Food Allergy Stages

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Disclosures

Dr. Bingemann has been a consultant for Aimmune, PI for Novartis and speaker for Sanofi.

Dr. Bartnikas does not have any relevant disclosures.



Learning Objectives

01

Learning Objective #1

Discuss developmental aspects of managing and coping with food allergy

02

Learning Objective #2

Provide strategies for gradually involving children in food allergy self-management over time

03

Learning Objective #3

Utilize the Food Allergy Stages Educational Handouts created by the AAAAI Adverse Reactions to Foods Committee, to efficiently and effectively provide ageappropriate food allergy guidance to patients and families

Pillars of Food Allergy Management

- Avoid allergens
- Read labels
- Communicate
- Educate



These must be applied at all times and in all settings

- Have an Anaphylaxis Action Plan
- Recognize anaphylaxis
- Carry and use epinephrine autoinjector
- Activate emergency response

Quality of life is the ongoing measure of food allergy disease burden





















Common Psychosocial Concerns in Food Allergy Management

- Impact of dietary restrictions and social limitations on quality of life
- Adherence to management routines/plans
- Anxiety about potential accidental exposures, allergic reactions, and emergency treatment
- Living with uncertainty and risk
- Dealing with differences and potential for food allergy-related bullying
- Coping with medical procedures and treatments (e.g., oral food challenges, oral immunotherapy)
- Transition of responsibility to others (babysitters, school staff, children/teens)

Herbert, Shemesh, & Bender, 2016; Polloni & Muraro, 2020; Cooke, Ramos & Herbert, 2021

Building Caregiver Self-efficacy for Food Allergy Management

PARENTAL SELF-EFFICACY IN FOOD ALLERGY

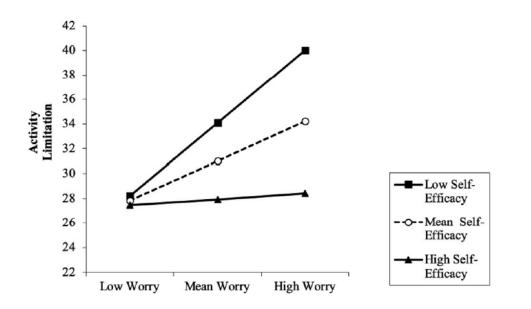


Figure 1. Examination of parental self-efficacy as a moderator of the association between parental worry and child activity limitation. High worry and high self-efficacy refer to 1 *SD* above the mean, whereas low worry and low self-efficacy refer to 1 *SD* below the mean.

Conclusions: Higher caregiver selfefficacy for managing a child's food allergy may allow for children to be more engaged in social activities, regardless of parent anxiety.

Clinical implications: Normalize some anxiety, help families direct their efforts towards adaptive vigilance/ food allergy management that help children safely participate in activities.

McLaughlin et al., 2020



Why a Developmental Approach?

- Consistent pillars of food allergy management AND
- Changes in food allergy concerns as children mature
 - Safety issues
 - Psychosocial issues
 - Understanding of food allergy & roles for the child in management
- Gradual approach to building children's skills & knowledge over time:
 - Increases safety
 - Decreases anxiety
 - Increases confidence

Identifying an unmet need

"Is there a good resource for helping my child cope with food allergies that's tailored to her age?"

66



I don't think so, but there should be... can we create it?

And the work begins . . .

Underlying Aims

AAAAI Work Group Report

American Academy of Allergy Asthma & Immunology

The Development of Age-Based Food Allergy Educational Handouts for Caregivers and Patients—A Work Group Report of the AAAAI Adverse Reactions to Foods Committee

Jennifer S. LeBovidge, PhD^{a,b}, Linda J. Herbert, PhD^{a,d}, Ashley Ramos, PhD^{a,d}, Nancy Rotter, PhD^{b,e}, Scott H. Sicherer, MD^{f,g}, Michael C. Young, MD^{a,h}, Michael Pistiner, MD, MMSc^{e,h}, Wanda Phipatanakul, MD, MS^{a,h}, Lisa M. Bartnikas, MD^{a,h,*}, and Theresa A. Bingemann, MD^{i,j,*} Boston, Mass; Washington, DC; New York, NY; and Rochester, NY

- Reliable, evidence-based information
- Focus on "balanced coping" / inclusion of psychosocial issues
- Practical tips for integrating food allergy management into daily life
- "Roadmaps" for involving children in food allergy management over time
- Easily accessible (online, free, meet varied health literacy needs)



Handout development

- Project team of allergists & psychologists
- Content based on:
 - Practice parameters/guidelines (AAAAI, NIAID)
 - Published research on psychosocial & developmental aspects of managing food allergy
 - Clinical experience

Organizing Structure

- Developmental stages based on American Academy of Pediatrics Ages & Stages handouts
- Topics consistent across stages, with content tailored by stage

TABLE I. Handout topics

Teaching Children about Food Allergy* Allergen Exposure Label Reading Recognizing and Treating an Allergic Reaction Managing Food Allergies at Home Eating out at Restaurants Educating Other Caregivers† Managing Food Allergies at Childcare and School Navigating Social Activities Supporting Self-Esteem* Managing Anxiety and Feeling Confident Preparing Children for Medical Visits* Managing Food Allergies at College‡ Preparing to Manage Your Healthcare‡

*Topic included in age-specific handouts only. †Topic included in the Basics for All Ages handout only. ‡Topic included in the Young Adult handout only. Food Allergy Stages: Food Allergy Basics for All AgesFood Allergy Stages: Baby (0–12 months)Food Allergy Stages: Toddler (1–3 years)Food Allergy Stages: Preschool (3–5 years)Food Allergy Stages: Early Grade School (5–8 years)Food Allergy Stages: Late Grade School (8–11 years)Food Allergy Stages: Early Teen (11–14 years)Food Allergy Stages: Late Teen (14–18 years)Food Allergy Stages: Young Adults (18–21 years)

Caregiver survey

- 57 caregivers of children with food allergy, 2 young adults with food allergy reviewed handouts and completed online survey
- Majority of caregivers: likely to use the handouts, satisfied with amount of content, agreed handouts used elements of plain language writing

| | %, n | | | | |
|------------------------------------------------------------------------------------------------------|-------------------|------------------------|--------------|----------------------|-------------|
| What do you think about the amount of information included in the handouts?* | Not enough inform | Not enough information | | Too much information | |
| Food Allergy Basics for All Ages Handout | 1.7, 1 | | 81.0, 47 | 17.2, 10 | |
| Handout for your child's age | 8.6, 5 | | 79.3, 46 | 12.1, 7 | |
| | | | | %, n | |
| How likely would you be to use these handouts as a resource for managing your child's food allergy?† | | Not at a | ll likely So | omewhat likely | Very likely |
| Food Allergy Basics for All Ages Handout | | 3.5, 2 | 38 | 3.6, 22 | 57.9, 33 |
| Handout for your child's age | | 1.8, 1 | 35 | 5.1, 20 | 63.3, 36 |

TABLE III. Participant feedback on handout acceptability

*Percentages based on 58 participants completing this question.

†Percentages based on 57 participants completing this question.

Caregiver feedback

- <u>Participants valued</u>: developmental focus, information about emotional aspects of coping with food allergy
- <u>Participant feedback</u>: content good, but handouts too "text heavy"; ideas for areas where more concrete examples would be helpful
- Handouts revised based on caregiver feedback
- Graphic design by AAAAI



"I haven't seen them tailored to age before and I think this helps with the mental/emotional side of managing an allergy." (parent of 6-year-old)



Food Allergy Stages Handouts

Different skills are needed for managing and coping with food allergies in daily life at different ages. The Food Allergy Stages handouts were designed to help families manage food allergies and teach children about food allergies at different developmental stages. Use the *Food Allergy Basics for All Ages* handout to learn about important information all parents should know when they have a child with food allergies. Use the Food Allergy Stages handout *for your child's age* for specific tips on managing food allergies at their stage of development. Always speak with your child's allergist if you have questions or before making changes to your child's food allergy management plan.

Food Allergy Stages: Food Allergy Basics for All Ages Food Allergy Stages: Baby (0-12 months) Food Allergy Stages: Toddler (1-3 years) Food Allergy Stages: Preschool (3-5 years) Food Allergy Stages: Early Grade School (5-8 years) Food Allergy Stages: Late Grade School (8-11 years) Food Allergy Stages: Early Teen (11-14 years) Food Allergy Stages: Late Teen (14-18 years) Food Allergy Stages: Young Adults (18-21 years)

Access the handouts in Spanish.

Doctors: Use this PDF/flyer to promote the handouts in your office.



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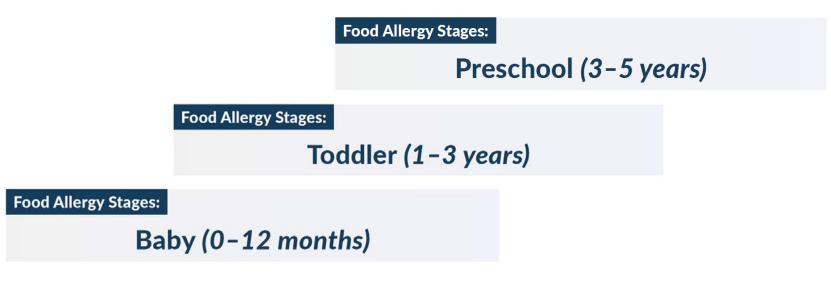
aaaai.org/foodallergystages

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Babies, Toddlers, and Preschoolers: Supporting Parents of the Active and Curious



Babies, Toddlers, and Preschoolers: Concepts

- Children are active, curious, and need careful monitoring.
- Children pay attention to what adults do and learn by imitation and play.
 - Parents as role models—your child is watching!
 - Daily routines = sense of security
 - Simple, *safety-focused* language about food allergy
- Caregivers are primarily responsible for food allergy management.
- When parents follow consistent food allergy management routines, children will learn this is an important part of daily life.







Babies, Toddlers, and Preschoolers: Challenges

- It is common for parents to feel overwhelmed, frustrated, or worried at times when a child is first diagnosed with a food allergy.
- Specific concerns may include:
 - Introducing new foods
 - Monitoring for allergic reactions in preverbal children who cannot describe symptoms
 - Concerns about accidental exposures at a stage when children have frequent mouthing behaviors
- Concerns may limit family social activities and inform choices about leaving the child in the care of others.
- As parents learn more about managing food allergies, they will feel more confident and will develop routines that help keep their child healthy and safe.







Babies, Toddlers, and Preschoolers: Management Tools

• When teaching children about food allergies, use a calm tone, simple terms, and focus on safety routines.

> You are allergic to eggs. Eggs can make you sick.

> > We have our medicine bag, so now we can go to the park!

• Explain routines out loud so that children will learn they are important.

We read the label, so we know there are no eggs in these cookies. They are safe for you to eat.

Babies, Toddlers, and Preschoolers: Management Tools

 Teach your child not to share food. Parents can practice language with older toddlers directly or through play. Support children's self esteem by helping them label feelings, giving simple choices to increase their sense of control, and praising them for following routines.

No thank you, I have allergies.

It seems like you're mad you can't eat what your brother is eating. Let's find a food you enjoy that is safe for you.

Daddy brought snacks to the park. Would you like the crackers or the fruit?

Great job washing your hands before you eat!



School-Aged Children: Emerging Awareness and Involvement

Food Allergy Stages:

Late Grade School (8-11 years)

Food Allergy Stages:

Early Grade School (5-8 years)

School-Aged Children: Concepts

- Caregivers are tasked with developing food allergy management strategies to enable the child's safe participation in activities outside of the home.
- Children are working on building a sense of control and independence.
- Children can understand more about food allergies and follow simple safety rules.
 - This is a good age to involve the child in food allergy management with parental supervision.
- Gradually including children in food allergy management helps them build the skills and confidence they will need to manage food allergies independently in the future.





School-Aged Children: Challenges

- Transitions, such as school entry, that require reliance on third parties and increased child responsibility for food allergy management may be a source of caregiver anxiety.
- Children are developing a greater awareness of differences from peers.
 - "Special to different transition"
 - Need management strategies that emphasize both safety and social inclusion to foster confidence
- Children may experience increased anxiety about accidental exposure to allergens and allergic reactions in situations they previously navigated with confidence.
- Factors that may contribute to anxiety:
 - Greater cognitive awareness of risks
 - Misperceptions about the level of risk associated with casual contact
 - Greater independence in food allergy management
- Children may be at increased risk of bullying or teasing by peers, particularly in school.





School-Aged Children: Management Tools

 Teach children about food allergies in the same way you talk about other safety issues.

Eggs can make you sick. We read labels and keep your medicine with us because these strategies work really well to keep you safe. Teach children why reading ingredient labels is important. As they learn to read, let them practice label reading with you.

> We read the label, so we know there are no eggs in these cookies. They are safe for you to eat.

Just like we stay on safe paths and always wear a helmet when we ride a bike, we read ingredient labels and always keep your epinephrine auto-injector close by.

School-Aged Children: Management Tools

• Be consistent with and reinforce important rules and routines.

If there is no label, we can't eat the food.

Use the bathroom, grab your coat, and make sure we have your epinephrine auto-injector. Role play or practice language ahead of time for common scenarios so children will feel more confident.

I have food allergies to wheat and soy.

No thank you, I have food allergies.

I have to ask my parent.

School-Aged Children: Management Tools

 Help children return to usual allergy management routines after a reaction. Talk about parts of the emergency plan that worked well, and anything you might do differently to stay safe in the future.

You did the right thing when you told me your throat felt tight.

Your auto-injector stopped the reaction quickly.

 Support self esteem by letting children know it's okay to feel frustrated or sad, encouraging them to come to parents if they feel upset, and praising them for making good choices.

> I know it was hard when you couldn't eat the snack at soccer. I was proud when you said "no thank you." Let's get a safe treat now.







Teens and Young Adults: Transitioning to Independence

Food Allergy Stages:

Young Adults (18–21 years)

Food Allergy Stages:

Late Teen (14-18 years)

Food Allergy Stages:

Early Teen (11-14 years)

Adolescents: Concepts

- Focus more on friends and social relationships
- Fitting in with peers is important at this age.



• Some children may feel self-conscious about their food allergies or embarrassed to speak up about allergies in social situations



- Your tween/teen will take cues from you consider your messaging
- Play a larger role in their food allergy management
- Continue to build skills and work towards independence
- They need continued adult support
- Providing graduated responsibility allows for confidence

Adolescents: Challenges

Environment

- Less "structured" environments/move away from allergen-free tables
- More time away from direct adult supervision
- Greater awareness of risks can lead to more worry/vigilance
- New experiences that will lead to new questions and concerns
- What are they comfortable with?



Still developing problem solving and organizational skills

- Be clear about management expectations, but collaborate on how to reach goals
- Make sure teens understand & can use their anaphylaxis management plan
- Be clear about the division of management responsibilities
- Balance parental desires and what they want/are comfortable
- Discuss epinephrine carrying self-injectable epinephrine at school or not

Adolescents: Management

Open and ongoing communication

Ask questions to understand their experience and concerns

- How do they handle get-togethers when food is present?
- Are they reading labels?
- Are they comfortable with the plan at school?
- Do they ask about ingredients or speak up about their allergies when out with friends?
- Encourage them to ask questions and speak up if they have a concern
- Involve them in plans for situations they are worried about
- Anticipate and talk about handling new situations- dating, alcohol
- Check in and keep lines of communication open

Epinephrine

- Discuss how they would like to handle self-injectable epinephrine at school
- Importance of carrying and using epinephrine if needed
- Do they know when and how to use it?
- Are they willing to use it?



Young Adults (18-21 years)

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Young Adults: Concepts

Young adults should be ready to take the primary responsibility for day-to-day food allergy management.



- Provide continued support
- Remind them they are not alone
- Family, friends, roommates can be a great support
- They will feel more confident over time

Young Adults: Challenges

Preparing to Manage Your Healthcare

- Talk about skills you will need to take a lead role in your healthcare.
- Prepare for appointments with your allergist
- Consider attending appointments with your allergist independently
- Or make sure to have one-on-one time with the allergist
- Think about strategies to remember to refill prescriptions
- Find out the location of the nearest hospital or medical facility

Young Adults: Management

Managing Food Allergies at College

- Know your options at college
- Disability services office
- Find out how food is prepared in dining halls
- How do students access allergen information?
- What special meal options may be available?
- Emergency plans in dining facilities.
- Housing and roommate options
- Private mini-fridge and microwave
- Is a kitchen needed?
- Find out whether your resident advisor (RA) will be trained on managing food allergies.
- Speak with your RA and roommates;
 - How to keep your living space safe
 - What to do in an emergency.



Why Stage-Based Handouts Are Important







Ongoing education is important Different challenges and concerns over time.

As children age they notice more differences between themselves and others



Increased independence

New situations (dating, less time with parental supervision)



Roadmap to independent care



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How to Use the Handouts

During visits

Online by families

Educating others

Resources for Further Management

| Food Allergy Stages: | | | | |
|------------------------------------------------|------------------------------------|-------------------------------------------|--|--|
| Food Allergy | Your doctor | | | |
| Label reading | Recognizing and treating reactions | Schools and childcare settings | | |
| Professional and patient support organizations | | Food assistance and reduced cost programs | | |
| | | | | |

Trained mental health professional

Acknowledgements

American Academy of Allergy, Asthma & Immunology (AAAAI)

Food Allergy Stages Project team



Thank you to the caregivers and patients who reviewed the Food Allergy Stages handouts and shared their feedback to improve this resource.

