁰ Nicas, M., and Best, D.J. "A study quantifying the hand-to-face contact rate and its potential application to predicting respiratory tract infection." Journal of Occupational Environmental Hygiene 5.6 (2008): 347-52.
- ¹¹ Roberts, G., Golder, N. and Lack, G. "Bronchial challenges with aerosolized food in asthmatic, food-allergic children." Allergy 57.8 (2002): 713-7.
- ¹² Hefle, S.L. et al. "Consumer attitudes and risks associated with packaged foods having advisory labeling regarding the presence of peanuts." The Journal of Allergy and Clinical Immunology 120.1 (2007): 171-176.
- ^{13.} Perry, T.T. et al. "Distribution of peanut allergen in the environment." Journal of Allergy and Clinical Immunology 113.5 (2004): 973-6.
- ^{14.} Sampson, H.A., Mendelson, L. and Rosen, J.P. "Fatal and near-fatal anaphylactic reactions to food in children and adolescents." New England Journal of Medicine 327 (1992): 380-384.
- ^{15.} Rudders, S.A. et al. "Multicenter study of repeat epinephrine treatments for food-related anaphylaxis." Pediatrics 125.4 (2010): e711-e718.
- ¹⁶ Bock, A.S., Muñoz-Furlong, A. and Sampson, H.A. "Fatalities due to anaphylactic reactions to foods." The Journal of Allergy and Clinical Immunology 107.1 (2001): 191-193.
- ^{17.} Pumphrey, R.S.H. "Fatal posture in anaphylactic shock." The Journal of Allergy and Clinical Immunology 112.2 (2003): 451-452.

- ^{18.} Simon, E. et al. "World Allergy Organization guidelines for the assessment and management of anaphylaxis." World Health Organization World Allergy Organization Journal (2011) 21-22.
- ¹⁹ Ellis, A.K. and Day, J.H. "Incidence and characteristics of biphasic anaphylaxis: a prospective evaluation of 103 patients." Annals of Allergy, Asthma & Immunology 98.1 (2007): 64-69.
- ²⁰ Muñoz-Furlong, A. "Daily Coping Strategies for Patients and Their Families." Pediatrics 11.3 (2003): 164-1664.
- ^{21.} Young, M.C., Munoz-Furlong, A. and Sicherer, S.H. "Management of food allergies in schools: a perspective for allergists." Journal of Allergy and Clinical Immunology 124.2 (2009): 175–182.
- ^{22.} McIntyre, C.L., Sheetz, A.H., Carroll, C.R. and Young, M.C. "Administration of epinephrine for life-threatening allergic reactions in school settings." Pediatrics 116.5 (2005): 1134-1140.
- ^{23.} Sicherer, S., Furlong, T.J., DeSimone, J., and Sampson, H.A. "The US Peanut and Tree Nut Allergy Registry: Characteristics of reactions in schools and daycare." Pediatrics 38 (2001): 560-565.
- ^{24.} Furlong, T.J., DeSimone, J. and Sicherer, S.H. "Peanut and tree nut allergic reactions in restaurants and other food establishments." The Journal of Allergy and Clinical Immunology 108.5 (2001): 867-870.
- ^{25.}Cohen, B.L., Noone, S., Munoz-Furlong, A. and Sicherer, S.H. "Development of a questionnaire to measure quality of life in families with a child with food allergy." Journal of Allergy and Clinical Immunology 114 (2004): 1159-63.
- ^{26.} Mandell, D., Curtis, R., Gold, M., and Hardie, S. "Families coping with a diagnosis of anaphylaxis in a child. A qualitative study of informational and support needs." Allergy & Clinical Immunology International Journal of the World Allergy Organization 14 (2002): 96-101.
- ^{27.} DunnGalvin, A., Gaffney, A. and Hourihane, J.O'B. "Developmental Pathways in food allergy: a new theoretical framework." Allergy European Journal of Allergy and Clinical Immunology 64.4 (2009): 560-568.
- ^{28.} Sampson, M.A., Munoz-Furlong, A. and Sicherer, S.H. "Risk-taking and coping strategies of adolescents and young adults with food allergy." Journal of Allergy and Clinical Immunology 117.6 (2006): 1440-5.
- ^{29.} Monks, H. et al. "How do teenagers manage their food allergies?" Clinical and Experimental Allergy 40.10 (2010): 1533-1540.
- 30. Chapman, J.A. et al. "Food allergy: a practice parameter." Annals of Allergy, Asthma & Immunology 96.3 (2006): S1-S68.

